

**NATIONAL SOCIETY OF**  
**GENETIC**  
**COUNSELORS**  
**OUR PROFESSION**  
**ELEVATED**

Conference Program  
Book Sponsored by:  
Booth #232



**38<sup>th</sup> Annual Conference**  
**November 5-8, 2019**

Salt Lake City, Utah  
Salt Palace Convention Center

# REGENXBIO is a leading clinical-stage biotechnology company seeking to improve lives through the curative potential of gene therapy.



- > Committed to Patients
- > Powered by Science
- > Driven by Experience



Amelia, CLN2



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Geri, Wet AMD

Our investigational gene therapy product candidates are designed to deliver genes to cells to address the genetic defects or to enable cells in the body to produce therapeutic proteins that are intended to impact disease.

- 4 clinical stage programs in retinal, metabolic, and neurodegenerative diseases
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[REGENXBIO.com](https://www.regenxbio.com)

# Welcome to Salt Lake City!

**O**n behalf of the National Society of Genetic Counselors (NSGC), the Annual Conference Program Committee and the NSGC Board of Directors, thank you for joining us!

NSGC is excited to bring you education and networking opportunities designed to help you elevate the field of genetic counseling. Educational sessions will cover a variety of topics at the forefront of genomics, such as gene editing, polygenic risk scores and artificial intelligence.

Educational highlights you do not want to miss include: 40 years of the Genetic Counseling Profession: A Foundation for the Future, The NSGC and ASHG Joint Session: Genetic Counselors in Research: From Dabbling in Clinic to an NIH Grant and the Professional Issues Panel. You can make the most of your Annual Conference experience by building your schedule around education sessions specific to your professional interests.

The NSGC Annual Conference is about more than just education! We encourage you to take advantage of the Welcome Reception, SIG meetings, program reunions and NSGC Central to network with more than 2,300 of your peers. Discover the latest products and services for our profession in the Exhibitor Suite. Catch up with old friends and make new, lasting connections during this year's conference.

This year, we will be celebrating NSGC's 40th anniversary throughout the conference! Learn more about our professional organization during the conference by exploring the timeline wall of major NSGC milestones, testing your knowledge of NSGC through daily quizzes and looking for fun facts woven into conference material.

We hope you enjoy your time in Salt Lake City, learning about the latest innovations and developments in the profession of genetic counseling and exploring this energetic city!

## Table of Contents

Conference Information	5
Schedule-at-a-Glance	8
Convention Center Map	13
Reunion Information	14
Session Speakers + Objectives	16
Platform Presentations	28
Posters with Authors	30
NSGC Sponsors	48
Learning Lounge Presentations	50
NSGC Awards	52
Networking Activities & Meetings	53
Annual Conference Program Committee	54
Meals + Refreshments	55
Exhibitor Directory	56
Exhibitor Suite Map	57
Exhibitor Index	59



**Katherine Lafferty, MS, CGC**  
2019 Program Committee Chair



**Rachel Mills, MS, CGC**  
2019 Program Committee Vice-Chair

## Download the Official Annual Conference Mobile App

NSGC delivers everything Annual Conference directly to your fingertips via the 2019 NSGC Annual Conference mobile app. View conference session descriptions, speakers and schedule information. Use the interactive maps to navigate the Exhibitor Suite with ease, search the exhibitor directory and stay in-the-know with conference alerts. On your smartphone or tablet, search for "NSGC" in your app store or direct your mobile browser to [www.nsgc.org/mobileapp](http://www.nsgc.org/mobileapp). Follow what others are saying or post your own insights on Twitter during the Annual Conference using [#NSGC19](https://twitter.com/NSGC19).



# The one-time-only dose to stop SMA progression

NOW APPROVED

**zolgensma**<sup>®</sup>  
(onasemnogene abeparvovec-xioi)  
suspension for intravenous infusion

ZOLGENSMA is a gene therapy for pediatric patients less than 2 years of age with spinal muscular atrophy (SMA), that is delivered as a single-dose, 1-hour intravenous infusion<sup>1</sup>

## ✓ Significant survival

91% (20/22) of patients in the STRIVE trial were alive, free of permanent ventilation, and continuing in the study as of the March 2019 data cut (at a mean age of 13.8 months)<sup>2,a-c</sup>

## ↗ Rapid onset

As early as 1 month post infusion, CHOP INTEND scores increased from baseline by a mean of 6.9 points (N=22)<sup>2,a</sup>

## ↻ Sustained effect

In the ongoing study, patients continue to attain new milestones and have maintained existing milestones at successive data cuts. 50% (11/22) of patients achieved the ability to sit without support for ≥30 seconds at a mean of 8.2 months post treatment as of the March 2019 data cut<sup>2,a</sup>

The efficacy of ZOLGENSMA was studied in STRIVE, an ongoing, open-label, single-arm, multicenter, Phase 3 clinical trial of patients with SMA Type 1 (genetically confirmed bi-allelic *SMN1* deletion, 2 copies *SMN2*, and symptom onset <6 months of age; N=22).<sup>1,a,b</sup> STRIVE has completed enrollment and the data above represent a data cut from March 2019.<sup>2</sup>

☎ Consider ZOLGENSMA today: Call 1-855-441-GENE (4363) or learn more at ZOLGENSMA-hcp.com

<sup>a</sup>One patient was initially classified as presymptomatic and removed from the intent-to-treat (ITT) data set included in the Prescribing Information. The patient was later confirmed to be symptomatic at baseline and will be included in the final ITT analysis.

<sup>b</sup>One patient died at 7.8 months due to causes unrelated to treatment. One patient withdrew consent at 11.9 months of age.

<sup>c</sup>Event is defined as death or the need for permanent ventilatory support consisting of ≥16 hours of respiratory assistance per day continuously for ≥14 days.

## Indication and Important Safety Information

### Indication

ZOLGENSMA is an adeno-associated virus vector-based gene therapy indicated for the treatment of pediatric patients less than 2 years of age with spinal muscular atrophy (SMA) with bi-allelic mutations in the *survival motor neuron 1 (SMN1)* gene.

### Limitations of Use

The safety and effectiveness of repeat administration or the use in patients with advanced SMA (e.g., complete paralysis of limbs, permanent ventilator dependence) has not been evaluated with ZOLGENSMA.

### Important Safety Information

#### BOXED WARNING: Acute Serious Liver Injury

**Acute serious liver injury and elevated aminotransferases can occur with ZOLGENSMA. Patients with pre-existing liver impairment may be at higher risk. Prior to infusion, assess liver function of all patients by clinical examination and laboratory testing (e.g., hepatic aminotransferases [aspartate aminotransferase (AST) and alanine aminotransferase (ALT)], total bilirubin, and prothrombin time). Administer a systemic corticosteroid to all patients before and after ZOLGENSMA infusion. Continue to monitor liver function for at least 3 months after infusion.**

## WARNINGS AND PRECAUTIONS

### Thrombocytopenia

Transient decreases in platelet counts, some of which met the criteria for thrombocytopenia, were observed at different time points after ZOLGENSMA infusion. Monitor platelet counts before ZOLGENSMA infusion and on a regular basis for at least 3 months afterwards.

### Elevated Troponin-I

Transient increases in cardiac troponin-I levels were observed following ZOLGENSMA infusion. Monitor troponin-I before ZOLGENSMA infusion and on a regular basis for at least 3 months afterwards.

## ADVERSE REACTIONS

The most commonly observed adverse reactions (incidence ≥5%) in clinical studies were elevated aminotransferases and vomiting.

**Please see Brief Summary of Prescribing Information on the adjacent page.**

**References:** 1. ZOLGENSMA [prescribing information]. Bannockburn, IL: AveXis, Inc; 2019. 2. Data on file. AveXis, Inc. Bannockburn, IL.

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US-ZOL-19-0221 08/2019



# Conference Information



## Statement of Purpose

The NSGC Annual Conference showcases advancements across the breadth of the genetic counseling profession to provide education and build community. Attendees will gain knowledge of clinical and scientific best practices and insights into emerging research. The conference provides a unique opportunity to engage and network with colleagues and pursue professional development.



## Session Evaluation Claiming/ Process CEUs

Individuals claiming CEUs must complete session evaluations, however NSGC greatly appreciates feedback from all attendees. An attendance verification code will be provided in each session. Each session listing (beginning on page 15) has a blank space to assist you in tracking verification codes for the sessions that you have attended. Signs with session codes are posted inside of each session room. Some attendees also find it helpful to take photos of the signs as a reminder of sessions attended and codes. To complete your session evaluations, follow these steps:

1. Log in to the NSGC website, and go to [www.nsgc.org/conferenceevaluations](http://www.nsgc.org/conferenceevaluations).
2. Click on the "Session Evaluation" link to be directed to the evaluation website.
3. For each session, add the attendance verification code that you received in the session room, and then evaluate the session.
4. Save each session as you go. The website will log you out after 10 minutes of inactivity. (If this happens, you must go back to the NSGC website and repeat steps 1 and 2 to log in again.)  
PLEASE NOTE: Although your responses to the individual session evaluation questions will save each time you click "Save and Continue," the attendance verification code will need to be re-entered if you re-enter that session to edit your responses.
5. Review your evaluation to make sure you claimed credit for each session you attended. Then print your final certificate of credits earned for your records. Attendees are responsible for maintaining their own record of credits earned.

**Note:** Once you have printed your certificate, you are not able to go back and edit any additional sessions. This certificate is your final CEU certificate for the conference.

The deadline to complete session evaluations is **December 19, 2019**. Please contact the NSGC Executive Office at [nsgc@nsgc.org](mailto:nsgc@nsgc.org) if you need assistance. NSGC will not issue CEU certificates if session evaluations are not completed by **December 19, 2019**. No exceptions will be made.



## Overall Conference Evaluation

NSGC has commissioned Freeman Research and Measurement to conduct our 2019 overall conference evaluation. You will receive a link to the overall conference evaluation via email within one week following the conference. Please be assured that your answers will be used in summary form only, and your personal information will be held in strict confidence.

NSGC is continually looking to improve your conference experience and would greatly appreciate your feedback. Thank you in advance for completing the evaluation.



## 2019 Annual Conference Session Recordings

View sessions you miss in Salt Lake City, earn additional CEUs and review the valuable information you gathered during the conference by pre-purchasing the 2019 Annual Conference recordings. The conference recordings package includes synced audio and PowerPoint Presentations for pre- and post-conference symposia, plenary and educational breakout sessions.\*

The session recordings package is available at a reduced price of \$149 for all conference attendees.\*\* Registered attendees will be able to order the Annual Conference session recordings through November 8, 2019, at the discounted rate, or following the conference at full price. The Annual Conference recordings package will be made available to purchasers in January 2020.

To earn Category 1 CEUs for recordings, it is required that you complete and pass a quiz included at the conclusion of each session.

Visit [www.nsgc.org/conference](http://www.nsgc.org/conference) or stop by the registration desk to add session recordings to your registration.

*\*With speaker approval.*

*\*\*Discounted package rates only available when purchased with conference registration.*



## Attendee List Information

Attendee lists are posted on the NSGC website. An updated list will be posted following the conference along with session handouts. Attendee lists are provided solely for networking and may not be used for solicitation purposes. NSGC is not responsible for errors or omissions.



## Handouts and Presentations

NSGC offers electronic versions of session handouts, when submitted in advance by speakers. All session handouts (provided by speakers) are posted on the NSGC website and in the NSGC Annual Conference mobile app, and will be available until March 1, 2020.

To download session handouts go to:

[www.nsgc.org/conferencehandouts](http://www.nsgc.org/conferencehandouts)

To download pre- and post-conference symposia handouts go to:

[www.nsgc.org/PCShandouts](http://www.nsgc.org/PCShandouts)

# Conference Information continued



## Registration Hours

### East Registration

#### MONDAY, NOVEMBER 4

5:00 pm – 7:00 pm

#### TUESDAY, NOVEMBER 5

7:00 am – 7:00 pm

#### WEDNESDAY, NOVEMBER 6

6:30 am – 7:00 pm

#### THURSDAY, NOVEMBER 7

7:00 am – 6:30 pm

#### FRIDAY, NOVEMBER 8

7:30 am – 2:30 pm



## Exhibitor Suite Hours

### Exhibit Halls A-B, Level 1

#### TUESDAY, NOVEMBER 5

5:00 pm – 8:00 pm

#### WEDNESDAY, NOVEMBER 6

9:30 am – 10:15 am

11:45 am – 1:30 pm

3:45 pm – 4:15 pm

5:30 pm – 7:30 pm

#### THURSDAY, NOVEMBER 7

9:45 am – 10:20 am

11:35 am – 3:00 pm



## Job Boards

Bulletin boards for attendees to post job opportunities are available in the booth across from NSGC Central in the Exhibitor Suite. Other forms of advertising are not permitted. Posted material will be monitored and inappropriate information is subject to removal at NSGC's discretion.



## Business Center Hours

The Business Center is located on the second floor of the Salt Palace Convention Center near conference room 252.

**Monday – Friday**

9:00 am – 5:00 pm



## Internet Access

Wireless Internet is available in all meeting spaces and common areas at the Salt Palace Convention Center.

To get onto the WiFi:

1. Connect to **NSGC2019**
2. Enter password **40years!**
3. Launch a web browser and click on the connect button on the splash page



## Conflict of Interest Disclosures

All presenters are required to disclose any conflicts of interest (COI) related to their presentation.

To view COI disclosures, visit [www.nsgc.org/conferencedisclosures](http://www.nsgc.org/conferencedisclosures).



## Sponsored Meal Sessions

Sponsored meal sessions require pre-registration. If you pre-registered to attend a session, a ticket was printed with your badge. To be admitted to each session, please bring your conference badge and the ticket that pertains to that session. We encourage you to arrive early for each session to allow all attendees time to be seated. If you did not pre-register for a session but are still interested in attending, please visit the registration desk to check availability for each session.

Please note that because quantities are limited, not all attendees will receive food and beverage with their admittance. Please check your ticket to see whether the sponsor will provide food, or if you are encouraged to bring your own.



## Executive Office Information

### NSGC Executive Office

330 N. Wabash Avenue, Suite 2000

Chicago, IL 60611 USA

Phone: 312.321.6834

Email: [nsgc@nsgc.org](mailto:nsgc@nsgc.org)

Website: [www.nsgc.org](http://www.nsgc.org)

### EXECUTIVE DIRECTOR

**Meghan Carey**

[mcarey@nsgc.org](mailto:mcarey@nsgc.org)

Peanut butter & jelly.  
Donuts & coffee.  
Cookies & milk.

## Some combinations are meant to be.

At Invitae, we are proud to work alongside genetic counselors, providing patients with the best possible care. By making genetic information more affordable and accessible, we are transforming healthcare. Together, we help patients make better decisions about:

- hereditary cancer
- reproductive health
- cardiology
- neurology
- pediatrics
- metabolic disorders
- and more

Invitae and genetic counselors—  
making healthcare **better, together.**



# Schedule-at-a-Glance

<b>MONDAY, NOVEMBER 4</b>						
12:00 pm – 6:00 pm	NSGC Leadership Development Program   Room 258					
5:00 pm – 7:00 pm	Registration Open   East Registration					
7:00 pm – 10:00 pm	Association of Genetic Counseling Program Directors (AGCPD) Annual Meeting   Room 155D					
<b>TUESDAY, NOVEMBER 5</b>						
7:00 am – 7:00 pm	Registration Open   East Registration					
7:30 am – 9:30 am	Accreditation Council for Genetic Counseling (ACGC) Office Hours   Room 258					
8:00 am – 2:00 pm	CEU Pre-Conference Symposia   Pre-registration required					
	A01: A Heart to Heart Training: Advanced Topics in Traumatic Events Using Cardiogenetics as an Illustration Room 155BC	A02: Building Skill for Cultural Conversations in Genetic Counseling Room 155EF	A03: Practical Tips for the Practicing Genetic Counselor: Somatic Testing and Hematologic Cancers Room 255EF	A04: Measuring Up: Incorporating Patient Reported Outcomes in Clinic and Research Room 255BC	A05: Perinatal Palliative Care and the Genetic Counselor: Optimizing Multi-Disciplinary Collaboration for Holistic Care of Critically Ill Infants and Their Families Room 355BC	A06: Redesigning the Way We Work to Improve Efficiency Room 355EF
1:30 pm – 2:30 pm	Welcome to the Annual Conference: First-Time Attendees   Room 251					
3:00 pm – 3:15 pm	Opening Remarks   Grand Ballroom					
3:15 pm – 3:45 pm	CEU A07: 40 Years of the Genetic Counseling Profession: A Foundation for the Future   Grand Ballroom					
3:45 pm – 4:15 pm	Natalie Weissberger Paul National Achievement Award   Grand Ballroom					
4:15 pm – 4:45 pm	CEU A08: Enabling the Beautiful Uncertainty of Life: My Journey With PGT-M   Grand Ballroom					
5:00 pm – 8:00 pm	Welcome Reception in Exhibitor Suite   Exhibit Halls A-B, Level 1 <b>Sponsored by: AveXis</b>					
5:45 pm – 7:00 pm	CEU A09: Posters With Authors, Group A Posters   Exhibit Halls A-B, Level 1					
7:00 pm – 8:15 pm	Sanofi Genzyme Meeting Room 255D		Rhythm Gold Academy Program Room 355D		Late Career SIG Room 258	
7:00 pm – 10:00 pm	Various Program Reunions   See page 14 for more information					
7:15 pm – 8:00 pm	Public Health SIG   Room 260A					
7:30 pm – 9:30 pm	Journal of Genetic Counseling Editorial Board Meeting   Room 257A					
<b>WEDNESDAY, NOVEMBER 6</b>						
6:30 am – 7:00 pm	Registration Open   East Registration					
7:00 am – 7:45 am	Sponsored Breakfast Sessions					
	CEU B01: Look Before You Leap: The Clinical Value of Genome-Wide NIPT Room 250 <b>Sponsored by: Roche Diagnostics</b>			B02: Termination of Pregnancy for Indications of Genetic Disorder or Fetal Anomaly in Advanced Gestations at Boulder Abortion Clinic Room 251 <b>Sponsored by: Boulder Abortion Clinic</b>		
7:00 am – 7:45 am	Student / New Member SIG Meeting   Room 258					
7:00 am – 8:30 am	Accreditation Council for Genetic Counseling (ACGC) Office Hours   Room 257A					
8:00 am – 8:35 am	CEU B03: Janus Lecture: Enzyme Replacement Therapy for Mucopolysaccharidosis: How Ongoing Research Can Change the Understanding of Rare Diseases Grand Ballroom					
8:35 am – 9:35 am	CEU B04: Professional Issues Panel   Grand Ballroom					
9:30 am – 10:15 am	Exhibitor Suite Open / Networking Break   Exhibit Halls A-B, Level 1					



**KEY:**

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<span style="background-color: #FFDAB9; border: 1px solid black; display: inline-block; width: 15px; height: 10px;"></span> PRE-CONFERENCE SYMPOSIA (ORANGE)	<span style="background-color: #DDA0DD; border: 1px solid black; display: inline-block; width: 15px; height: 10px;"></span> EDUCATIONAL BREAKOUT SESSIONS & WORKSHOPS (FUCHSIA)
<span style="background-color: #ADD8E6; border: 1px solid black; display: inline-block; width: 15px; height: 10px;"></span> POST-CONFERENCE SYMPOSIA (TEAL)	<span style="background-color: #FFB6C1; border: 1px solid black; display: inline-block; width: 15px; height: 10px;"></span> SPONSORED SESSIONS (SALMON)
<span style="background-color: #90EE90; border: 1px solid black; display: inline-block; width: 15px; height: 10px;"></span> PLENARY SESSIONS (LIME)	<span style="background-color: #C8A2C8; border: 1px solid black; display: inline-block; width: 15px; height: 10px;"></span> PROGRAM REUNIONS (LILAC)
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<span style="background-color: #ADD8E6; border: 1px solid black; display: inline-block; width: 15px; height: 10px;"></span> EXHIBITOR SUITE (BLUE)	

<b>WEDNESDAY, NOVEMBER 6 CONTINUED</b>						
11:15 am – 12:15 pm	<b>CEU Workshops and Lectures</b>   <i>*Pre-registration required</i>					
	<b>B05:</b> Should All Women With Breast Cancer be Offered Genetic Testing? A Debate <i>Grand Ballroom</i>	<b>*B06:</b> Building Stronger Communities: Confronting White Womanhood <i>Room 155BC</i>	<b>*B07:</b> How to Review a Manuscript for a Journal: A Practical Workshop Aimed at Facilitating Research and Professional Development for Genetic Counselors <i>Room 155EF</i>	<b>*B08:</b> Improving Your Communication With All Your Patients: Techniques to Communicate Across Literacy and Language <i>Room 255BC</i>	<b>*B09:</b> Leadership Workshop for New Genetic Counselors <i>Room 355EF</i>	<b>*B10:</b> So Consumer Genetics Is Here... What Is the Role of the Genetic Counselor, and How Do We Deal With This in Clinic? <i>Room 355BC</i>
11:45 am – 1:30 pm	<b>Exhibitor Suite Open</b>   <i>Exhibit Halls A-B, Level 1</i>					
12:30 pm – 1:00 pm	<b>Marketing and Communications Workgroup Meeting</b>   <i>Room 259</i>					
12:30 pm – 1:30 pm	<b>Committee Meetings</b>					
	<b>Education Committee</b> <i>Room 355A</i>	<b>Outcomes Committee</b> <i>Room 260B</i>		<b>Public Policy Committee Meeting</b> <i>Room 257B</i>		
12:30 pm – 1:45 pm	<b>CEU Sponsored Lunch Sessions</b>					
	<b>B11:</b> Unparalleled Clarity and New Mutations: Clinical RNA Testing Provides Answers Beyond DNA <i>Room 250</i> <b>Sponsored by: Amry Genetics</b>	<b>B12:</b> Important Advancements for Precision Medicine in Oncology and Prenatal Genetics <i>Room 251</i> <b>Sponsored by: Myriad Genetic Laboratories</b>				
12:45 pm – 1:45 pm	<b>Membership Committee</b>   <i>Room 260A</i>					
1:15 pm – 2:15 pm	<b>Committee Meetings</b>					
	<b>Access and Service Delivery Committee</b> <i>Room 257A</i>	<b>Program Committee</b> <i>Room 255D</i>		<b>Practice Guidelines Committee</b> <i>Room 258</i>		
2:30 pm – 3:45 pm	<b>CEU Educational Breakout Sessions</b>					
	<b>B13:</b> “Dear Seymour”: The Work and Applications of Dr. Seymour Kessler’s Seminal Papers on Psychosocial Aspects of Genetic Counseling <i>Room 155BC</i>	<b>B14:</b> Digging Into Polygenic Risk Scores for Complex Disorders: Cancer, Cardio, Psychiatry... and More! <i>Grand Ballroom</i>	<b>B15:</b> From Genetics to Genomics: Evolving Liability Implications for Practitioners <i>Room 255BC</i>	<b>B16:</b> Hot Topics in Teratology: Zika, Marijuana and Maternal Therapies for Genetic Disease <i>Room 255EF</i>	<b>B17:</b> Seriously, Can Online Education Work for Genetic Counseling? Adapting to the Demands of Training More and Diverse Genetic Counselors <i>Room 155EF</i>	
3:45 pm – 4:15 pm	<b>Exhibitor Suite Open / Networking Break</b>   <i>Exhibit Halls A-B, Level 1</i>					
4:15 pm – 5:20 pm	<b>CEU B18:</b> Dr. Beverly Rollnick Memorial Lecture: Living a Life Worth Celebrating   <i>Grand Ballroom</i>					
5:20 pm – 5:50 pm	<b>CEU B19:</b> Audrey Heimler Special Project Award Presentation   <i>Grand Ballroom</i>					
5:30 pm – 7:30 pm	<b>Exhibitor Suite Open</b>   <i>Exhibit Halls A-B, Level 1</i>					
6:00 pm - 7:15 pm	<b>SIG Leaders Reception</b>   <i>Room 255D</i>					
6:00 pm - 7:15 pm	<b>Past Board Member Reception</b>   <i>Room 355A</i>					
6:15 pm – 7:30 pm	<b>CEU B20:</b> Posters With Authors, Group B Posters   <i>Exhibit Halls A-B, Level 1</i>					
7:00 pm – 10:00 pm	<b>Various Program Reunions</b>   <i>See page 14 for more information</i>					
7:30 pm – 8:45 pm	<b>CEU Sponsored Evening Sessions</b>					
	<b>B21:</b> Understanding Residual Risk in Expanded Carrier Screening: Self-Reported Ancestry vs. Molecular Ancestry <i>Room 250</i> <b>Sponsored by: Sema4</b>	<b>B22:</b> An Overview of the Historical Perspective and Current Status of Personalized/Precision Medicine <i>Room 251</i> <b>Sponsored by: Sanofi Genzyme</b>				
8:00 pm – 8:45 pm	<b>Tour of Myriad Genetic Laboratories</b>   <i>Myriad Genetic Laboratories</i>   <i>Pre-registration required</i>   <i>See page 53 for more information</i>					
8:50 pm – 9:35 pm	<b>Tour of Myriad Genetic Laboratories</b>   <i>Myriad Genetic Laboratories</i>   <i>Pre-registration required</i>   <i>See page 53 for more information</i>					

# Schedule-at-a-Glance continued

THURSDAY, NOVEMBER 7							
7:00 am – 6:30 pm	Registration Open   East Registration						
7:00 am – 7:45 am	SIG Meetings						
	CF and CFTR Spectrum SIG Room 257A	Education SIG Room 257B	Leadership and Management SIG Room 255D	International SIG Room 355A	Psychiatric SIG Room 258	Ophthalmology and Hearing Loss SIG Room 260A	Metabolic/LSD SIG Room 260B
7:00 am – 7:45 am	CEU Sponsored Breakfast Sessions						
	C01: Chromosomal Microarray: Going, Going, Gone? Comprehensive Copy Number Variant Detection from Next Generation Sequencing Data Room 250 Sponsored by: <b>PreventionGenetics</b>			C02: The Undiagnosed Second Diagnosis: Utilizing Genomic Technologies to Identify and Understand Complex Phenotypes Room 251 Sponsored by: <b>PerkinElmer</b>			
7:00 am – 8:00 am	Mindful Yoga   Marriott Hotel, Deer Valley Room   Pre-registration required Sponsored by: <b>Progenity</b>						
8:00 am – 9:15 am	CEU C03: NSGC State of the Society Address   Grand Ballroom						
9:15 am – 9:45 am	Incoming Presidential Address   Grand Ballroom						
9:45 am – 10:20 am	Exhibitor Suite Open / Networking Break   Exhibit Halls A-B, Level 1						
10:20 am – 11:35 am	CEU Platform Presentations						
	C04: Access and Service Delivery Room 255EF	C05: Cancer Grand Ballroom	C06: Cardiovascular Room 255BC	C07: Conversations Around Diversity Room 155EF	C08: Prenatal Room 155BC		
11:35 am – 3:00 pm	Exhibitor Suite Open   Exhibit Halls A-B, Level 1						
12:00 pm – 1:15 pm	SIG Meetings						
	Cancer SIG Room 155D	Research SIG Room 257B	Neurogenetics SIG Room 355A	ART/Infertility SIG Room 355D	Laboratory/Industry SIG Room 258	Cardiovascular SIG Room 259	Pediatric and Clinical Genetics SIG Room 260B
12:00 pm – 1:15 pm	CEU Sponsored Lunch Sessions						
	C09: Functional Modeling – The Next Frontier in Variant Interpretation Room 250 Sponsored by: <b>Invitae</b>			C10: How to Avoid Legal and Ethical Pitfalls as a Genetic Counselor Room 251 Sponsored by: <b>GeneDX</b>			
12:15 pm – 12:45 pm	American Board of Genetic Counseling (ABGC) Business Meeting   Grand Ballroom						
12:45 pm – 1:15 pm	Accreditation Council for Genetic Counseling (ACGC) Presentation   Grand Ballroom						
12:15 pm – 1:15 pm	Precision Medicine SIG Meeting   Room 255D						
1:20 pm – 2:35 pm	CEU C11: Posters With Authors, Group C Authors   Exhibit Halls A-B, Level 1						
2:45 pm – 3:00 pm	The Gnome and Beyond Scavenger Hunt and Passport to Prizes Drawing   NSGC Central Booth #415						
3:10 pm – 4:40 pm	CEU Educational Breakout Sessions						
	C12: A History of Genetic Discrimination: Reviewing Our Past and Looking Toward the Future Room 255BC	C13: NSGC and ASHG Joint Session: Genetic Counselors in Research: From Dabbling in Clinic to an NIH Grant Room 255EF	C14: Beyond Cystic Fibrosis: Pulmonary Genetic Disorders in Adulthood Room 155BC	C15: Challenging the Comfort Zone: Debated Testing Strategies in Cardiovascular Genetics Room 155EF	C16: The New GC in Town: Demystifying the Role of Gene Curation in Variant Interpretation, Clinical Reporting and Case Reanalysis Grand Ballroom		
5:00 pm – 5:35 pm	CEU C17: Human Genome Editing: The Current State of Research and Clinical Practice   Grand Ballroom						
5:35 pm – 5:50 pm	CEU C18: Best Full Member Abstract Award   Grand Ballroom						
5:50 pm – 6:05 pm	CEU C19: Beth Fine Kaplan Best Student Abstract Award Presentation   Grand Ballroom						
6:05 pm – 6:35 pm	CEU C20: Jane Engelberg Memorial Fellowship (JEMF) Presentation   Grand Ballroom						

**KEY:**

<span style="background-color: #FFC0CB; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> REGISTRATION AND BREAKS (PINK)	<span style="background-color: #90EE90; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> CONCURRENT PAPERS/POSTER PRESENTATION (GREEN)
<span style="background-color: #FFDAB9; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> PRE-CONFERENCE SYMPOSIA (ORANGE)	<span style="background-color: #DDA0DD; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> EDUCATIONAL BREAKOUT SESSIONS & WORKSHOPS (FUCHSIA)
<span style="background-color: #ADD8E6; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> POST-CONFERENCE SYMPOSIA (TEAL)	<span style="background-color: #FFB6C1; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> SPONSORED SESSIONS (SALMON)
<span style="background-color: #90EE90; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> PLENARY SESSIONS (LIME)	<span style="background-color: #C8A2C8; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> PROGRAM REUNIONS (LILAC)
<span style="background-color: #FFD700; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> NSGC COMMITTEE, SIG AND LEADERSHIP ACTIVITIES (YELLOW)	<span style="background-color: #DC143C; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> ORGANIZATIONAL EVENTS (RED)
<span style="background-color: #ADD8E6; border: 1px solid black; display: inline-block; width: 20px; height: 10px;"></span> EXHIBITOR SUITE (BLUE)	

<b>THURSDAY, NOVEMBER 7 CONTINUED</b>					
6:45 pm – 7:30 pm	Available Resources and Support for Telegenetics: Programs of the NYMAC Regional Genetics Network   <i>Room 259</i>				
7:00 pm – 9:00 pm	Code Talker Award Ceremony <i>Room 251</i> <b>Presented by: Invitae and NSGC</b>				
7:00 pm – 10:00 pm	Unwind at Keys on Main <i>242 South Main St.</i> <b>Sponsored by: ARUP Laboratories</b>				
7:00 pm – 10:00 pm	Various Program Reunions   <i>See page 14 for more information</i>				
<b>FRIDAY, NOVEMBER 8</b>					
7:00 am – 1:00 pm	Annual Conference Outreach Event   <i>Room 255D</i>				
7:30 am – 2:30 pm	Registration Open   <i>East Registration</i>				
7:00 am – 7:45 am	Sponsored Breakfast Sessions				
	CEU D01: A Brave New World: A Family's Experience With New Therapies for Spinal Muscular Atrophy <i>Room 250</i> <b>Sponsored by: Integrated Genetics</b>	D02: The ABC's of DTC Genetic Testing <i>Room 251</i> <b>Sponsored by: 23andMe</b>			
8:00 am – 9:30 am	CEU Education Breakout Sessions				
	D03: In Utero Stem Cell Transplantation: Historical Context, Present State and the Future of Fetal Molecular Therapies <i>Room 155BC</i>	D04: The Emerging Roles of Genetic Counselors as Consumers Embrace Healthy Genomic Screening <i>Room 255EF</i>	D05: Getting to the Heart of Our Practice: Developing an Evidence Base to Improve Cardiovascular Genetic Counseling <i>Room 255BC</i>	D06: How to Talk to Your Patients About Imaging: What to Do When There Aren't NCCN Guidelines <i>Grand Ballroom</i>	D07: Weighing the Alternatives: Non-traditional Approaches to Improve Genetic Counseling Access and Efficiency <i>Room 155EF</i>
10:00 am – 10:50 am	CEU D08: Meeting the Demand for Genetic Counseling Through Artificial Intelligence: Can We Clone Our Skill Set?   <i>Grand Ballroom</i>				
10:50 am – 11:50 am	CEU D09: Late-Breaking Plenary: Emerging Therapies for Adult-Onset Neurologic Diseases: Possibilities, Pitfalls and Patient Impact   <i>Grand Ballroom</i>				
12:15 pm – 1:30 pm	CEU Platform Presentations				
	D10: Education <i>Room 255EF</i>	D11: Ethical and Psychosocial Research <i>Room 255BC</i>	D12: Neuromuscular/ Psychiatric <i>Room 155EF</i>	D13: Patient Utilization of Genetic Test Results <i>Room 155BC</i>	D14: Innovations in Somatic Tumor Testing <i>Grand Ballroom</i>
2:00 pm – 5:30 pm	CEU Post-Conference Symposia   <i>Pre-registration required</i>				
	D15: Genetic Counselor Fingerprints on the Business Side: Clinical Product Strategy, Development and Lifecycle Skills Workshop <i>Room 355BC</i>	D16: Genetics Beyond the Binary: How to Incorporate Gender Diversity Into the Concepts of Genetics <i>Room 255EF</i>		D17: Late-Breaking Cancer Topics <i>Room 355EF</i>	

Join us at the

# NSGC

38th Annual Conference



**November 5-8, 2019**

Salt Palace Convention Center  
Salt Lake City, Utah

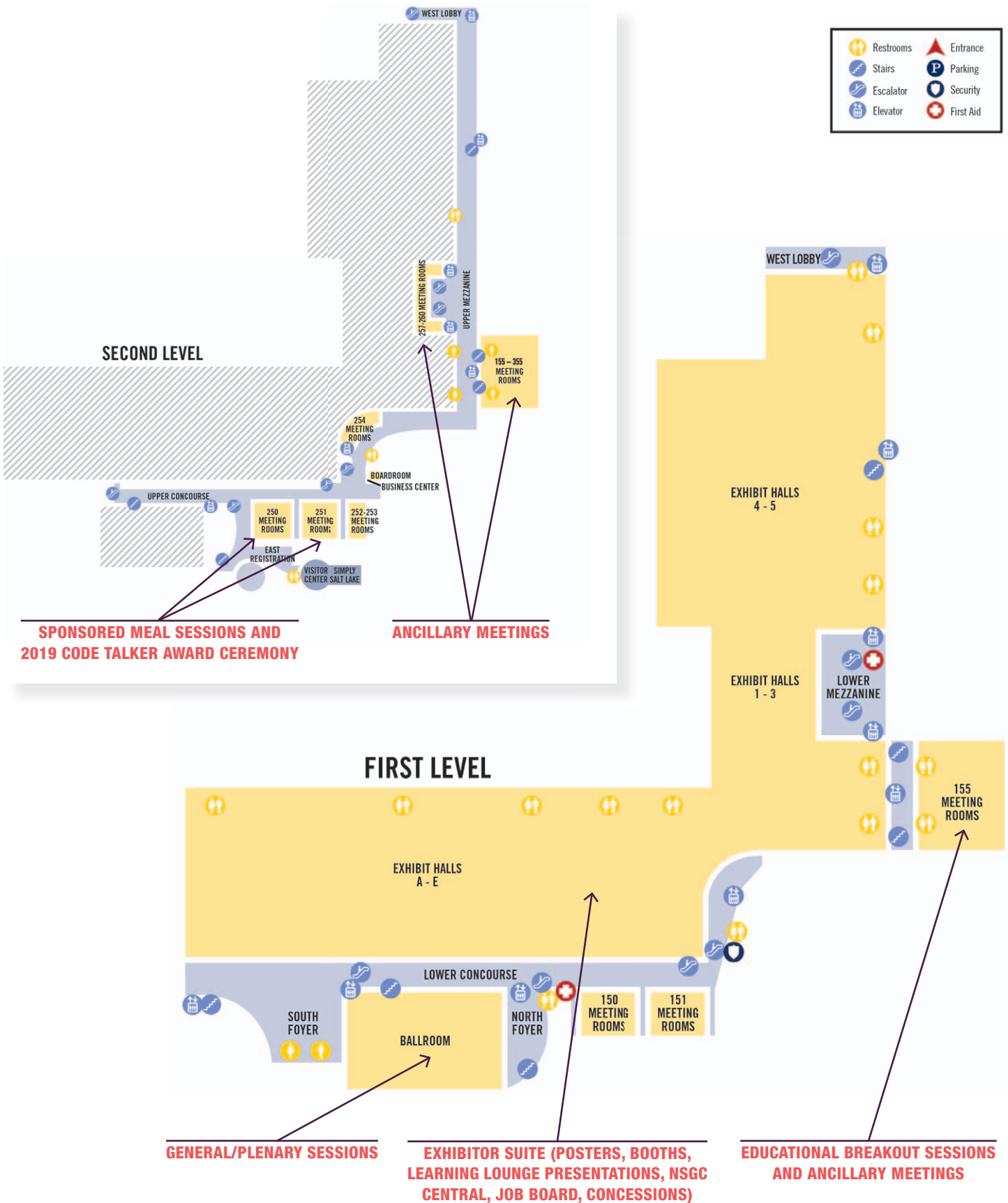
**Visit Booth #802**

to learn more about  
communication and collaboration  
in biomarker testing.

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in oncology at **AZOncologyID.com**

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# Convention Center Map



# Reunion Information

Time	Reunion Name	Location
<b>TUESDAY, NOVEMBER 5</b>		
7:00 pm	University of Maryland	<b>Lake Effect</b> 155 West 200 Street   801.285.6494
7:00 pm	University of Utah Graduate Program in Genetic Counseling	<b>Squatters Pub</b> 147 Broadway   801.363.2739
7:30 pm	The Ohio State University Genetic Counseling Graduation Program	<b>BTG Wine Bar</b> 404 South West Temple Street   801.359.2814
7:30 pm	Case Western Reserve University	<b>Settebello</b> 260 South 200 West   801.322.3556
7:30 pm	University of Arkansas for Medical Sciences	<b>Buca di Beppo</b> 202 West 300 South   901.575.6262
8:00 pm	Stanford Genetic Counseling Program	<b>Under Current (Mezzanine)</b> 270 South 300 East   801.574.2556
<b>WEDNESDAY, NOVEMBER 6</b>		
7:00 pm	Sarah Lawrence College	<b>Squatters Pub</b> 147 Broadway   801.363.2739
7:00 pm	University of Alabama at Birmingham	<b>Buca di Beppo</b> 202 West 300 South   801.575.6262
7:00 pm	Keck Graduate Institute	<b>T.F. Brewing</b> 936 South 300 West   385.270.5972
7:30 pm	Bay Path University Masters of Science in Genetic Counseling Program	<b>Salt Lake Marriott Downtown at City Creek</b> 75 South West Temple   801.537.0800
7:30 pm	Boston University Genetic Counseling Program	<b>Bourbon House</b> 19 East 200 South   801.746.1005
7:30 pm	University of Pittsburgh Genetic Counseling Program	<b>Kimpton Hotel Monaco</b> 15 West 200 South   801.595.0000   Please RSVP: <a href="mailto:publichealth.pitt.edu/nsgc">publichealth.pitt.edu/nsgc</a>
7:30 pm	Wayne State University	<b>Poplar Street Pub</b> 242 South 200 West   801.532.2715
8:00 pm	Brandeis University	<b>Lake Effect (Rabbit Hole Room)</b> 155 West 200 Street   801.285.6494
8:00 pm	Cincinnati Genetic Counseling Graduate Program	<b>Squatters Pub (The Potting Shed Room)</b> 147 Broadway   801.363.2739
8:00 pm	University of Minnesota Genetic Counseling Program	<b>Stanza Bistro and Wine Bar</b> 454 East 300 South   801.746.4441
8:00 pm	University of Michigan	<b>Gracie's</b> 326 South West Temple   801.819.7565
<b>THURSDAY, NOVEMBER 7</b>		
6:30 pm	Augustana-Sanford Genetic Counseling Graduate Program	<b>Gracie's</b> 326 South West Temple   801.819.7565
6:30 pm	Emory Genetic Counseling Training Program	<b>Sonoma Grill</b> 110 West Broadway   801.890.6612
7:00 pm	LIU Post Genetic Counseling Graduate Program	<b>Kimpton Hotel Monaco Salt Lake City (Bambara Restaurant)</b> 15 West 200 South   801.990.9731
7:00 pm	Mount Sinai Genetic Counseling Program	<b>Sonoma Grill</b> 110 West Broadway   801.890.6612
7:00 pm	University of Texas Genetic Counseling Program	<b>Squatters Pub (#134)</b> 147 Broadway   801.363.2739
7:30 pm	Northwestern University Graduate Program in Genetic Counseling	<b>Caffe Molise</b> 404 South West Temple   801.364.8833
8:00 pm	Canadian Programs Reunion	<b>From Scratch</b> 62 East Gallivan Avenue   801.961.9000



*Introducing*



**BEYOND DNA FOR  
UNPARALLELED CLARITY**

+RNAinsight works in tandem with DNA testing to identify more patients with hereditary cancer, decrease variants of unknown significance in real-time, and provide more accurate results to inform patient care.<sup>1,2</sup>

[RNAinsight.com/NSGC2019](https://RNAinsight.com/NSGC2019)

1. Ambrly Genetics, internal data on file  
2. Karam R. *et al.* RNA Genetic Testing in Hereditary Cancer Improves Variant Classification and Patient Management. ACMG 2019.

# Session Speakers + Objectives

**TUESDAY, NOVEMBER 5**

## Pre-Conference Symposia

8:00 am – 2:00 pm

### **A01: A Heart to Heart Training: Advanced Topics in Traumatic Events Using Cardiogenetics as an Illustration**

**5.0 Contact Hours**

*Heather MacLeod, MS CGC, SDY Case Registry Data Coordinating Center; Samuel Sears, PhD, East Carolina University; Cindy James, ScM, PhD, CGC, Johns Hopkins University; Jodie Ingles, MPH, PhD, The University of Sydney; Christina Rigelsky, MS, LGC, Cleveland Clinic; Rebecca Miller, LCGC, Inova Health System; Rebecca McClellan, MGC, CGC, Johns Hopkins Center for Inherited Heart Disease; Tara Hart, MS, CGC, GeneDx; Shannon Hourigan, PhD, Inherited Cardiac Arrhythmia Program at Boston Children's Hospital*

- Examine the psychosocial impact of traumatic cardiac events on the patient.
- Explore how traumatic diagnoses affect family members and family relationships.
- Illustrate the impact of genetic testing on patients and families facing traumatic events.
- Identify resources to support patients and families experiencing traumatic diagnoses events.

Attendance Verification Code: \_\_\_\_\_

### **A02: Building Skill for Cultural Conversations in Genetic Counseling**

**5.0 Contact Hours**

*Liza Talusan, PhD, LT Coaching and Consulting, LLC*

- Examine our own individual identities and the role that our identities play in our work.
- Identify salient learned biases that have been developed in our work and lives.
- Build skills for engaging in difficult conversations around identity and identity-consciousness.
- Create individual, departmental and institutional action plans for how to get proximate to issues of identity.

Attendance Verification Code: \_\_\_\_\_

### **A03: Practical Tips for the Practicing Genetic Counselor: Somatic Testing and Hematologic Cancers**

**5.0 Contact Hours**

*Jennie Vagher, CGC, Huntsman Cancer Institute; Jaclyn Schienda, ScM, LGC, Dana-Farber Cancer Institute; Brian Shirts, MD, PhD, University of Washington; Jilliane Sotelo, MS, LGC, Thermo Fisher Scientific; Dana Farengo Clark, MS, MS, LCGC, University of Pennsylvania-Abramson Cancer Center; Kelly Knickelbein, MS, CGC, Thermo Fisher Scientific; Shannon Stasi, MS, LCGC, Seattle Children's Hospital; Pia Summerour, MS, CGC, Ambry Genetics; Prapti Patel, MD, UT Southwestern Medical Center; Elise Fiala, MS, CGC, Memorial Sloan Kettering*

- Summarize the current state of the science of hematological malignancies, including new hereditary hematological malignancy gene discovery, common hematological malignancies encountered in family history, and clonal hematopoiesis of indeterminate potential (CHIP).
- Present a clinical toolkit for incorporating somatic testing into a genetic counselor's clinic workflow including referrals from oncologists, discussions at tumor boards and test selection.
- Compare the technologies and bioinformatic strategies used in different aspects of somatic testing including: solid tumors, hematologic cancers and liquid biopsies.

Attendance Verification Code: \_\_\_\_\_

### **A04: Measuring Up: Incorporating Patient Reported Outcomes in Clinic and Research**

**5.0 Contact Hours**

*Megan T. Cho, ScM, Johns Hopkins University, National Institute of Health Genetic Counseling Training Program; Kelly East, MS, CGC, HudsonAlpha Institute for Biotechnology; Karen Sepucha, PhD, Massachusetts General Hospital; Marion McAllister, MSc, PhD, Cardiff University, University Hospital of Wales; Barbara Biesecker, PhD, MS, CGC, RTI International; Janet L. Williams, MS, LGC, Geisinger; Vincent Staggs, PhD, Children's Mercy Kansas City, University of Missouri KC; Courtney Berrios, MSc, ScM, CGC, Children's Mercy Kansas City*

- Summarize important criteria in evaluating and selecting patient reported outcome measures (PROMs) for use in clinic and research.
- Discuss interpretation and limitations of statistical analysis of PROMs.
- Practice applying PROMs to research questions.
- Consider ways to incorporate outcome measurement into one's clinical practice.

Attendance Verification Code: \_\_\_\_\_



## A05: Perinatal Palliative Care and the Genetic Counselor: Optimizing Multi-Disciplinary Collaboration for Holistic Care of Critically Ill Infants and Their Families

### 5.0 Contact Hours

Rebecca Carter, MS, CGC, The University of Texas Health Science Center at Houston; Callie Diamonstein, MS, LCGC, UT Southwestern Medical Center, prior Inova Health System; Katrina Villegas, MA, Mama's Organized Chaos; Kristine Kowalski, MDiv, BCC, Johns Hopkins Hospital; Melissa Eatherly, MSN, FNP-BC, RNC-NIC, Inova Children's Hospital; Ryann Bierer, MD, University of Utah School of Medicine; Kathie Kobler, PhD, APRN, PCNS-BC, CHPPN, FPCN, Advocate Children's Hospital; Katelynn Sagaser, MS, CGC, Johns Hopkins Hospital

- Summarize existing literature surrounding palliative care in perinatal loss.
- Illustrate the roles of multiple healthcare professionals contributing to a perinatal palliative care team, including the distinct input of prenatal and pediatric genetic counselors.
- Describe proposed methods of collaboration with other disciplines and organizations to achieve optimal palliative care practice.
- Examine self-care techniques related to the professional and personal impact of working in palliative care.

Attendance Verification Code: \_\_\_\_\_

## A06: Redesigning the Way We Work to Improve Efficiency

### 5.0 Contact Hours

Maria Ana Barrera, BA, MPS, Designit; Erin Miller, MS, LGC, Cincinnati Children's Hospital Medical Center; Kendra Schaa, ScM, CGC, University of Iowa Hospitals and Clinics; Alekhya Narravula, MSc, MS, CGC, Centogene AG

- Identify common areas of inefficiencies and the benefits of addressing such areas to the genetic counseling workforce.
- Recognize principles of creative problem solving and design methodologies in the healthcare setting.
- Discuss application of learned methods in the healthcare setting.
- Apply learned methods to arrive at creative solutions to common inefficiencies reported by genetic counselors.

Attendance Verification Code: \_\_\_\_\_

## Plenary Sessions

3:15 pm – 3:45 pm

### A07: 40 Years of the Genetic Counseling Profession: A Foundation for the Future

#### 0.50 Contact Hour

Wendy Uhlmann, MS, CGC, University of Michigan Medical Center; Jennifer Malone Hoskovec, MS, CGC, University of Texas Medical School Houston; Mary Freivogel, MS, CGC, Invitae

- Examine the specific ways NSGC has supported growth of the profession of genetic counselors in the past, present and future.
- Illustrate strategies that successful genetic counselors have used to elevate our profession in the past and present that can be applied to the future.
- Examine how the history of our profession and its professional organization impacts genetic counselors today and in the future.

Attendance Verification Code: \_\_\_\_\_

4:15 pm – 4:45 pm

### A08: Enabling the Beautiful Uncertainty of Life: My Journey With PGT-M

#### 0.50 Contact Hour

Lee Cooper, JD, MBA, The IGDP

- Summarize a patient's practical, clinical and emotional experience with having a life-threatening inherited genetic condition and using PGT-M to have a child free from the inherited disease.
- Examine the important role, from a patient's perspective, of genetic counselors and other healthcare providers in communicating patient's family planning options.
- Outline "take-home" messages that will improve messaging/knowledge about PGT-M.

Attendance Verification Code: \_\_\_\_\_

## WEDNESDAY, NOVEMBER 6

## Sponsored Breakfast Sessions

7:00 am – 7:45 am

### B01: Look Before You Leap: The Clinical Value of Genome-Wide NIPT

#### 0.50 Contact Hour

Sarah Brandenberger, MS, CGC, MBA, Medical and Scientific Liaison, Women's Health, Roche Diagnostics; Liz Kunz, MD, Global Medical Affairs Director, NIPT/Women's Health, Roche Sequencing Solutions

- Examine the technology that makes whole-genome NIPT possible.
- Explore why whole-genome NIPT is not equivalent to a noninvasive whole genome screening test.
- Review the clinical data surrounding an expanded menu with NIPT screening.
- Give examples of potential dilemmas surrounding counseling patients on expanded NIPT results.

Sponsored by: 

Attendance Verification Code: \_\_\_\_\_

### B02: Termination of Pregnancy for Indications of Genetic Disorders or Fetal Anomaly in Advanced Gestations at Boulder Abortion Clinic

Warren Hern, PhD, Director of the Boulder Abortion Clinic

- Describe the relevance of these services to genetic counseling.
- Identify the purpose, basic principles and components of clinical practice including grief support.
- Outline the basic operative procedures and clinical results of this care.

Sponsored by: 

BOULDER ABORTION CLINIC

# Session Speakers + Objectives continued

## Plenary Sessions

8:00 am – 8:35 am

### **B03: Janus Lecture: Enzyme Replacement Therapy for Mucopolysaccharidosis: How Ongoing Research Can Change the Understanding of Rare Diseases**

0.50 Contact Hour

*Ashley Simpson Volz, MS, CGC, BioMarin Pharmaceutical, Inc.*

- Describe the historical and current landscape of enzyme replacement therapies (ERT) for Lysosomal Storage Disorders (LSD).
- Examine how the pharmaceutical industry has adapted clinical trial design and support of post-marketing research to meet the needs of patients with Mucopolysaccharidosis (MPS).
- Discuss how the genetic counseling role within clinic and industry is evolving to address new challenges presented by MPS patients receiving ERT.

Attendance Verification Code: \_\_\_\_\_

8:35 am – 9:35 am

### **B04: Professional Issues Panel**

1.00 Contact Hour

*Jodi Glickman*

- Summarize the fundamentals of executive presence.
- Review techniques for increasing your confidence when speaking in front of a group.
- Identify ways to communicate with more clarity and credibility.

Attendance Verification Code: \_\_\_\_\_

## Workshops and Lectures

10:15 am – 12:15 pm

### **B05: Should All Women With Breast Cancer Be Offered Genetic Testing? A Debate**

No Pre-registration required

2.0 Contact Hours

*Mark E. Robson, MD, Memorial Sloan Kettering Cancer Center; Peter Beitsch, MD, Dallas Surgical Group - TME/Breast Care Network; Sue Friedman, DVM, FORCE; Lisa Madlensky, PhD, CGC, UC San Diego – Moores Cancer Center; David Euhus, MD, Johns Hopkins University*

- Distinguish the relative risks and benefits of germline genetic testing for all women with breast cancer.
- Compare different panel testing strategies for all women with breast cancer.
- Propose potential implementation of germline genetic testing for all women with breast cancer.

Attendance Verification Code: \_\_\_\_\_

### **B06: Building Stronger Communities: Confronting White Womanhood\***

2.0 Contact Hours

*Rhiannon Childs, Ohio Women's Alliance; Heather Marie Scholl, BA, MFA, Confronting White Womanhood; Sophie Ellman-Golan, BA, Jews Against White Nationalism*

- Define privileged identity.
- Articulate experiences of privilege and racial harm.
- Examine how to use one's own experiences to engage with other privileged people with differing views.
- Analyze areas where one can use their privileged identity to support underrepresented individuals.

Attendance Verification Code: \_\_\_\_\_

*\*We do not believe in creating white-only spaces; all people are welcome to attend our workshop. We recognize that as a society, there are many areas to tackle in order to fully address privilege and discrimination. We designed this particular workshop to focus on educating and informing white women, committed to being part of an intersectional feminist movement, to unpack the ways they uphold and benefit from white privilege. We anticipate that these frank discussions and stories may be triggering, especially for people of color, and invite you to share your concerns with our trained moderators.*

### **B07: How to Review a Manuscript for a Journal: A Practical Workshop Aimed at Facilitating Research and Professional Development for Genetic Counselors**

2.0 Contact Hours

*Kami Wolfe Schneider, MS, CGC, University of Colorado, Children's Hospital Colorado; Beverly Yashar, MS, PhD, University of Michigan; Heather Zierhut, PhD, MS, LGC, University of Minnesota; Melanie Myers, PhD, Cincinnati Children's Hospital Medical Center; Christina Palmer, MS, PhD, LCGC, UCLA*

- Summarize the personal and professional benefits of acting as a peer reviewer for manuscripts that have been submitted for potential publication in journals.
- Differentiate elements of the process of manuscript review.
- Formulate the critical features of a manuscript review.
- Identify ethical considerations associated with reviewing a manuscript for a journal.

Attendance Verification Code: \_\_\_\_\_

## **B08: Improving Your Communication With All Your Patients: Techniques to Communicate Across Literacy and Language**

### **2.0 Contact Hours**

*Galen Joseph, PhD, University of California San Francisco; Mari Gilmore, MS, CGC, Kaiser Permanente Center for Health Research; Laura Amendola, MS, CGC, University of Washington; Robin Tropp Lee, MS, LCGC, University of California San Francisco*

- Identify principles of and evidence-based strategies for effective communication with patients of various health literacy and numeracy levels.
- Identify excerpts in transcripts of genetic and genomic counseling sessions in which communication strategies impeded and enhanced the genetic counseling process.
- Discuss specific communication strategies and techniques for improving patient engagement, comprehension and satisfaction in the counseling session.
- Practice strategies that improve patient comprehension and engagement.

**Unrestricted educational support provided by:**  **Amicus Therapeutics**

Attendance Verification Code: \_\_\_\_\_

## **B09: Leadership Workshop for New Genetic Counselors**

### **2.0 Contact Hours**

*Elizabeth Kearney, MS, CGC, MBA; Erica Ramos, MS, LCGC, Geisinger*

- Explore qualities of leadership.
- Examine unconventional examples of leadership.
- Define leadership in terms of outcomes instead of title or position.
- List core values to begin an authentic leadership journey.

Attendance Verification Code: \_\_\_\_\_

## **B10: So Consumer Genetics Is Here... What Is the Role of the Genetic Counselor, and How Do We Deal With This in Clinic?**

### **2 Contact Hours**

*Teresa Krusselbrink, MS, LCGC, Mayo Clinic; Johanna Schmidt, MPH, MGC, LCGC, Westside Genetic Counseling; Robin King, MS, LCGC, PWNHealth; Altovise Ewing, PhD, LCGC, 23andMe; Amy Sturm, MS, LGC, Geisinger; Shannon Kieran, MS, LCGC, MBA, Intelliger Consulting; Sara Riordan, MS, LCGC, Intelliger Consulting; Elissa Levin, MS, CGC, Helix*

- Formulate an approach to critically assess consumer genetic testing products and services in order to best serve your patients, friends and family.
- Examine how genetic counselors are applying their core skills within the consumer genetics industry across a spectrum of roles to apply patient-centric approaches.
- Examine how clinical genetic counselors are creating roles to address the needs of consumers who have engaged in consumer-initiated genetic testing services, in both private and traditional clinical practice.

Attendance Verification Code: \_\_\_\_\_

## **Sponsored Lunch Sessions**

**12:30 pm – 1:45 pm**

## **B11: Unparalleled Clarity and New Mutations: Clinical RNA Testing Provides Answers Beyond DNA**

### **1.0 Contact Hour**

*Rachid Karam, MD, PhD, Ambry Genetics*

- Explain basic information about the role of RNA genetic testing in variant detection and classification.
- Demonstrate that overall impact of paired DNA/RNA genetic testing in the positive yield and VUS rate.
- Discuss latest data and specific simultaneous DNA/RNA genetic testing case examples.

**Sponsored by:**  **Ambry Genetics**  
A Konica Minolta Company

Attendance Verification Code: \_\_\_\_\_

## **B12: Important Advancements for Precision Medicine in Oncology and Prenatal Genetics**

### **1.0 Contact Hour**

*Dale Muzzey, PhD; Nassim Taherian, M.Sc.*

- Highlight the importance of genetics in all aspects of human health and disease.
- Define the critical role that genetic testing plays in oncology treatment.
- Define the history of expanded carrier screening.
- Illustrate the limitations of ethnicity-based carrier screening guidelines.

**Sponsored by:**  **myriad**

Attendance Verification Code: \_\_\_\_\_

# Session Speakers + Objectives continued

## Educational Breakout Sessions

2:30 pm – 3:45 pm

### B13: “Dear Seymour”: The Work and Applications of Dr. Seymour Kessler’s Seminal Papers on Psychosocial Aspects of Genetic Counseling

1.25 Contact Hours

*Liane J. Abrams, MS, LCGC, UCSF, CSU Stanislaus; Barbara Biesecker, PhD, MS, CGC, RTI International; Andrea Fishbach, MS, MPH, LCGC, Kaiser Permanente Medical Group; Kathryn Sptizer Kim, MS, CGC, Stanford University; Robert Resta, MS, LCGC, Hereditary Cancer Clinic, Swedish Medical Center*

- Review how teaching and counseling models can be integrated to meet client needs using challenging case examples.
- Examine the differences between client shame and guilt and how proper assessment is essential to achieving positive client outcomes.
- Identify the importance of understanding the inner world of the counselor to recognize and manage counter-transference.
- Underscore the importance of social systems and family coping assessment as part of genetic counseling practice.
- Highlight Dr. Kessler’s central and innovative contributions to the genetic counseling practice.

Attendance Verification Code: \_\_\_\_\_

### B14: Digging Into Polygenic Risk Scores for Complex Disorders: Cancer, Cardio, Psychiatry... and More!

1.25 Contact Hours

*Lasse Folkersen, MSc, PhD, Sankt Hans Mental Hospital; Tatiane Yanes, BSc, MSc, So+Gi Scan, UNSW Sydney; Jehannine Austin, PhD, CGC, University of British Columbia; Colleen Caleshu, MS, CGC, Stanford Center for Inherited Cardiovascular Diseases*

- Identify diseases best suited to polygenic risk scores.
- Critique the performance of different polygenic risk scores.

Attendance Verification Code: \_\_\_\_\_

### B15: From Genetics to Genomics: Evolving Liability Implications for Practitioners

1.25 Contact Hours

*Susan M. Wolf, JD, University of Minnesota; Gary Marchant, PhD, JD, Sandra Day O’Connor College of Law, Arizona State University; Bonnie S. LeRoy, MS, LGC, University of Minnesota*

- Describe the liability risks facing genetic counselors and other clinicians as genomic-scale testing becomes a part of medical care.
- Discuss how the current law addressing genetics must evolve to address genomics.

Attendance Verification Code: \_\_\_\_\_

### B16: Hot Topics in Teratology: Zika, Marijuana and Maternal Therapies for Genetic Disease

1.25 Contact Hours

*Victoria Wagner, MS, CGC, McGovern Medical School at The University of Texas Health; Myla Ashfaq, CGC, McGovern Medical School at The University of Texas Health; Jennifer Lemons, CGC, McGovern Medical School at The University of Texas Health*

- Summarize key features of congenital Zika syndrome and related genetic counseling considerations.
- Examine existing data regarding marijuana use in pregnancy and reported postnatal outcomes.
- Critique available information concerning potential teratogenicity of novel therapies for common genetic disorders.

**Unrestricted educational support provided by:**  Capital Women’s Services

Attendance Verification Code: \_\_\_\_\_

### B17: Seriously, Can Online Education Work for Genetic Counseling? Adapting to the Demands of Training More and Diverse Genetic Counselors

1.25 Contact Hours

*Jennifer Eichmeyer, MS, LCGC, Boise State University; Janice Berliner, MS, LCGC, Bay Path University; Nicolle Dickey, MS, Boise State University; Megan Parker, MS, Methodist Le Bonheur Healthcare; Stephanie Gandomi, MS, LCGC, Boise State University; Colleen Dougherty, MS, LCGC, Bay Path University; Leslie Ordol, MSc, CGC, Boise State University*

- Identify online education pedagogy and process.
- Summarize online education standards as well as methods for meeting ACGC standards for genetic counselor training utilizing online learning.
- Examine online versus on-ground adult learner characteristics, and how online education is used in adult learning.
- Generalize student and teacher experiences in the online learning processes.

Attendance Verification Code: \_\_\_\_\_

## Plenary Sessions

4:15 pm – 5:20 pm

### B18: Dr. Beverly Rollnick Memorial Lecture: Living a Life Worth Celebrating

1.00 Contact Hour

*Rebecca Alexander, LCSW-R, MPH*

- Examine the lived patient experience during the delivery of a genetic diagnosis.
- Illustrate one patient’s journey of loss, resilience, perseverance and hope following a diagnosis of Usher Syndrome.

Attendance Verification Code: \_\_\_\_\_

## B19: Audrey Heimler Special Project Award Presentation

0.50 Contact Hour

Sara Pirzadeh-Miller, MS, CGC; Andrea Durst, MS, DrPH, LCGC; Rebecca Vanderwall, MS, MPH; Raluca Kurz, MS, LCGC

- Review the history of the Audrey Heimler Special Project Award and provide an update on current initiatives.
- Describe the Public Health Genetics and Precision Medicine Roles fellowship and its impact in the first year of implementation through the NSGC Public Health Genetics SIG.

Attendance Verification Code: \_\_\_\_\_

## Sponsored Evening Sessions

7:30 pm – 8:45 pm

### B21: Understanding Residual Risk in Expanded Carrier Screening: Self-Reported Ancestry vs. Molecular Ancestry

1.0 Contact Hour

Ashley Birch, PhD, FCCMG, DABMGG; Mitchell W. Dillon, MS, CGC

- Describe how to calculate residual risk for autosomal recessive and X-linked conditions.
- Discuss how modifiers of residual risk may be used, focusing on Spinal Muscular Atrophy.
- Review molecular ancestry determination and how it might be used in personalized residual risk calculation.

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### B22: An Overview of the Historical Perspective and Current Status of Personalized/Precision Medicine

1.0 Contact Hour

Nadene Henderson, MS, LCGC, UPMC Children's Hospital of Pittsburgh; Neil Weinreb, MD, FACP, University of Miami Miller School of Medicine Miami, University Research Foundation for Lysosomal Storage Diseases, International Collaborative Gaucher Group, National Gaucher Foundation

- Examine how defining the phenotype/genotype relationship have clinical and therapeutic implications.
- Describe disease variability and associated conditions.
- Discuss prenatal screening and diagnosis as well as recommendations for managing patients with Gaucher disease (GD).
- Review genetic counseling issues, genetic testing, inheritance patterns and screening recommendations for GD.
- Apply knowledge gained of GD through a review of sample case examples.

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## THURSDAY, NOVEMBER 7

## Sponsored Breakfast Sessions

7:00 am – 7:45 am

### C01: Chromosomal Microarray: Going, Going, Gone? Comprehensive Copy Number Variant Detection From Next Generation Sequencing Data

0.50 Contact Hour

Diane J. Allingham-Hawkins, PhD, FCCMG, FACMG, PreventionGenetics

- Explain the benefits and limitations of copy number variant detection by next generation sequencing.
- Compare copy number variant detection by next generation sequencing to other methods of copy number variant detection such as chromosomal microarray.
- Provide examples of how performing copy number variant detection by next generation sequencing adds value to a sequencing test.

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### C02: The Undiagnosed Second Diagnosis: Utilizing Advanced Genomic Technologies to Identify Dual Diagnoses and Understand Complex Phenotypes

0.50 Contact Hour

Madhuri Hegde, PhD, FACMG, PerkinElmer Genomics

- Summarize the challenges of identifying dual diagnoses from a clinical perspective and a molecular laboratory perspective.
- Evaluate cases of complex histories resulting from dual diagnoses.

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## Plenary Sessions

8:00 am – 9:15 am

### C03: NSGC State of the Society Address

1.00 Contact Hour

Amy Sturm, MS, CGC, LGC

- Describe the activities of NSGC over the past year as related to the advancement of the profession of genetic counseling.
- Assess NSGC's advocacy efforts over the course of 2019.
- Identify opportunities for supporting diversity and inclusion in the profession of genetic counseling.

Attendance Verification Code: \_\_\_\_\_

# Session Speakers + Objectives continued

9:15 am – 9:45 am

## Incoming Presidential Address

*Gillian Hooker, PhD, ScM, LCGC*

- Welcome NSGC President-Elect Gillian Hooker, as she introduces herself to NSGC members and outlines her vision for NSGC and the genetic counseling profession in 2020.

Attendance Verification Code: \_\_\_\_\_

## Sponsored Lunch Sessions

12:00 pm – 1:15 pm

### C09: Functional Modeling – The Next Frontier in Variant Interpretation

1.0 Contact Hour

*Brandie Heald Leach, MS, LGC, Cleveland Clinic; Carlos Araya, PhD, Invitae*

- Indicate how often to expect VUS results with diagnostic testing and describe traditional approaches to VUS resolution.
- Describe the role of functional modeling as an additional evidence type that can assist in variant classification.
- Describe different functional approaches to variant interpretation and their utility.
- Review data from the retrospective implementation of a novel functioning modeling platform in a clinical laboratory, including impact on VUS rates.

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### C10: How to Avoid Legal and Ethical Pitfalls as a Genetic Counselor

1.0 Contact Hour

*Jane Pine Wood, Esq., BioReference Laboratories, Inc., Stephanie DeWard, MS, CGC, GeneDx, Rachel T. Klein, MS, CGC, My Gene Team, LLC*

- Describe legal and compliance considerations with billing and genetic test ordering.
- Discuss policies and best practice around duty to recontact.
- Identify and discuss clinical scenarios that present legal and ethical challenges from a HIPAA and compliance perspective.

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## Educational Breakout Sessions

3:10 pm – 4:40 pm

### C12: A History of Genetic Discrimination: Reviewing Our Past and Looking Toward the Future

1.5 Contact Hours

*Laura Hercher, MA, MS, CGC, Sarah Lawrence College; Tina Sacks, PhD, UC Berkeley's School of Social Welfare; Vivian Ota Wang, PhD, CGC, FACMG, NHGRI*

- Examine historical examples of eugenics and discrimination and their impact on current healthcare inequities and racial disparities in genetic medicine and research.
- Propose strategies that genetic counselors can implement in their own institutions to highlight existing genetic discrimination and proactively reduce barriers to genetic-based care.

Attendance Verification Code: \_\_\_\_\_

### C13: NSGC and ASHG Joint Session: Genetic Counselors in Research: From Dabbling in Clinic to an NIH Grant

1.5 Contact Hours

*Julia Wynn, MS, MS, CGC, Columbia University Irving Medical Center; Adam Buchanan, MS, MPH, CGC, Geisinger; Allison Cirino, MS, CGC, MGH Institute of Health Professions; Kira Dies, ScM, CGC, Boston Children's Hospital; Sarah Scollon, MS, CGC, Baylor College of Medicine, Texas Children's Hospital*

- Describe variable roles for genetic counselors in research.
- Recognize genetic counselor-led research activities and outcomes.
- Demonstrate strategies for engaging in research across variable practice areas.
- Prepare all types of genetic counselors to engage in research activities.

Attendance Verification Code: \_\_\_\_\_

### C14: Beyond Cystic Fibrosis: Pulmonary Genetic Disorders in Adulthood

1.5 Contact Hours

*Nikkola Carmichael, MSc, CGC, Boston Children's Hospital, Brigham and Women's Hospital; Janet Talbert, MS, CGC, InformedDNA, National Jewish Health; Maimoona Zariwala, MSc, PhD, FACMG, University North Carolina at Chapel Hill*

- Identify characteristics of pulmonary genetic disorders in personal or family medical histories.
- Describe the health implications of pulmonary genetic disorders for the affected individual and their family.
- Explore resources for referring patients to appropriate specialty centers and patient support groups for additional care.

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### **C15: Challenging the Comfort Zone: Debated Testing Strategies in Cardiovascular Genetics**

**1.5 Contact Hours**

*Lisa Castillo, MS, CGC, Northwestern University; Kyla Dunn, MS, LCGC, Stanford Center for Inherited Cardiovascular Disease; Melanie Care, MSc, CCGC, University Health Network – Toronto General Hospital; Melissa Kelly, MS, LGC, Geisinger; Heather MacLeod, MS, CGC, Sudden Death in the Young Case Registry*

- Determine whether readily available expanded testing can replace more conservative options.
- Evaluate the clinical utility of genetic testing for indications without irrefutable evidence.
- Examine clinical scenarios which challenge the traditional genetic testing approach in a family.

Attendance Verification Code: \_\_\_\_\_

### **C16: The New GC in Town: Demystifying the Role of Gene Curation in Variant Interpretation, Clinical Reporting and Case Reanalysis**

**1.5 Contact Hours**

*Alicia Scocchia, MS, LCGC, Illumina, Inc.; Erin Riggs, MS, CGC, Geisinger; Jackie Tahiliani, MS, CGC, Invitae; Kelly Radtke, PhD, Ambry Genetics; Erin Thorpe, MS, LCGC, Illumina, Inc.*

- Define the key principles and resources utilized in the practice of gene curation.
- Discuss how gene curation impacts variant interpretation.
- Examine the basic framework for gene curation, proposed by ClinGen.
- Examine how this framework is currently adapted by laboratories.
- Apply knowledge of gene-curation principles to critically assess clinical reports and ask informed questions of laboratories regarding gene-curation protocols.
- Illustrate the benefits and complexities of gene-curation reanalysis and how this may impact updated clinical reports.

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## **Plenary Session**

**5:00 pm – 5:35 pm**

### **C17: Human Genome Editing: The Current State of Research and Clinical Practice**

**0.50 Contact Hour**

*Forough Noohi, MSc, Human Genetics, McGill University*

- Summarize current human gene therapy basic research and clinical trial initiations and results around the world.
- Examine genetic counselors' role in informing patients' choices in the fast growing field of gene editing technologies.

Attendance Verification Code: \_\_\_\_\_

## **Best Full Member Abstract Award Presentation**

**5:35 pm – 5:50 pm**

### **C18: Clinical False-Negative Rate of Direct-to-Consumer Genetic Screening for Familial Hypercholesterolemia**

**0.25 Contact Hour**

*Sienna Aguilar, MS, LCGC*

- Describe a patient-initiated approach to genetic testing.

Attendance Verification Code: \_\_\_\_\_

## **Beth Fine Kaplan Student Abstract Award Presentation**

**5:50 pm – 6:05 pm**

### **C19: Navigating Through Burden: Communicator Perspectives of Familial Risk Communication After a Sudden Cardiac Death of a Young Family Member**

**0.25 Contact Hour**

*Franceska Hinkamp, MS, UCLA Institute for Precision Health, Division of Genetics, Department of Pediatrics*

- Identify the core challenges of risk communication faced by families who have experienced a sudden cardiac death in a young family member.

Attendance Verification Code: \_\_\_\_\_

## **Jane Engelberg Memorial Fellowship Presentation**

**6:05 pm – 6:35 pm**

**0.50 Contact Hour**

*Beverly Yashar, MS, PhD, CGC; Heather Zierhut, PhD, MS, CGC*

- Review the history of the Jane Engelberg Memorial Fellowship (JEMF) award and provide and update on current initiatives.
- Define motivational interviewing and give an example of how the strategy can be used in the context of communicating risk information to family members.

Attendance Verification Code: \_\_\_\_\_

# Session Speakers + Objectives continued

FRIDAY, NOVEMBER 8

## Sponsored Breakfast Sessions

7:00 am – 7:45 am

### D01: A Brave New World: A Family's Experience With New Therapies for Spinal Muscular Atrophy

Bob Wallerstein, MD; Amanda Schlemme

- Summarize how new spinal muscular atrophy (SMA) therapies are playing a critical role in the evolution of patient care for babies with SMA.
- Illustrate the importance of screening for SMA to identify affected children presymptomatically.
- Illustrate the clinical journey and genetic testing process that led to Colin's diagnosis.
- Examine the psychosocial journey that Colin's parents faced throughout the process.

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### D02: The ABC's of DTC Genetic Testing

Stacey Detweiler, MS, LCGC, 23andMe, Inc.; Altovise Ewing, PhD, LCGC, 23andMe, Inc.; Anne Greb, MS, CGC, 23andMe, Inc.

- Demonstrate how DTC genetic testing relates to other categories of genetic/genomic testing.
- Describe different types of DTC genetic tests including criteria for FDA regulation (analytical/clinical validity; clinical utility).
- Develop a mutually agreed upon genetic counseling agenda based on client motivations for DTC genetic testing.
- Summarize the importance of understanding the DTC genetic testing consumer experience, including examples of how customers can tailor their experience.

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## Educational Breakout Sessions

8:00 am – 9:30 am

### D03: In Utero Stem Cell Transplantation: Historical Context, Present State and the Future of Fetal Molecular Therapies

1.5 Contact Hours

Stefanie Kasperski, MS, LCGC, The Center for Fetal Diagnosis and Treatment at The Children's Hospital of Philadelphia; Billie Rachael Lianoglou, MS, UCSF Center for Maternal-Fetal Precision Medicine; Julie Harris-Wai, PhD, MPH, University of California San Francisco

- Detail the history of in utero stem cell transplantation.
- Summarize the risks and benefits of hematopoietic stem cell transplantation and the target diseases for which this therapy is currently offered.
- Describe target diseases for applying both in utero hematopoietic stem cell transplantation and other fetal molecular therapies including gene therapy.

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### D04: The Emerging Roles of Genetic Counselors as Consumers Embrace Healthy Genomic Screening

1.5 Contact Hours

Carrie Blout, MS, CGC, Brigham and Women's Hospital; Michelle Moore, MS, LCGC, Sanford Health Imagenetics; Allison Hazell, MSc, CGC, CCGC, Medcan; Sienna Aguilar, MS, LCGC, Invitae; Elissa Levin, MS, CGC, Helix; Jill Davies, MS, CGC, GeneMatters

- Define important considerations when developing a genomics clinic or program designed to provide preventive genomic screening options to seemingly healthy patients.
- Describe how clinical laboratories are adapting to meet consumer demands by offering healthy screening options.
- Describe healthy genomic screening options and considerations outside of the traditional clinical space.

Attendance Verification Code: \_\_\_\_\_



## **D05: Getting to the Heart of Our Practice: Developing an Evidence Base to Improve Cardiovascular Genetic Counseling**

### **1.5 Contact Hours**

*Susan Christian, MSc, University of Alberta, Alberta Health Services; Katherine Spoonamore, MS, CGC, Indiana University School of Medicine; Brittney Murray, MS, CGC, Johns Hopkins University; Cynthia A. James, ScM, PhD, CGC, Johns Hopkins University; Jodie Ingles, MPH, PhD, The University of Sydney; Charlotte Burns, MGC, The University of Sydney, Hannah Ison, MS, LCGC, Stanford Center for Inherited Cardiovascular Disease*

- Summarize predictors of uptake of cascade genetic testing.
- Describe the role of the genetic counseling-client relationship and demographic factors in predicting change in patient empowerment.
- Plan how to collect outcomes measures at your center.

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## **D06: How to Talk to Your Patients About Imaging: What to Do When There Aren't NCCN Guidelines**

### **1.5 Contact Hours**

*Yelena Wu, PhD, Huntsman Cancer Institute, University of Utah; Wendy Kohlmann, MS, Huntsman Cancer Institute, University of Utah; Sandra Buys, MD, Huntsman Cancer Institute, University of Utah; Luke Maese, DO, Huntsman Cancer Institute, University of Utah; Kristin Zelle, MSc, CGC, CCGC, Children's Hospital of Philadelphia; Mary-Louise Greer, MBBS, FRANZCR, The Hospital for Sick Children; Samantha Greenberg, MS, MPH, CGC, Huntsman Cancer Institute*

- Define the principles of screening and related imaging options.
- Evaluate screening recommendations for hereditary cancer syndromes to determine surveillance guidelines for rare and novel conditions.
- Differentiate standard and novel imaging approaches to make tailored recommendations to patients.

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## **D07: Weighing the Alternatives: Non-Traditional Approaches to Improve Genetic Counseling Access and Efficiency**

### **1.5 Contact Hours**

*Julia Wynn, MS, MS, CGC, Columbia University Medical Center; Tara Schmidlen, MS, LGC, Geisinger; Andrew Faucett, MS, LGC, Geisinger; Miranda Hallquist, MSc, LCGC, Geisinger; Sharon Aufox, MS, CGC, Center for Genetic Medicine, Northwestern University*

- Apply the CADRe framework to leverage the genetic counseling resource most effectively.
- Evaluate the design, implementation and assessment of alternative delivery models for different aspects of genetic counseling and education.
- Argue the benefits and risks of the use of alternative approaches to genetic counseling.

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## **Plenary Session**

**10:00 am – 10:50 am**

## **D08: Meeting the Demand for Genetic Counseling Through Artificial Intelligence: Can We Clone Our Skill Set?**

### **0.75 Contact Hour**

*Kaylene Ready, MS, CGC, GeneMatters; Cathy Wicklund, MS, CGC, Northwestern University; Tara Schmidlen, MS, LGC, Geisinger; Shivani Nazareth, MS, CGC, Clear Genetics*

- Define the use cases for artificial intelligence (AI) in healthcare, and the relevance to the field of genetic counseling.
- Provide a balanced perspective on creative ways to achieve scale and promote access in genetics.
- Demonstrate how chatbots, as an example of AI, can enable scale in genetic counseling.
- Highlight the overall trends in AI and debate their merits.

Attendance Verification Code: \_\_\_\_\_

# Session Speakers + Objectives continued

## Late-Breaking Plenary

10:50 am – 11:50 am

### D09: Emerging Therapies for Adult-Onset Neurologic Diseases: Possibilities, Pitfalls and Patient Impact

1.0 Contact Hour

*Sonia Vallabh, JD, PhD, Broad Institute*

- Describe two genetically targeted therapeutic approaches in clinical trials to treat adult-onset neurologic diseases.
- Summarize which hereditary adult-onset neurologic diseases currently have ongoing clinical trials of genetically targeted therapies.
- Describe the roles that motivated at-risk individuals play in all stages of drug development.
- Discuss forms of positive action available to at-risk individuals independent of drug development, including IVF-PGD.
- Appreciate the perspective of an individual who is gene positive for an adult-onset hereditary neurologic disease.

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## Post-Conference Symposia

2:00 pm – 5:30 pm

### D15: Genetic Counselor Fingerprints on the Business Side: Clinical Product Strategy, Development and Lifecycle Skills Workshop

3.0 Contact Hours

*Carrie Haverty, MS, LGC, Myriad Women's Health; Shivani Nazareth, MS, CGC, Clear Genetics; Kaylene Ready, MS, CGC, Gene Matters; Sarah Witherington, MS, LCGC, Quest Diagnostics*

- Describe specific roles for genetic counselors in clinical product development.
- Create a strategy for an imaginary genetic testing or services product.
- Formulate an elevator pitch for an imaginary genetic testing or genetic services product.

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### D16: Genetics Beyond the Binary: How to Incorporate Gender Diversity Into the Concepts of Genetics

3.0 Contact Hours

*Kaitlyn Brown, MS, CGC, Children's Hospital at Montefiore; Candice Metzler, MSW, CSW, Utah Pride Center, University of Utah; Clair Rock, Logic Dept.*

- Summarize the importance of using gender-inclusive language in the practice of genetic counseling.
- Apply inclusive language that remains scientifically accurate while describing genetic information.
- Evaluate resources for inclusivity of patients who identify as intersex, gender non-binary/non-conforming (GNB/GNC).

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### D17: Late-Breaking Cancer Topics

3.0 Contact Hours

*Sayoni Lahiri, MS, CGC, UT Southwestern Medical Center; Sara Pirzadeh-Miller, MS, CGC, UT Southwestern Medical Center; Veronica Greve, MS, CGC, HudsonAlpha Institute for Biotechnology; Carrie Blout, MS, CGC, Brigham and Women's Hospital; Miranda Hallquist, MSc, LCGC, Geisinger; Barry Tong, MS, CGC, UCSF Cancer Genetics and Prevention Program; Dena Goldberg Linder, MS, LCGC, UCSF Cancer Genetics and Prevention Program; Wendy Kohlmann, MS, CGC, Huntsman Cancer Institute; Sheryl Walker, MS, CGC, Medical City Dallas; Jacqueline Mersch, MS, CGC, Moncrief Cancer Institute, UT Southwestern; Amber Aelts, MS, LGC, The Ohio State University*

### Session 1: Implementation of Population Genetic Screening Programs Across Populations and Institutions

- Identify challenges with implementation and automation of screening processes for population-based screening programs.
- Identify methods for improving access to genetics services in underserved populations.
- Describe various methods for patient recruitment, including online recruitment, for population-level genetic screening.

### Session 2: Lie, Cheat & Steal: The Growing Epidemic of Genetic Testing Fraud in America

- Identify appropriate channels for reporting fraudulent health insurance activity.
- Improve strategy for evaluating genetic testing laboratories.

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**Sara, 27**  
Diagnosed with SED at age 8. Correct diagnosis of MPS IVA diagnosed at age 26.

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# Platform Presentations

THURSDAY, NOVEMBER 7   10:20 am – 11:35 am   1.25 CONTACT HOURS					
	<b>C04 Access and Service Delivery</b> <i>Room 255EF</i> <ul style="list-style-type: none"> <li>Explore novel approaches to improve access to genetic counseling.</li> <li>Examine tools and modalities to improve efficiency in clinical genetic counseling.</li> </ul>	<b>C05 Cancer</b> <i>Grand Ballroom</i> <ul style="list-style-type: none"> <li>Summarize various research studies related to hereditary cancer genetics.</li> <li>Examine different components of the cancer genetic counseling process.</li> </ul>	<b>C06 Cardiovascular</b> <i>Room 255BC</i> <ul style="list-style-type: none"> <li>Evaluate the application of molecular genetic technologies in cardiovascular genetic counseling.</li> <li>Examine the patient experience in cardiovascular genetic counseling.</li> </ul>	<b>C07 Conversations Around Diversity</b> <i>Room 155EF</i> <ul style="list-style-type: none"> <li>Examine methods for facilitating genetic counselor diversity.</li> <li>Illustrate the value of diversity in genetic counselor training programs.</li> </ul>	<b>C08 Prenatal</b> <i>Room 155BC</i> <ul style="list-style-type: none"> <li>Examine available resources and tools that can be used in prenatal genetic counseling.</li> <li>Illustrate the role of key stakeholders in the prenatal experience.</li> </ul>
10:20 am – 10:35 am	Impact of Service Delivery Model on Patient Perceptions and Utility of Genetic Counseling for Hereditary Breast and Ovarian Cancer: An Exploration of Group Genetic Counseling <i>Alyssa Gates</i>	Gaps in Genetic Testing Results Interpretation: Lessons Learned From Five Years of Education Efforts <i>Emily Edelman</i>	How Does Age at Diagnosis Impact Physical Activity and Health Related Quality of Life for Children Diagnosed With an Inherited Arrhythmia or Cardiomyopathy? <i>Susan Christian</i>	Assessing the Impact of Diversity and Inclusion Among Individuals in Genetic Counseling Student Cohorts <i>Gnyapti Majmudar</i>	“It is in God’s Hands”: An Investigation of Genetic Counselors’ Responses to Prenatal Patient Religious/Spiritual Statements <i>Alina Sitaula</i>
10:35 am – 10:50 am	Improving Genetic Counselor Efficiency While Maintaining High Patient Satisfaction <i>Kiley Johnson</i>	How Do Adolescents and Young Adults Experience Genetic Testing for Li-Fraumeni Syndrome? <i>Rowan Forbes Shepherd</i>	Clinical Evidence of Long QT Syndrome in Patients With <i>KCNQ1</i> Variants <i>Robyn Hyland</i>	Genetic Counseling Training Program Admissions Teams and Racial and Ethnic Diversity: Surveying the Gatekeepers <i>Ana Sarmiento</i>	Fragile X Carrier Screening Accompanied by Genetic Consultation Has Clinical Utility in Populations Beyond Those Recommended by Guidelines <i>Katie Johansen Taber</i>
10:50 am – 11:05 am	Re-Contacting Women With Previous Negative <i>BRCA1</i> & <i>BRCA2</i> Genetic Testing for Updated Testing Using a Multi-Gene Panel <i>Ryan Mooney</i>	Returning Polygenic Risk Scores to Participants in a Pragmatic Clinical Trial of Risk-Based Population Screening for Breast Cancer <i>Galen Joseph</i>	Molecular Autopsy: Experience in a Multidisciplinary Inherited Arrhythmia Clinic <i>Emma Leach</i>	Increasing Diversity in the Genetic Counseling Profession: A Pilot Study on Development of Effective Recruitment Tools for Black Undergraduate Students <i>Erica Price</i>	Exploring the Potential Yield of Prenatal Testing by Evaluating a Postnatal Population With Structural Abnormalities <i>Peyton Busby</i>
11:05 am – 11:20 am	No Thank You: Referrals Resulting in a Declined Appointment Over a Five Year Period <i>Heather Rocha</i>	Downstream Revenue Generated by a Cancer Genetic Counselor <i>Caitlin Maurer</i>	The Cardiac Genome Clinic: A Model for Integrating Whole Genome Sequencing Into Clinical Cardiology <i>Eriskay Liston</i>	Moderated Discussion	Deciding Whether to Take Antidepressants During Pregnancy: A Grounded Theory <i>Catriona Hippman</i>
11:20 am – 11:35 am	Breast Cancer Genetic Testing Station: A Model for Increasing Access for Large Patient Volume <i>Desiree Stanley</i>	Pathogenic Variants in Cancer and Hematologic Disease Susceptibility Genes Identified in Blood and Marrow Transplant Patients With Acute Myeloid Leukemia and Myelodysplastic Syndrome and Their HLA-Matched Unrelated Donors <i>Lara Sucheston-Campbell</i>	Evaluation of Clinical Practices and Needs About Variants of Uncertain Significance Results in Inherited Cardiac Arrhythmia and Inherited Cardiomyopathy Genes <i>Reka Muller</i>		The First Prenatal Visit: An Opportunity for Collaboration Between Genetic Counselors and Obstetric Healthcare Providers to Support Patients’ Prenatal Genetic Testing Decisions <i>Ruth Farrell</i>

	<b>D10 Education</b> <i>Room 255EF</i> <ul style="list-style-type: none"> <li>Summarize approaches in genetic counseling education.</li> <li>Examine the patient experience in cardiovascular genetic counseling.</li> </ul>	<b>D11 Ethical and Psychosocial Research</b> <i>Room 255BC</i> <ul style="list-style-type: none"> <li>Illustrate ethical implications across the genetic counseling process.</li> <li>Evaluate psychological and social issues for genetic counseling patients.</li> </ul>	<b>D12 Neuromuscular/ Psychiatric</b> <i>Room 155EF</i> <ul style="list-style-type: none"> <li>Explore various aspects of patient experiences with neurological disorder diagnoses and testing.</li> <li>Summarize students' perspectives of psychiatric illness.</li> </ul> <i>Unrestricted educational support provided by:</i> 	<b>D13 Patient Utilization of Genetic Test Results</b> <i>Room 155BC</i> <ul style="list-style-type: none"> <li>Identify responses to genetic testing and results disclosure.</li> <li>Explore the impact of cascade testing.</li> </ul>	<b>D14 Innovations in Somatic Tumor Testing</b> <i>Grand Ballroom</i> <ul style="list-style-type: none"> <li>Explore the utility of somatic genetic testing methodologies in clinical practice.</li> <li>State the impact of somatic genetic test results and implications for patients and families.</li> </ul>
12:15 pm – 12:30 pm	Application of the Reciprocal Engagement Model of Supervision (REM-S): What Is Happening in Genetic Counseling Student Supervision Meetings? <i>Carrie Atzinger</i>	Examining the Relationship Between Parenting Stress and Anxiety in Children With 22q11.2 Deletion Syndrome <i>Jacquelynn Berton</i>	Genetic Counseling Students' Attitudes Towards Psychiatric Illness <i>Rebecca Haegedorn</i>	Ready or Not: Hypothetical Reactions to Receiving Unsolicited Results of Family Member's BRCA1/2 Gene Testing <i>Amber Aeilts</i>	Paired Tumor-Germline Sequencing in Adolescents: Motivators, Attitudes and Knowledge <i>Michelle F. Jacobs</i>
12:30 pm – 12:45 pm	Genetic Counselors With Advanced Skills: A New Career Trajectory Framework <i>Bonnie Baty</i>	The Role of Ethnicity in Views and Attitudes Toward Precision Medicine Research: A Systematic Review of Qualitative and Quantitative Studies <i>Elena Fisher</i>	Rates and Causes of Mortality in Pediatric Patients With Known or Presumed Genetic Epilepsy <i>Colleen Kennedy</i>	Assessing Readiness for Hereditary Cancer Cascade Genetic Testing <i>Erica Bednar</i>	Evaluation of a Referral Triage Protocol Based on Tumor Genomic Profiling Results and Personal/Family History: A Pilot Study at a Community Cancer Center <i>Kate Partynski</i>
12:45 pm – 1:00 pm	Entrustment Decisions in Genetic Counseling Training: Exploring Supervisor Perspectives <i>Kelsey N. Lenhart</i>	Investigation of Media Type of Educational Resources on Patient Knowledge and the Role of Health Literacy <i>Jacqueline Neminski</i>	Mosaic Sequence and Copy Number Variants in a Large Clinical Genetic Testing Cohort <i>Daniel Pineda-Alvarez</i>	The Effect of a Video Intervention on Research Participant Understanding and Perceived Usefulness of Negative Genetic Test Results <i>Austin Bland</i>	Baylor College of Medicine Advancing Sequencing in Childhood Cancer Care (BASIC3): A Synopsis of Germline and Tumor Exome Sequencing Results in 283 Pediatric Oncology Patients <i>Sarah Scollon</i>
1:00 pm – 1:15 pm	Educational Session to Increase Awareness, Knowledge, Attitudes and Behaviors Towards Family Health History and Referral to Genetic Services in Hispanic Community Health Workers <i>Laura Moreno</i>	Decisional Conflict Among Adolescents and Parents Making Decisions About Genomic Results <i>Preethi Raghuram Pillai</i>	Genetic Test Disclosure and Genetic Counseling in Parkinson's Disease: Outcomes From the Widespread Recruitment Initiative (WRI) <i>Jenny Verbrugge</i>	Uptake of Post-Result Disclosure Follow-Up and Cascade Genetic Testing Chatbots Among Patients Receiving Clinically Actionable Exome Sequencing Results <i>Tara Schmidlen</i>	Germline BRCA Alterations Detected by Circulating Tumor DNA Testing Among Patients With Advanced Cancer <i>Krysten Shipley</i>
1:15 pm – 1:30 pm	The Results Are In: Examining Whole Exome Sequencing Follow-Up Care for Pediatric Patients <i>Katherine Ozelius</i>	The Role of Genetic Counselors in the Recognition and Prevention of Sexual Abuse in Populations With Intellectual Disability <i>Rebecca Sheedy</i>	Current Attitudes and Practices Regarding Discussion of Disease-Modulating Treatment for Spinal Muscular Atrophy Among Prenatal Genetic Counselors <i>Bethany Zettler</i>	Cascade Testing Uptake in First-Degree Relatives After Receiving a Cancer or Cardiovascular Result From a Population Genomic Screening Program <i>Amy Sturm</i>	Germline Testing Recommendations for Patients With BRCA1/2 Mutations on Somatic Tumor Testing at Stanford <i>Katherine Vlessis</i>

# Posters With Authors

## Objectives:

- Recognize varied approaches to building an evidence base to support best practices in genetic counseling.
- Identify opportunities for the genetic counseling community to expand the reach of genetic/genomic-based care.
- Evaluate the varied settings in which genetic counseling expertise is utilized.

### GROUP A POSTERS

Tuesday, November 5  
5:45 pm – 7:00 pm  
CONTACT HOURS: 1.25

### GROUP B POSTERS

Wednesday, November 6  
6:15 pm – 7:30 pm  
CONTACT HOURS: 1.25

### GROUP C POSTERS

Thursday, November 7  
1:20 pm – 2:35 pm  
CONTACT HOURS: 1.25

## ACCESS AND SERVICE DELIVERY

- A – 1** The Participant Perspective of a Novel Whole Genome Sequencing Delivery Model for Ostensibly Healthy Individuals  
*Kaitlyn Givens*
- A – 4** Integrating Genetic Counseling Services Into a Multi-Disciplinary Breast Clinic  
*Amanda Schott*
- A – 7** Cascade Screening With a Large, Multi-Gene Panel Test Identifies High Rate of Incidental, Clinically Actionable Findings  
*Lauren Ryan*
- A – 10** The Effect of an Educational Video on Knowledge and Intent in an OB/GYN Population  
*Brighton Goodhue*
- A – 13** Impact of Reminder Calls on Questionnaire Completion Rates  
*Elise Watson*
- A – 16** Use of BRCA-Related Familial Risk Stratification Tools Among Physician Assistants  
*Jason Murphy*
- A – 19** Webinar Stimulates Genetic Counseling Student Knowledge and Interest in Automation as a New Service Delivery Model  
*Sonja Higgins*
- A – 22** Uptake of Pre- and Post-Test Genetic Counseling for Individuals Undergoing Consumer-Directed Genetic Testing  
*Scott Weissman*
- A – 25** High Satisfaction With Genetic Counseling Using Telephone-Based Delivery Method for Return of Results: A Pilot  
*Lily Servais*
- A – 28** Bridging the Genetic Care Gap Between the Deaf and Hearing: A Study of Genetic Service Accessibility for the Deaf Community  
*Mackenzie Mosera*
- A – 31** Effective Communication of Genetic Test Results to Non-Specialist Clinicians and Patients  
*Gabriel Recchia*

- A – 34** Identifying Genetic Counseling Candidates by Utilizing Genetic Counseling Assistants and High Risk Navigators in a High Risk Breast Program  
*Jenna Harris*
- A – 37** Adolescents' Attitudes Towards Direct-to-Consumer Genetic Testing  
*J. Fitzpatrick Doyle*
- A – 40** Assessing the Utility of a Machine Learning Algorithm in the Provision of Genetics-Based Care  
*Lauren Seemann*

## ADULT

- A – 43** Uptake of Genetic Testing in Patients With Early-Onset Colorectal Cancer in Traditional Cancer Genetics Versus Multidisciplinary Clinical Settings  
*Dianne Samad*
- A – 46** Investigating the Potential Impact of Gene Therapy on Identity in Individuals With Hemophilia  
*Mercedes Zoeteman*

## CANCER

- A – 49** Possibly Mosaic *TP53* Mutation: Circulating Tumor Cells or Li-Fraumeni Syndrome?  
*Ryan Noss*
- A – 52** Somatic Tumor Testing Identifies Germline *BARD1* Mutation in a Patient With Ewing Sarcoma: Implications for Familial Testing and Genetic Counseling  
*Rosemarie E. Venier*
- A – 55** Adult Presentations of a Classic Pediatric Tumor Predisposition Syndrome: Hereditary Retinoblastoma  
*Christine Steele*
- A – 58** Clinical and Familial Characteristics of Children and Young Adults With Thyroid Cancer: A Case Series  
*Regina Nuccio*

- A – 61** Possible *CDKN2A* Founder Mutation Associated With Increased Risk for Pancreatic Cancer in Hispanic Population  
*Karlana Lara-Otero*
- A – 64** Incidental *MITF, p.E318K* Pathogenic Variant in Three Independent Cases Undergoing Hereditary Cancer Risk Assessment  
*Jessica Ordonez*
- A – 67** The Identification and Workup of Two *BRCA2* De Novo Cases  
*Rania Sheikh*
- A – 70** Alternative Genetic Counseling Model for Advanced Prostate Cancer Patients: Impact on Clinical Management  
*Kelsey Breen*
- A – 73** Improving Access to Genetic Counseling for Women With Epithelial Ovarian Cancer in Nova Scotia, Canada  
*Ashley Warias*
- A – 76** Women's Responses and Understanding of Polygenic Breast Cancer Risk Information  
*Tatiane Yanas*
- A – 79** The Effect of Select Modifiable Lifestyle Factors on Breast Cancer Risk in *BRCA1* and *BRCA2* Mutation Carriers: A Systematic Review of the Evidence  
*Laura Braunstein*
- A – 82** Utilization of Genetic Testing When Assessing Risk for *BRCA1*- and *BRCA2*-Associated Hereditary Breast and Ovarian Cancer: Education and Importance of Referral to Genetics  
*Erin Barone*
- A – 85** Genetics Clinic Re-Contact of Patients With Unexplained Defective Mismatch Repair  
*Julia Cooper*
- A – 88** Cascade Genetic Testing at an Interdisciplinary Program for Families With *CDH1*  
*Grace-Ann Fasaye*
- A – 91** Cascade Genetic Testing: Feedback From a Michigan-Based Patient Focus Group  
*Natalie Waligorski*
- A – 94** RNA Research Program Continues to be a Valuable Tool in Variant Reclassification  
*Susana San Roman*
- A – 97** Clinical Utility of Hereditary Cancer Panel Testing: Impact of *PALB2, ATM, CHEK2, NBN, BRIP1, RAD51C* and *RAD51D* Results on Patient Management and Adherence to Provider Recommendations  
*Katie Johansen Taber*
- A – 100** Communication Practices of Cancer Genetic Counselors  
*Morgan Danowski*
- A – 103** Investigating the Use of Electronic Distress Screening Questionnaires for Initiating Genetic Counseling Referrals  
*Kevin Capehart*
- A – 106** Clinical Experience With *MITF* in High Volume Cancer Genetics Program  
*Jordan Berg*
- A – 109** A Study of Germline Mutations and Family History in High Risk Pancreatic Cancer Cohort  
*Frances Oh*
- A – 112** Outreach Opportunities for the Genetic Counseling Community: Who Is Ordering Predictive Testing of Minors for Adult-Onset Cancer Risk?  
*Kylin Boehler*
- A – 115** Genetic Counseling in Pediatric Oncology is Associated With Improved Parental Levels of Knowledge and High Satisfaction  
*Olivia Juarez*
- A – 118** Prevalence and Characterization of Germline *RET* Proto-Oncogene Gene Mutations in a Pan-Cancer Cohort  
*Margaret Sheehan*
- A – 121** The Frequency of Cancer-Related Secondary Findings in a Cohort of Individuals Undergoing Clinical Exome Sequencing  
*Becky Milewski*
- A – 124** Tumor-Only Genetic Testing as an Indication for Dedicated Germline Testing: An Analysis of Current Practices  
*Amie Blanco*
- A – 127** Extending the Reach of Cancer Genetic Counseling to the Underserved: Genetic Counselors' Experience With Three Counseling Modes  
*Robin Lee*
- A – 130** Establishing a Partnership Between Cancer Genetic Counselors and a High-Volume Urology Practice to Increase Access to Genetic Counseling and Testing for Patients With High-Grade Prostate Cancer  
*Erin Borchart*
- A – 133** Awareness of Breast Cancer Risk and Screening Guidelines Among Women With Neurofibromatosis Type 1  
*Kara Anstett*
- A – 136** Using Prevalence and Mutation Allele Frequency of Germline Variants Identified on the *Ucsf500* Paired Tumor/Germline Test to Guide Clinical Practice When Confronted With a Tumor Only Variant in a Cancer Predisposition Gene  
*Amie Blanco*

## CARDIOLOGY

- A – 139** CATSHL Syndrome – Consider in the Differential Diagnosis for Marfan Syndrome Without Cardiac or Lens Involvement  
*KT Curry*
- A – 142** At Least One-Third of Patients With Amphetamine-Related Cardiomyopathy Have Evidence of Familial Disease  
*Tia Moscarello*

# Posters With Authors continued

**A – 145** Process and Impact of Disclosing Genetic Research Results to Cardiovascular Biobank Participants  
*Adelyn Beil*

**A – 148** Hypertriglyceridemia Is Common in Patients With Familial Hypercholesterolemia  
*Emily Brown*

## COUNSELING/PYCHOSOCIAL ISSUES

**A – 151** Call Interrupted – Counseling Distracted Patients  
*Karina Nall*

**A – 154** Complexities in Genetic Counseling for Medically Actionable Variants in “Healthy” Individuals: Is It a Secondary Finding, a Primary Diagnosis or Somewhere in Between?  
*Margaret Harr*

**A – 157** Association of Coping Strategies and Effectiveness With Psychological Well-Being in Parents of Children With Undiagnosed Genetic Conditions  
*Courtney Berrios*

**A – 160** ‘Unless You’ve Been There, You Can’t Understand’: How Genetic Counselors Can Facilitate Peer-to-Peer Support Utilization Among Cancer Caregivers  
*Angela Wang*

**A – 163** Discussing History of Mental Illness in a General Genetic Counseling Setting: Patient and Caregiver Interest and Comfort  
*Alena Faulkner*

**A – 166** Attitudes of Genetic Counselors Regarding Affective Forecasting and Patient Decision-Making  
*Stacey Greanias Wallen*

**A – 169** “For Better or for Worse?” Disclosure of Genetic Information Within Relationships  
*Porter Pavalko*

**A – 172** Understanding the Patient Experience of Individuals With Differences in Sex Development  
*Marlise Combe*

**A – 175** Patient Coping as an Outcome of Genetic Counseling: Results From a Systematic Literature Review  
*Barbara Biesecker*

## Education

**A – 178** Experience Is Key: Shadowing Remains an Important Component of Applications for Genetic Counseling Graduate Programs  
*Anna Essendrup*

**A – 184** An Assessment of Genetic Counselors’ Knowledge and Attitudes Toward Counseling for Gene Therapy  
*Ashley Wong*

**A – 187** Creation of a Genetic Counseling Resource to Aid in Delivering Difficult News by Telephone  
*Caitlyn May*

**A – 190** Assessing Risk of Breast Cancer Through Outreach to Latinas With Education and Support (ARBOLES): A Genetics Education Program for Bilingual Community Health Workers Increases Knowledge, Genetic Literacy and Self-Efficacy  
*Charité Ricker*

**A – 193** Sickle Cell Trait Information on YouTube: A Content Analysis  
*Kelsie McVeety*

**A – 196** From One Clinical Rotation to Another: A Pilot Study on the Use of Standard Patient Encounters to Foster Transition in Genetic Counseling Training  
*Kathleen Swenson*

**A – 199** Genetic Counseling Student Demographics and How They Have Evolved: An Empirical Investigation  
*Andrea Stoddard*

## ETHICAL, LEGAL AND SOCIAL ISSUES

**A – 202** Fostering Equitable Care: Pediatric Genetic Counseling Challenges in Cases of Children in Foster Care  
*Bri Dingmann*

**A – 205** Impact of Health Literacy and Genetic Knowledge on Patient Empowerment in Individuals With Inherited Retinal Diseases  
*Eleanor Westfall*

**A – 208** When Family Members Disagree: Implications of Family-Based Enrollment in Genomic Research for Return of Results and Data Sharing Policies  
*Carolyn Applegate*

## GENETIC/GENOMIC TESTING

**A – 211** Application of Mosaicism Ratio From Cell-Free DNA (cfDNA) Screening to Multifetal Gestations  
*Jill Rafalko*

**A – 214** All Testing Platforms Are Not Created Equal – the Importance of Considering Maternal Cell Contamination in Products of Conception Analysis  
*Carrie Couyoumjian*

**A – 217** Hyperferritinemia-Cataract Syndrome Resulting From a Novel Missense Variant in the Non-Coding Region of FTL  
*Selina Casalino*

**A – 220** Success of NIPT Based on Maternal Weight and Gestational Age  
*Sidra Boshes*

**A – 223** Investigation of TTN Variants in Patients With Skeletal Myopathy and/or Cardiomyopathy Identifies Novel Titinopathies  
*Kelly Rich*

**A – 226** Patient Experience and Barriers With Family Communication After Receiving Genomic Information From a Biobank  
*Caitlin O’Brien*



- A – 229** Predictive Genetic Testing of Children for Adult-Onset Cancer Risk: Testing Indications and Value of the Laboratory Genetic Counselor  
*Elaine Weltmer*
- A – 232** Utility of Genomic Sequencing in Cases of Early-Onset and Familial Dementia  
*Meagan Cochran*
- A – 235** Gene Panel Based Prediction of Homologous Recombination Deficiency in Adolescent and Young Adult Breast Cancers  
*Tomoko Watanabe*
- A – 238** Impact of a Molecular vs. Clinical Diagnosis on the Illness Representation of Individuals With Ataxia  
*Arianna Guillard*
- A – 241** Patient Experience With the Sanford Preemptive Genetic Screening Program: Perspectives From the Pilot Population  
*Brittany Noble*
- A – 244** Noonan Syndrome Screening by Non-Invasive Prenatal Testing for Single-Gene Disorders  
*Pooja Mohan*
- A – 247** Utilization of Whole Genome Sequencing to Improve Diagnostic Yield in Pediatric Patients With a Suspected Genetic Disorder  
*Justin Leighton*
- A – 250** Integrating Genomics Research With Clinical Care in the NICU Setting  
*Laura Hendon*
- A – 253** *MYH9* Diagnostic Yield: Reported Phenotypic Specificity Highlights Opportunity for Increased Clinician-Laboratory Partnership  
*Stefanie N. Dugan*
- A – 256** SouthSeq: Genome Sequencing in Newborn Nurseries Across the Deep South  
*Kelly East*
- A – 259** Curating the Human Genome in an Objective and Scalable Process to Ensure Accurate Clinical Interpretation and Reporting  
*Jackie Tahiliani*
- A – 262** Whole Exome Sequencing Results Broken Down by Ethnicity, Diagnostic Yield and VUS Rates in a Diverse Patient Population: The Experience of One Institution  
*Samantha Augustyn*
- A – 265** Use of Direct-to-Consumer Genetic Testing by Adult Adoptees  
*Heewon Lee*
- A – 271** A Case Report of Epsilon Gamma Delta Beta Thalassemia: Implications for Genetic Counseling  
*Kristin Zajo*
- A – 274** Psychosocial and Ethical Implications of Secondary Findings From Pediatric Tumor Profiling: A Case of One Family  
*Krista Buch*
- A – 277** Identification of a Founder Variant in the *ITGB4* Gene That Results in Epidermolysis Bullosa With Pyloric Atresia  
*Emily Bonnell*
- A – 280** Utilization of Genetic Services in Pediatric Emergency Medicine  
*Madeline Miller*
- A – 283** Parental Preferences for Genetic Testing Factors in a Pediatric Neurodevelopmental Disorder Population  
*Jessica Clark*
- A – 286** Parents' Reflections of Their Child's Initial Visit to Metabolic Clinic: A Qualitative Study  
*Laura Marx*
- A – 289** Diagnostic Yield of a Multi-Gene Panel for Neurodevelopmental Disorders at Children's Hospital Colorado  
*Calan Szmyd*
- A – 292** Genetic Testing Yield in a Cohort of Pediatric Patients With Immunohematologic Disorders  
*Elizabeth Varga*
- A – 295** Social Media and the Diagnostic Odyssey: The Experience of Parents of Participants in the Stanford Undiagnosed Disease Network (UDN)  
*Natalie Deutch*
- A – 298** Development and Outcomes of a Multidisciplinary Pediatric Cancer Predisposition Program in Its First Two Years  
*Elena Kessler*
- A – 301** Utilization of Genetic Testing in the Diagnosis of Neurofibromatosis Type 1  
*Erin Moore*

## PRE- AND PERINATAL

- A – 304** Implications of Chimerism for cfDNA/NIPT Prenatal Screening  
*Michelle Hackbardt*
- A – 307** Why Current ACOG Guidelines About Parallel Aneuploidy Screening May Prohibit Some Patients From Useful Information  
*Kendall Snyder*
- A – 310** Importance of Update Carrier Screening in the Setting of a Family History: Case Report in Family With Atypical Autosomal Recessive Polycystic Kidney Disease  
*Elizabeth Wignall*
- A – 313** Unusual Phenotype in an Infant With a 22q11.2 Deletion Ascertained Through cfDNA Screening  
*Sarah Belsky*

## PEDIATRICS

- A – 268** One Thing Leads to Another: Infant With Three Independent Genetic Alterations; A Diagnostic and Counseling Challenge  
*Shannon Holtrop*

# Posters With Authors *continued*

**A – 316** Whole Exome Sequencing for the Purpose of Carrier Screening in a Consanguineous Couple

*Deirdre Sumski*

**A – 319** Fetal MRI and SNP-Array Lead to Identification of Intronic *POMT2* Variants in a Fetus With Severe Ventriculomegaly by Prenatal Ultrasound

*Katelynn G. Sager*

**A – 322** Detection of X;18 Unbalanced Translocation After Multiple Aneuploidy on cfDNA Screen

*Nevena Krstic*

**A – 325** Reproductive Endocrinologists' Utilization of Genetic Counselors and Their Services: Is There an Unmet Need?

*Meaghan Dwan*

**A – 328** Uptake of Chromosomal Microarray in Women Undergoing Amniocentesis

*Clare Gibbons*

**A – 331** Understanding of Clinical Variability, Perceived Disease Burden and Reproductive Decision-Making of Adults With Tuberos Sclerosis Complex

*Diane Biederman*

**A – 334** WGS-Based NIPS Without a Fetal Fraction Threshold: What are the Clinical Outcomes of No-Calls?

*Susan Hancock*

**A – 337** A First Look at the Accessibility of Prenatal Genetic Screening Services Among Incarcerated Women in the United States: Perspectives of Genetic Counselors

*Natalie Waligorski*

**A – 340** Carrier Screening in 2019: Expanded Panels Are on the Rise

*Dana Neitzel*

**A – 343** The Incidence of RASopathies in a Prenatal Polyhydramnios Cohort

*Rachel Mangels*

**A – 346** Time to Screen for the Common: Reproductive Genetic Carrier Screening for Fragile X Syndrome With AGG Interruption Analysis in a Large, Diverse Patient Population

*Casey Duld*

**A – 349** Impact of Infant Sex on Maternal Mood in a North American Population: Implications for Prenatal Counseling

*Caitlin Slomp*

**A – 352** Impact of Co-Morbidity and Demographics on Effective Diagnosis and Treatment of 22q11.2 Deletion Syndrome in the Setting of Inpatient Consultations

*Donna McDonald-McGinn*

## PROFESSIONAL ISSUES

**A – 355** "I am a Genetic Counselor": A Qualitative Exploration of Field Leaders' Perceptions of the Title "Genetic Counselor"

*Chandler Means*

**A – 358** Peer Group Supervision Practices Among Canadian Genetic Counselors

*Courtney Ells*

**A – 361** Utilizing Genetic Counseling Assistants to Ease the Burden of Multi-State Genetic Counselor Licensure

*Matt Tschirgi*

**A – 364** Factors Influencing Cultural Competency in Genetic Counselors

*Nivedita Rajakumar*

**A – 367** How Genetic Counselor Personal Strengths Influence Career Choices and Job Satisfaction

*Brita Christenson*

**A – 370** Perspectives on the Role of Genetic Counselors Within the Pharmaceutical Industry

*Catherine Wicklund*

**A – 373** Streamlining Exposure to Genetic Counseling as a Profession Through Hospital-Based Genetic Counseling Career Day Event

*Lori Dobson*

## PSYCHIATRY/NEUROLOGY

**A – 376** Patient With Spastic Paraplegia and Congenital Cataracts Has Heterozygous *ATAD3A* Variant

*Allison Schreiber*

**A – 379** Developing a Genetics Educational Intervention for Psychiatry Residents

*Catherine Skefos*

**A – 382** Challenging the Huntington Disease Paradigm: Evaluation of Psychosocial Issues in Persons at-Risk for Genetic Prion Disease

*Madeline Williamson*

**A – 385** Understanding the Diagnostic Experience of Individuals With Friedreich's Ataxia

*Sarah Donoghue*

## Public Health

**A – 388** SMA Prevention Readiness: Population-Based Carrier Testing and Presymptomatic Diagnosis in Old Order Amish, Mennonite and Hutterite (Plain) Populations

*Karlla Brigatti*

## Research Issues

**A – 391** IRB Practices in Reviewing Genetic Studies Involving Direct Contact of Relatives

*Katherine Donohue*

**A – 394** Community Stakeholder Views on Data Sharing and the Consent Process

*Heather Nick*

## UTILIZATION MANAGEMENT

- A – 400** Impacts of a Unique Genetic Utilization Management Initiative at Sanford Health  
*Kaylee Dollerschell*
- A – 403** Genetic Counselor Involvement in Prior Authorization Case Review Improves Authorization Outcomes  
*Julie Kaylor*

## GROUP B POSTERS

### ACCESS AND SERVICE DELIVERY

- B – 2** Trans-Inclusive Genetic Counseling Services: Recommendations From the Transgender Community on Pedigree Symbols and Clinical Practice  
*Heather Barnes*
- B – 5** Use of an EMR-Based Tool for Identification and Referral of Patients Eligible for Cancer Genetic Counseling at an Academic Cancer Center  
*Melinda E Simonson*
- B – 8** Patient and Counselor Preferences Regarding Remote Genetic Counseling Service Delivery Models  
*Rebecca Baud*
- B – 11** Analysis of Key Factors in the Implementation of New Service Delivery Models in Genetic Counseling Practice  
*Ambreen Khan*
- B – 14** Exploring Perceptions of What Genetic Counseling Is Amongst Families Affected by Genetic Conditions, Who Have Not yet Had Genetic Counseling Themselves  
*Stephanie Cordeiro*
- B – 17** A Qualitative Evaluation of Patient Experiences With the UAB Undiagnosed Diseases Program  
*Dorothea Siebold*
- B – 20** Genetic Counselor Experiences Delivering Difficult News by Telephone  
*Caitlyn May*
- B – 23** Non-Genetics Healthcare Provider Training to Deliver Whole-Genome Sequencing Results  
*Veronica Greve*



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# Posters With Authors continued

- B – 26** Flipping the Model: Developing a Cutting-Edge Genetics Pipeline to Expand Access and Increase Capture of Patients at Risk for Hereditary Cancer  
*Dena Goldberg*
- B – 29** Facing the Facts: Alternative Genetic Health Service Delivery Settings May Not Be Preferred by Patients  
*Mackenziew Mosera*
- B – 32** Medical Care Needs, Gaps and Barriers for Young Children With Cornelia de Lange Syndrome  
*Shaydah Kheradmand*
- B – 35** Communication of Non-Disclosure Preimplantation Genetic Testing for Huntington's Disease  
*Elizabeth Schweitzer*
- ADULT**
- B – 41** Adult Patients With Undiagnosed Conditions and Their Responses to Clinically Uncertain Results From Exome Sequencing  
*Ahna Neustadt*
- B – 44** Searching for Answers: Assessment of Information-Seeking by Young People at Risk for Huntington Disease  
*Colby L. Chase*
- B – 47** Whole Exome Sequencing in the Adult Population: A Single Center Experience  
*Radhika Dhamija*
- CANCER**
- B – 50** Deep Intronic *PMS2* Variant Explains Early Onset Colon and Endometrial Cancers in Siblings  
*Julia Cooper*
- B – 53** De Novo *SDHB* Gene Mutation in a Family With a Sporadic Extra-Adrenal Paraganglioma  
*Caitlin Mauer*
- B – 56** Differentiated Thyroid Cancer in Teenagers With FAP: A Case for Earlier Screening?  
*Kristin Zelley*
- B – 59** The Introduction of a Novel Cell-Free Tumor DNA Test for Molecular Residual Disease Detection, Recurrence Monitoring and Therapeutic Response Monitoring in Cancer Care  
*Jody Wallace*
- B – 62** Clinical Phenotype of the *MITF* Gene Variant E318K in a Hereditary Cancer Clinic  
*Kelly Warsinske*
- B – 65** A Case Study: Ampullary Adenocarcinoma and an Inherited *BRCA1* Mutation  
*Forum Shah*
- B – 68** Case Review of Individual With *HOXB13* G84E Variant  
*Ashley Woodson*
- B – 71** Patient-Provider Dialogue Matters: Factors That Impact Medical Management Decisions Among Women With Pathogenic Variants in Moderate-Penetrance Genes Associated With Hereditary Breast Cancer  
*Melissa Henderson*
- B – 74** Outcomes of Panel Testing in the Context of a Known Familial Variant  
*Meghan Ferguson*
- B – 77** Uptake of Polygenic Breast Cancer Risk Information Among High-Risk Women  
*Tatiane Yanes*
- B – 80** *BRCA1* or *BRCA2* Mutations Identified Through Tumor Genomic Profiling: Assessing Genetic Counseling Outcomes  
*Jamie Warner*
- B – 83** The Co-Occurrence of *MUTYH* European Founder Variants and Pathogenic Variants in Separate Genes, One Laboratory's Experiences and Implications for Genetic Counseling on Direct-to-Consumer Genetic Test Results  
*Anna Victorine*
- B – 86** The Perspectives of Emerging Adults With Hereditary Diffuse Gastric Cancer  
*Carrie Anderson*
- B – 89** Multigene Panel Testing in *BRCA1/2* Mutation-Negative Breast Cancer Patients: Findings From a Community Genetics Clinic  
*Meridith Kidd*
- B – 92** Genetic Counselors' Approaches to Testing Cancer Genes in the Absence of Published Medical Management Guidelines  
*Ismam Islam*
- B – 95** Characterization of "Non-Core" Cancers in Individuals With Positive *BRCA1* or *BRCA2* Results Identified Through a Large-Scale Population Genomic Screening Program  
*Marci Schwartz*
- B – 98** Genetic Evaluation of Patients and Families With Concern for Hereditary Tumor Syndromes Within the OSU James Multidisciplinary Neuroendocrine/Thyroid Cancer Clinic  
*Jennifer Gauerke*
- B – 104** Survey of Attitudes Toward Preimplantation Genetic Diagnosis and Quality of Life for Individuals With Hereditary Diffuse Gastric Cancer Syndrome  
*Kimberly A. Amoroso*
- B – 107** Rates of Tumor Identification Amidst Screening of Patients With *SDHx* Pathogenic Variants  
*Samantha Greenberg*
- B – 110** Analysis of Individuals With Multiple Heterozygous Pathogenic or Likely Pathogenic Variants in Cancer Predisposition Genes  
*Kelsey Moriarty*

**B – 113** Where Have All the Patients Gone? Poor Genetic Testing Rates in the Male Breast Cancer and Young Female Breast Cancer Populations in Ontario, Canada

*Ji-Sun Kim*

**B – 116** Decision-Making and Experience of Tamoxifen as Chemoprevention by Young Women With a *BRCA1/2* Mutation

*Laura Forrest*

**B – 119** Reviewing Somatic Tumor Test Results: An Emerging Role for Genetic Counselors

*Kristen Hanson*

**B – 122** Clinical Presentation and Germline Status of Individuals Referred for Multigene Hereditary Myelodysplastic Syndrome and Leukemia Testing

*Amanda Bartenbaker Thompson*

**B – 125** Expanded Germline Panels Across Cancer-Types: Diagnostic Yield and Clinical Actionability in a 100,000 Patient Dataset

*Barbara Hamlington*

**B – 128** EGFR-Associated Hereditary Lung Cancer Syndrome: Analysis of *EGFR* T790M Mutation Carriers Among Patients Undergoing Hereditary Genetic Testing

*Darcy Berry*

**B – 134** Family Sharing of Genetic Test Results and Testing Rates Among Women With Mutations in *BRCA* Genes Compared to Other Inherited Breast Cancer Genes

*Deborah Cragun*

## CARDIOLOGY

**B – 137** Use of Cosegregation Data and Laboratory-Clinic Communication to Enhance Variant Classification: *TNNT2* p.Arg139His Segregates With Dilated Cardiomyopathy Phenotypes in a Four-Generation Family

*Katrina Kotzer*

**B – 140** Three Patients With 7q36.1 Deletions at Risk for Long QT Syndrome Due to Hemizygosity of *KCNH2*

*Julie Rutberg*

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# Posters With Authors continued

**B – 143** Genetic Testing in a Heterogeneous Cohort of HCM Patients: Implications for Genetic Counseling  
*Shea Rauch*

**B – 146** Acceptability and Familiarity of Genetic Treatment Technologies: A Survey of Individuals With Sudden Arrhythmic Death Syndrome Conditions  
*Katherine Myers*

**B – 149** Penetrance of Dilated Cardiomyopathy in at-Risk Children and Young Adults  
*Amy Shikany*

## COUNSELING/PYSCHOSOCIAL ISSUES

**B – 152** Going Against the Grain: The Decision to Test a Minor for a Familial *BRCA1* Mutation in an Extenuating Circumstance  
*Niri Carroll*

**B – 155** Being the Bearer of Unexpected News: A Genetic Counselor's Reflections on Returning a Non-Actionable Finding From Healthy Exome Analysis  
*Emily Higgs*

**B – 158** Analyzing Non-Directive vs. Directive Counseling Trends in Genetic Counseling  
*Alexa Rosenblum*

**B – 161** Assessing the Impact of Predictive Testing Protocols on Provider Burden for Huntington's Disease  
*Paige Ernste*

**B – 164** Parental Support Needs of Children Diagnosed With Alopecia Areata  
*Dayna Cohen*

**B – 167** I'm Sorry: A Qualitative Exploration of Genetic Counselor Use of Self-Involving Responses in a Clinical Setting  
*Iman Kashmola-Perez*

**B – 170** Parental Perceptions of Pediatric Clinical Exome Sequencing in a Latino Population  
*Daniel Luksic*

**B – 173** "A Calming Reassurance": The Role of Patients' Religion/Spirituality in Prenatal Genetic Counseling Appointments at Religiously-Affiliated and Non-Religiously Affiliated Institutions  
*Ryan Kuehl*

**B – 176** Deaf Individuals' Attitudes and Perceptions of Genetic Counseling and Genetic Testing  
*Julie Howell*

## EDUCATION

**B – 179** Further Validation of the Genetic Counseling Self-Efficacy Scale (GCSES): Its Relationship With Personality Characteristics  
*Haley Keller*

**B – 182** Understanding Disparities Due to Implicit Racial Bias in Genetic Counseling Communication: An Observational Analysis  
*Chenery Lowe*

**B – 185** A Genomic Variant Interpretation Video Series: Exploring a Social-Media Strategy to Provide Focused Educational Resources  
*Karen E. Wain*

**B – 188** Disability Service Learning: A Study on the Potential Impact of an Educational Intervention on the Attitudes and Biases of Genetic Counseling Students Toward Disability  
*Michelle Bina*

**B – 191** Assessing the Disease Specific Knowledge Gaps in Patients, Caregivers and Families Living With Lysosomal Storage Diseases  
*Georgia Loucopoulos*

**B – 194** Changes in Self-Perceived Breast Cancer Risk and Self-Perceived Impact of Breast Cancer Risk Factors After a Breast Cancer Education Session and Individualized Risk Assessment  
*Alexandra Magnante*

**B – 197** Gene Therapy on the Horizon: Perception and Understanding of Gene Therapy Research by the Bleeding Disorders Community  
*Meg Bradbury*

**B – 200** International Genetic Counseling: What Do Genetic Counselors Do?  
*Laura Hayward*

## ETHICAL, LEGAL AND SOCIAL ISSUES

**B – 203** Therapy or Travesty: Genetic Counselor Experiences With and Attitudes Toward Growth Attenuation Therapy  
*Katherine Anderson*

**B – 206** New Insights to a CRISPR World: A Cross-Sectional Analysis of Individual's and Advocacy Group Views Into Genomic Editing  
*Dylan Platt*

**B – 209** Amish Perspectives of the Genetic Counseling Process  
*Brianna Teapole*

## GENETIC/GENOMIC TESTING

**B – 212** Molecular Diagnosis of an Epileptic Encephalopathy Patient Aided by RNA Analysis  
*Taryn Athey*

**B – 215** Case Series: Identifying and Classifying Haplotype Results  
*Michael Setzer*

**B – 218** The Value of CNV Analysis for Inherited Retinal Diseases  
*Meghan DeBenedictis*

**B – 221** Participant Motivation, Satisfaction and Outcomes of Population-Based Genomic Research  
*Ashley Cannon*

- B – 224** Identifying Ethnicity-Associated Differences in Genetic Testing Results for Patients With Suspected Inherited Retinal Degeneration  
*Samuel Miller*
- B – 227** Exploring the Impact of Negative Genetic Test Results on Personal Utility and Perceived Value: Does Having a Personal or Family History of Condition Make a Difference?  
*Sinead Horgan*
- B – 230** Non-Genetics Pediatric Providers' Understanding and Interpretation of a VUS Result  
*Chelsea Menke*
- B – 233** Investigating Variants of Uncertain Significance: Reclassification Triggers and Drivers in Breast Cancer Predisposition Genes  
*Kirsten Kelly*
- B – 236** Seeking Authorization for Elective Genomic Tests: How Does Cost Play a Role?  
*Emily Qian*
- B – 239** Eight Years of Testing and Over One Million Patients Screened: A Statistical Review of the Latest MaterniT<sup>®</sup>21 PLUS Assay Enhancements  
*Kimberly Fanelli*
- B – 242** False Reassurance in Returning Uninformative Genomic Screening Results to Healthy Individuals  
*Megan Bell*
- B – 245** Triploidy: It's Not Just a First Trimester Diagnosis  
*Melissa K. Maisenbacher*
- B – 248** Experience From the First 150 Cases of Low Pass Genome Sequencing (5X) Demonstrates Clinical Utility and Provides Potential Alternative to Traditional Microarray in the Clinical Settings  
*Alka Chaubey*
- B – 251** Relationship Between Phenotypic Complexity and Diagnostic Results From a Large Autism/Intellectual Disability Cohort  
*Jane Schuette*
- B – 254** Understanding and Impact of Negative Direct-to-Consumer BRCA Test Results  
*Kristen Pauley*

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# Posters With Authors continued

- B – 257** Utility and Diagnostic Rates of Exome Sequencing for Ataxia-Related Disorders  
*Mary Beth Stosser*
- B – 260** Utilization of a SNP Array for Homozygosity: Prenatal Delineation of Recessive Diseases  
*Stuart Schwartz*
- B – 263** Expanding Patient Data Sharing: GenomeConnect's Pilot to Engage External Registries in Data Sharing  
*Juliann Savatt*
- B – 266** Interpreting VUSs: GSD1a  
*Kristy Nguyen*

## PEDIATRICS

- B – 269** Novel De Novo Loss of Function Mutation in *PTDSS1* in a Female With Typical Growth, Autism Spectrum Disorder and Developmental Delay  
*Sara Gracie*
- B – 272** The Phenotypic Spectrum of Wiedemann-Steiner Syndrome in Minority Populations Based on Findings From P3EGS  
*Tiffany Yip*
- B – 275** Expanding the Molecular Basis and Phenotype of Grange Syndrome  
*Diane Clements*
- B – 278** Parental Beliefs and Attitudes Toward False Positive Newborn Screening Results for Krabbe Disease: A Qualitative Study  
*Laiken Peterson*
- B – 284** Assessing Parental Perceptions Toward Disclosure of Increased Risk of Psychiatric Illness to Their Child With 22q11.2 Deletion Syndrome  
*Jennifer Kennedy*
- B – 287** Adolescents' and Parents' Attitudes About Genetic Testing for Carrier Status and Adult-Onset Conditions  
*Bryana Rivers*
- B – 290** Genetic Counseling and Testing in a Pediatric Population With Autism Spectrum Disorder  
*Abigail Schaber*
- B – 293** Genotypic and Sociodemographic Associations With Increased Age of Diagnosis in Duchenne Muscular Dystrophy Patients  
*Kevin Counterman*
- B – 299** Pediatric Specialty Genetic Counselors: Clinical Activities and Position Structure  
*Katie Rembisz*
- B – 302** Exploring the Impact of Insurance on Pediatric Genetic Counseling Testing Practices  
*Kristen Young*
- ## PRE- AND PERINATAL
- B – 305** A Case of Disputed Variant Classification: In-Frame Duplications of DMD Exons 17-30 Cannot be Categorized as Pathogenic  
*Jillian Tokarczyk*
- B – 308** Copy Number Variant Encompassing *SOX5* in Two Generations With a Normal Phenotype  
*Emily Chien*
- B – 311** Severe Prenatal Presentation of Familial Hypophosphatasia With Novel Mutation in *ALPL* Gene  
*Catherine Burson*
- B – 314** Recurrent Fetal Cystic Hygroma With Normal Pediatric Outcomes  
*Erin Swartz*
- B – 317** X-Linked Myotubular Myopathy Identified by Exome Sequencing in a Family With Two Neonatal Male Deaths With Non-Specific Autopsy Findings: A Case Report  
*Amanda Buchanan*
- B – 320** Mosaic Trisomy 21 Results by Cell Free DNA Screening in a Fetus With Low-Level Mosaicism Leads to Unique Genetic Counseling Challenges  
*Katelynn G. Sagaser*
- B – 323** Yield of NIPT After the Prenatal Identification of a Soft Maker: Experiences at UCSD Maternal-Fetal Care and Genetics  
*Amy Stenhouse*
- B – 326** Assessing Clinical Education Tools on Expanded Carrier Screening  
*Chloe Dugger*
- B – 329** Classifying the Severity of Conditions on an Expanded Carrier Screening Panel  
*Aishwarya Arjunan*
- B – 335** Current Practices and Perspectives of Genetic Counselors and Reproductive Endocrinologists Regarding Transfer of Mosaic Embryos  
*Angelica Starnes*
- B – 338** Cell-Free DNA Analysis for Prenatal Aneuploidy Assessment: An Analysis of International Professional Society Statements  
*Renee Jones*
- B – 341** The Meaning of Preparation: Parental Experiences Following the Prenatal Diagnosis of Aneuploidy  
*Molly Ford*
- B – 347** Underlying Causes of Fetal Sex Discordance Between NIPT and Ultrasound: A Case Series Review  
*Tess Levy*
- B – 350** Quality and Quantity: Outcome of Whole Gene Sequencing in Expanded Carrier Screening of Routine Preconception and Prenatal Female Patients  
*Heather Fecteau*



## PROFESSIONAL ISSUES

- B – 353** Quagmire of Incidental Uncertain Maternal Result After POC Testing Without Informed Consent  
*Michelle Bosworth*
- B – 356** The Canadian Genetic Counselling Workforce: Perspectives From Employers and Recent Graduates  
*Taylor Costa*
- B – 359** Community Member Perspectives on Proposed Pedigree Nomenclature for Transgender and Non-Binary Patients  
*Hallie Lyninger*
- B – 362** Multiple Mini Interviews in Genetic Counseling Admissions: The Applicant Perspective  
*Holly Zimmerman*
- B – 365** Exploration of Formal Training for Genetic Counseling Assistants  
*Kelsey Hogan*
- B – 368** Factors Contributing to Job Satisfaction and Longevity in Millennial Genetic Counselors  
*Kimberly Kinnear*

- B – 371** Assessing Financial Recognition of Genetic Counseling Training Program Educators  
*Karin M. Dent*
- B – 374** Exploring the Ethical and Professional Challenges Encountered by Clinical Genetic Counselors Who Are Engaged in Research  
*Amanda Schaefer*

## PSYCHIATRY/NEUROLOGY

- B – 377** Genetic Findings From 50 Patients in a Dementia Clinic  
*Bradley Rolf*
- B – 380** Perceived Utility of Genetic Counseling for Individuals With Eating Disorders  
*Juliann Streukens*
- B – 383** Identifying Interest in and Barriers to Psychiatric Genetic Counseling  
*Samantha Montgomery*



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# Posters With Authors continued

## PUBLIC HELATH

- B – 386** Developing a Standardized Approach to Creating Patient Resources: Fetal Surgery for Myelomeningocele  
*Andrea Filthaut*
- B – 389** High School Carrier Screening: Feelings and Attitudes of Students in Cree Communities  
*Jessica Le Clerc-blain*

## RESEARCH ISSUES

- B – 392** Do You Check All the Boxes? Current Reporting Practices in Genetic Counseling Research and How We Can Move Toward Evidence-Based Practice  
*Jessica Davidson*
- B – 395** The Evolution of a Natural History Database Framework Across Three Ultra-Rare Genetic Disorders  
*Puneet Rai*
- B – 398** Parental Perspectives on Research Genetic Testing: Distinction Among Sociodemographic Groups  
*Heather Hain*

## UTILIZATION MANAGEMENT

- B – 401** Time to Electronic Reporting and Patient Notification of Germline Genetic Test Results: One Center's Experience  
*Hannah Chung*
- B – 404** Implementation of Whole Exome Sequencing Order Review at a Pediatric Institution  
*Erin McGinnis*

## GROUP C POSTERS

### ACCESS AND SERVICE DELIVERY

- C – 3** Genetic Counselor Perspectives and Opinions of Population Genetic Testing  
*Nicole Deckard*
- C – 6** Lost in Translation: Assessing Interpretation in Genetic Counseling Settings  
*Cassandra Gurganus*
- C – 9** Does Supply Equal Demand? The Workforce of Direct Patient Care Genetic Counselors in Wisconsin  
*Carlee Dawson*
- C – 12** Reducing Wait-Time for Genetic Services: Adapting an Older Model for the Needs of Today  
*Alex Whitaker*
- C – 15** Geographical Barriers to Genetic Counseling for Hereditary Cancer and Cardiovascular Disease  
*Stephanie E. Wallace*
- C – 18** Referral Trends to a Cancer Genetics Clinic Over Time  
*Sarah Austin*

- C – 21** Oncologist-Mediated Genetic Testing: The Holy Grail of Cancer Genetics?  
*Jeanna McCuaig*
- C – 24** BRCA1/2 Mutation Carriers Support Direct Consumer Access to BRCA1/2 Testing but Emphasize Role of Genetic Counseling  
*Caitlyn Mitchell*
- C – 27** Training Program Development and Clinical Continual Quality Improvement: A Telegenetics Success Story  
*Katharine Bisordi*
- C – 30** A Quantitative Content Analysis of Post-Visit Written Summary Communications in Genetic Counseling  
*Marissa Younan*
- C – 33** Telegenetic Education in Genetic Counseling Graduate Programs  
*Natasha Robin Berman*
- C – 36** Family Planning via Assisted Reproductive Technologies: Assessing Patient Advocacy Group Perceptions of, Access to and Utilization of Educational Resources on Reproductive Technologies  
*Meghan Dean*
- C – 39** The Role of Social Media in the Cystic Fibrosis Community and How It Relates to Healthcare Provider Relationships  
*Ashlee Vargason*

### ADULT

- C – 42** Lived Experiences of Individuals With Cystic Fibrosis on CFTR-Modulators  
*Annelise Page*
- C – 45** Counseling the Active-Duty Military Population: Knowledge, Attitudes and Experience of Clinical Genetics Providers  
*Jennifer Jacober*

### CANCER

- C – 48** Expanding the Phenotype: Case Report Detailing the Youngest Diagnosis of Renal Cancer Observed in an Individual With a BAP1 Pathogenic Variant  
*Carolyn Garby Haskins*
- C – 51** Characterization of the Fumarate Hydratase (FH) c. 1431\_1433dupAAA Variant in Hereditary Leiomyomatosis and Renal Cell Cancer: A Case Series  
*Nanor Haladjian*
- C – 54** Li-Fraumeni Syndrome – The Importance of Cascade Testing Even in Families That Meet Clinical Criteria  
*Rebekah Moore*
- C – 57** Glioblastoma and Multiple Café-Au-Lait Macules Diagnosed in the Context of a Family History of Cancer: Simultaneous MSH2 and NF1 Mutations or Constitutional Mismatch Repair Deficiency Syndrome?  
*Maureen Mork*

- C – 60** Promoter Region RB1 Gene Pathogenic Variant: Saving Vision in Two Brothers  
*Debra Collins*
- C – 63** Double Check *CHEK2*: A Cautionary Tale of Variant Allele Frequency  
*Jennifer Brzosowicz*
- C – 66** Genetic Counseling Challenges Highlighted by a Novel Presentation of a Familial ATM Mutation and Ataxia-Telangiectasia  
*Morgan Turner*
- C – 69** Molecular Tumor Profiling: Expect the Unexpected  
*Rachelle Chambers*
- C – 72** Predictors of a Positive Genetic Test Result in a Cohort of Renal Cell Carcinoma Patients  
*Andrea Kokorovic*
- C – 75** An Investigation of Approaches to Genetic Counseling Regarding Moderate-Penetrance Breast Cancer Susceptibility Genes  
*Elizabeth Del Buono*
- C – 78** Comparison of Somatic and Germline Variant Interpretation in Hereditary Cancer Genes  
*Emily Moody*
- C – 81** Exploring Patient Perceptions and Misconceptions: Beliefs Regarding Hereditary Cancer  
*Margaret Flach*
- C – 84** Genetic Evaluation Following *MUTYH* Analysis for European Founder Variants Is Critical to Identify at-Risk Patients: A Laboratory's Experience  
*Anna Victorine*
- C – 90** Correlation Studies in Families With Familial Non-Medullary Thyroid Cancer  
*Marie-Louise Henry*
- C – 93** Pediatric Precision Oncology: Parent and Adolescent Experiences  
*Larissa Waldman*
- C – 96** Putative Germline *BRCA1/2* mutations in Patients (pts) With Advanced Gastrointestinal (GI) Cancers Using Circulating Cell-Free Tumor DNA (cfDNA) Analysis in the GOZILA study  
*Yumie Hiraoka*

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# Posters With Authors continued

- C – 99** Evaluating the Psychological Needs of Young Adults With Lynch Syndrome  
*Kathryn Dunn*
- C – 102** Somatic MMR Testing: The Gap Between Preferred and Current Practices  
*Danielle Williams*
- C – 105** Clinician-Initiated Retrospective Review of Variants of Uncertain Significance  
*Natalie Waligorski*
- C – 108** Inclusion of Genetics in a Multidisciplinary Endocrine Tumor Board: An Emerging Role for Genetic Counselors  
*Gwen Reiser*
- C – 111** Genetic Counselor Roles in Somatic Tumor Testing in a System-Wide Oncology Practice  
*Karen Huelsman*
- C – 114** Broadening the Germline Genetics of Inherited Renal Cancer  
*Tiffiney Hartman*
- C – 117** Determining the Proportion of Early-Onset Colorectal Cancer That is Potentially Preventable  
*Keith Pelstring*
- C – 120** Breast Cancer Screening Compliance in Women at Increased Risk for Breast Cancer  
*Samantha McAllister*
- C – 123** Attitudes Toward Dating BRCA-Positive Previsors  
*Kalisi Logan*
- C – 126** Genetic Testing for Therapeutic Implications in Patients With Metastatic Breast Cancer and Pancreatic Adenocarcinoma: A Comparison of a GC-Led Versus MD-Led Service Delivery Model  
*Breanna Roscow*
- C – 129** A Pilot Study to Evaluate Interventions Aimed to Improve Response to a Risk Notification Letter Following Mammography  
*Katharine Imrie*
- C – 132** Better Than the Guidelines? Pre- and Post-Genetic Testing Data Suggests Change in Management Trends  
*Zoe Powis*
- C – 135** Factors Influencing Compliance With National Comprehensive Cancer Network (NCCN) Guidelines Following a Positive Test Result for a Pathogenic Gene Mutation  
*Cortlandt Martin*

## CARDIOLOGY

- C – 138** Dual Diagnoses of Inherited Cardiovascular Disease: Ascertainment, Clinical Management and Care of Patients and Family Members  
*Chloe Reuter*
- C – 141** Cantu Syndrome: A Longitudinal Review of Vascular Findings in Two Patients  
*Ashley Parrott*

- C – 144** Genetic Testing Interpretation: An Assessment of Cardiology Fellows' Knowledge  
*Cody Carlson*
- C – 147** Phenotypes Associated With Expected Pathogenic Cardiac Variants Identified Through Genomic Screening of Unselected Adult Biorepository Participants  
*Melissa Kelly*

## COUNSELING/PYCHOSOCIAL ISSUES

- C – 150** Now What Do We Do? A Case of Misdiagnosis of Myotonic Dystrophy Type 1  
*Lydia Hellwig*
- C – 153** AJ Ancestry Evaluation: A Tool for Cancer Genetic Counseling  
*Devin Cox*
- C – 156** Serving the Psychosocial Needs of Patients Following Telehealth Genetic Counseling Sessions Addressing Increased Reproductive Risk  
*Melanie Hardy*
- C – 159** Assessing Cutaneous Neurofibroma Related Intimacy Concerns in the Adult Neurofibromatosis Type I Population  
*Jacynda Woodman-Ross*
- C – 162** Genetic Counseling for Transgender Patients: Perceptions, Terminology and Disclosure of Transgender Status  
*Hallie Lyninger*
- C – 168** Evaluation of the Impact of Genetic Counseling on Psychological Well-Being and Perceived Risks in Cases on Sudden Unexplained Death in Childhood  
*Susan Reilly*
- C – 171** A Needs Driven Approach to Developing Disease Specific Patient Educational Materials for Pompe Disease  
*Jamie Love-Nichols*
- C – 174** Family Communication and Coping Strategies in Families With Huntington's Disease  
*Amanda Schatzle*
- C – 177** Knowledge and Attitudes about Genetic Counseling in Patients at a Major Hospital in Addis Ababa, Ethiopia  
*Michelle F. Jacobs*

## EDUCATION

- C – 180** Webinar Outreach: An Effective Tool for Recruiting Potential Genetic Counseling Program Applicants  
*Sarah Huguenard*
- C – 183** A Fly on the Wall? A Study of the Experiences and Perceptions of the NSGC Community With Genetic Counseling Career Shadowing  
*Christine Koellner*

- C – 186** Assessing the Frequency With Which Practicing Physician Assistants Use Standardized Genetic and Genomic Competencies in Practice  
*Megan Parker*
- C – 189** Understanding Stigma Among Genetic Counselors and Students Towards Mental Illness Using the Opening Minds Stigma Scale for Health Care Providers (OMS-HC)  
*Anuja Anil Chitre*
- C – 192** Sources of Genetics Misconceptions in a Population Sample  
*Beth Lincoln Boyea*
- C – 195** International Genetics Provider Perspectives on Hosting Genetic Counseling Students for Summer Rotations  
*Smita Rao*

## ETHICAL, LEGAL AND SOCIAL ISSUES

- C – 201** Somatic Testing for Optic Glioma: Incidental Findings and Implications for Minor Patient  
*Lauren Palange*
- C – 204** Secondary Data Usage in Direct-to-Consumer Genetic Testing: To What Extent are Customers Aware and Concerned?  
*Janessa Mladucky*
- C – 207** Deconstructing Culture Bumps: Interpreters' Views in the Genetic Counseling Setting  
*Marc Rosenbaum*

## GENETIC/GENOMIC TESTING

- C – 210** Monosomy Seven: Uncovering the Enigma by Molecular Cytogenetics and Molecular Genetic Pathogenesis  
*Suneeta Madan-Khetarpal*
- C – 213** Diagnosing the Undiagnosed: Expanding the Genetic Etiology and Phenotypic Spectrum of Rare Pediatric Conditions  
*Theresa Mihalic Mosher*
- C – 216** Genotype vs Phenotype: Pathogenic Variant in *TSC1* in a Three-Generation Family Without Clinical Evidence of Tuberous Sclerosis Complex  
*Haley Streff*
- C – 219** Detection of Unbalanced and Balanced Chromosomal Rearrangements via a Genome Sequencing Test  
*Erin Thorpe*
- C – 222** Utility of Gene Panel Testing in Children With Seizure Onset After Two Years of Age: Results From a European and Middle Eastern Epilepsy Genetic Testing Program  
*Tero-Pekka Alastalo*
- C – 225** Understanding the Practice of Genetic Result Communication to Extended Family Members by Participants in the Undiagnosed Diseases Network (UDN)  
*Courtney Studwell*

- C – 228** Which Test is Best? Evaluating the Diagnostic Yield of Sequencing-based Testing Approaches for Patients With Neurodevelopmental Disorders at a Pediatric Institution: A Retrospective Chart Review  
*Nicholas Little*
- C – 231** Genotype-First Analysis of Whole Exome Sequencing: Diagnostic Yield of Whole Exome Sequencing Trio Testing Including CNV Analysis  
*Jennifer Schleit*
- C – 237** High Mapping Quality and Coverage in the Homologous PKD1 Gene Results in a High Diagnostic Yield  
*Shea Rauch*
- C – 240** A Review of Non-Traditional Indications for Non-Disclosure Preimplantation Genetic Testing (PGT)  
*Agnes Machaj*
- C – 243** Outcome of High Risk for Double Aneuploidy Results From SNP-Based Non-Invasive Prenatal Testing (NIPT) and Incidence in Products of Conception (POC) Testing  
*Trudy McKanna*
- C – 246** Gene Curation in a Clinical Whole Genome Sequencing Context and Its Effect on Variant Reporting  
*Amanda Buchanan*
- C – 249** Copy Number Variants (CNVs) in Inherited Retinal Disorders: Results From Genetic Testing of Over 2,700 Patients  
*Lauren Moissiy*
- C – 252** Lack of Genotype-Phenotype Correlation in Individuals With DMPK CTG Repeat Expansions  
*Seema M. Jamal*
- C – 255** Next Generation Sequencing With Copy Number Analysis for Primary Immunodeficiencies: Findings From a Cohort of Over 3,900 Unrelated Patients  
*Jessica Connor*
- C – 258** Theoretical Diagnostic Yield of a Rapid, Targeted Genetic Panel for Critically Ill Pediatric Patients and Newborns  
*Danuta Stachiw-Hietpas*
- C – 261** Early Experiences With Whole Genome Sequencing in a State-Funded Research Initiative  
*Whitley Kelley*
- C – 264** Trio-Based Genetic Testing for Leukodystrophies: High Positive Diagnostic Rate in Both Adults and Children  
*Courtney Downtain Pickersgill*

## PEDIATRICS

- C – 267** De Novo *TFE3* Variants in Two Females With Severe Neurocognitive Delays, Pigmentary Mosaicism Following the Lines of Blaschko and Coarse Facial Features  
*Jullianne Diaz*

# Posters With Authors continued

- C – 270** Further Evidence of *GABRA4* and *TOP3B* as Autism Susceptibility Genes  
*Jacquelyn Riley*
- C – 273** Cautions of a Case Report: An Update on a Previously Described Case of Digenic Inheritance  
*Leighann Sremba*
- C – 276** Homozygous *GNG3* Pathogenic Variants in Three Siblings With Epileptic Encephalopathy, Infantile Spasms, Global Developmental Delays, Hypotonia and Cortical Visual Impairment  
*Katie Angione*
- C – 279** Assessment of the Impact of a Positive Family History and Genetic Counseling on Parental Knowledge of Neurofibromatosis Type 1 (NF1)  
*Emily Solem*
- C – 282** Metabolic Control, Quality of Life and Body Image in Patients With Glycogen Storage Disease Type 1a  
*Alexa Bream*
- C – 285** Exploring the Intersection of Pediatric Genetic Counseling and the U.S. Foster Care System  
*Talia Flamos*
- C – 288** Attitudes of Healthcare Professionals Towards the Utilization of Genetics Professionals Following the Diagnosis of Autism Spectrum Disorder  
*Sydney Alexandra Lau*
- C – 291** Behind the Seizure(TM): Enabling Early Molecular Diagnosis for Children With Epilepsy  
*Hannah White*
- C – 294** What Should I Order? Genetic Testing Ordering Trends for Autism Spectrum Disorder  
*Catherine Schultz*
- C – 297** Genetics Referral Practices and Yield of Genetic Testing in a Pediatric Cancer Cohort  
*Kristin Zajo*
- C – 300** Newborn Screening for Four Lysosomal Storage Disorders: One Center's Experience Over Six Years  
*Meghan Strenk*
- C – 303** Parents' Perspectives on the Transition From Pediatric to Adult Healthcare in Cornelia de Lange Syndrome  
*Marisa Chamness*
- PRE- AND PERINATAL**
- C – 306** A Rare Case of Dizygotic Twins With Trisomy 13 and the Importance of Sampling Each Twin With Diagnostic Testing  
*Julia Weston*
- C – 309** Novel *L1CAMVUS* Identified via Whole Exome Sequencing in Patient With Two Male Pregnancies Affected With Agenesis of the Corpus Callosum  
*Jessalyn Gerber*
- C – 312** Prenatal Presentation of Megalencephaly-Polymicrogyria-Polydactyly-Hydrocephalus (MPPH) Syndrome  
*Catherine Burson*
- C – 315** Expanded Aneuploidy Analysis Reveals Trisomy Two: Evidence of Rare Aneuploidy via NIPS Provides Opportunity for Focused Care  
*Susan Hancock*
- C – 318** Recurrent Non-Immune Fetal Hydrops (NIFH) Due to Native American Myopathy (NAM) in an African-American Couple: Expanding the Phenotype of *STAC3*-Related Congenital Myopathy  
*Laura Hendon*
- C – 321** A Case of Mixoploidy in the Setting of a Normal Fetus  
*Nicole Poulos*
- C – 324** To Screen or Not to Screen: Perceived Barriers to Paternal Expanded Carrier Screening Following a Positive Maternal Result  
*Katherine Philo*
- C – 327** Termination for Fetal Anomaly: What Is the Impact of Genetic Counseling on Coping?  
*Cayleen Smith*
- C – 330** Minimizing Results Delivery Time for Couples Undergoing Carrier Screening: A "Tandem-Reflex" Strategy  
*Aishwarya Arjunan*
- C – 333** "On the Fringe:" Clinical Application of Less Commonly Used Ultrasound Markers for Down Syndrome  
*Emily Creque*
- C – 336** A First Look at the Accessibility of Prenatal Genetic Screening Services Among Incarcerated Women in the United States: Perspectives of Correctional Health Professionals  
*Natalie Waligorski*
- C – 339** An Innovative Non-Invasive Prenatal Testing (NIPT) Assay Offers the Potential for a Low-Cost, Highly-Accurate Aneuploidy Screen in the Global Population  
*Alka Chaubey*
- C – 342** Recall of Informed Consent for Prenatal Aneuploidy Screening  
*Pranali Shingala*
- C – 345** An Exploration of the Current Impressions and Experiences With NIPT Among Genetic Counselors  
*Charly Harris*
- C – 348** Exploring Experiences & Expectations of Prenatal Healthcare and Genetic Counseling/Testing in Immigrants Latinas  
*Georgiann Garza*
- C – 351** Observed and Modeled Positive Predictive Values Using cfDNA Testing for Fetal Trisomy in a Clinical Laboratory Population  
*Karen White*

## PROFESSIONAL ISSUES

- C – 354** Short-Term, Defined Mentorship Program Between Genetic Counselors and Genetic Counseling Assistants  
*Jade Mukri*
- C – 357** Knowledge and Opinions of the Genetic Counseling Profession of High School Students From Underrepresented Backgrounds  
*Joanna Urli*
- C – 360** Supervision in Genetic Counselor Training: A Systematic Review  
*Carly Siskind*
- C – 363** Impacts of Genesurance Considerations on Genetic Counselors' Practice and Attitudes  
*Emily Krosschell*
- C – 366** Coping With Compassion Fatigue and Burnout in Genetic Counselors Using the Provider Resilience Mobile Application  
*Lindsey Kelley*
- C – 369** Developing a Nationally Benchmarked Resource for Practice Outcome Measurement  
*Jessica M. Goehringer*
- C – 372** Forging a New Path: Emerging Roles for Genetic Counselors in the Insurance Industry  
*Abigail Sassaman*

## PSYCHIATRY/NEUROLOGY

- C – 375** *PIGA* Related Disorder as a Range of Phenotypes Rather Than Two Distinct Subtypes  
*Shelby Cash*
- C – 378** Novel *SCN2A* Missense Variant in Family With Benign Familial Neonatal Infantile Seizures Successfully Managed With Sodium Channel Blockers  
*Randall Beadling*

- C – 381** Comparison of Symptom Profiles in Patients With Inherited Myotonic Disorders  
*Alayne Meyer*
- C – 384** Psychiatric Genetic Counseling: Impact on Psychotropic Medication Adherence in People With Serious Mental Illness  
*Emily Morris*

## PUBLIC HEALTH

- C – 387** Evaluating the Impact of Public Health Efforts to Promote Guideline-Based Insurance Coverage of HBOC and Lynch Syndrome Genetic Testing  
*Mallory Wagner*
- C – 390** Are Individuals Pursuing Health Whole Genome Screening Really Healthy?  
*Lindsay Meyers*

## RESEARCH ISSUES

- C – 393** Positive Attitudes and Therapeutic Misconception Around Clinical Trials in the Huntington's Disease Community  
*Kristina Cotter*
- C – 396** Establishing a Protocol for Returning Incidental Genetic Research Findings to Former Study Participants  
*Ryan Mooney*
- C – 399** Content Analysis of Research Articles Published in the Journal of Genetic Counseling: A Multi-Year Perspective  
*Alexandra Wallgren*

## UTILIZATION MANAGEMENT

- C – 402** Understanding Dermatologists' Use, Self-Reported Knowledge and Attitudes Towards Genetic Testing  
*Emma Perez*



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## EDUCATIONAL SUPPORT



# Learning Lounge Presentations

Learning Lounge Presentations are 15-minute presentations given by select vendors and speakers in the Learning Lounge located in the NSGC Central (Booth #415) of the Exhibitor Suite. These presentations are a great way to learn more about a certain topic. Make the most of your time in the Exhibitor Suite by attending one of the following presentations:

## Tuesday, November 5

Sponsored by:  Rhythm  
PHARMACEUTICALS

5:15 pm – 5:30 pm

### Best Poster Abstracts – Lightning Round

*Various Speakers*

Join the nominees for this year's Best Poster Award as they present their work in the lightning round! Each nominee will have 60 seconds to describe their work, and explain why you should visit them during their poster session!

5:45 pm – 6:05 pm

### Not All Obesity Is the Same! Introduction to Rare Genetic Disorders of Obesity

*Heidi Shea, MD*

An introduction to rare genetic disorders of obesity as a subset within the disease of obesity and the urgency to appropriately identify the underlying causes of obesity.

6:20 pm – 6:35 pm

### Genetic Counseling Trainee Participation in an Inter-Professional, Case-Based Clinical Genetics Curriculum for Medical Students: An Experience in Peer-to-Peer Learning

*Kathleen Berentsen Swenson, MS, MPH, CGC*

There are many ways to raise awareness of the field through inter-professional education in genetic counseling training programs and post medical education to residents and fellows. The objective of our session is to share more on our experience using a case-based clinical genetics curriculum that can be applied in a variety of settings.

6:50 pm – 7:05 pm

### We Teach but Patients Teach Better: Building a National Patient-Teacher Registry

*Jacob Athoe, MS Candidate, Genetic Counseling*

Although the role of genetics in medicine is steadily increasing, awareness about rare diseases, especially biochemical or metabolic diseases remains poor. Teaching about the inborn errors of metabolism is inadequate in medical school and the vast majority of postgraduate medical training programs. This compromises patient care, as patients go for years without a diagnosis, resulting in lost opportunities for counseling and missed access to an increasing number of available treatments.

We will present the concept of a National Patient-Teacher Registry (NPTR), an initiative that utilizes the power of storytelling, and brings patients – live or recorded – into the educational realm for medical students, practicing medical and genetic health professionals, and their trainees.

7:20 pm – 7:35 pm

### A Beginner's Guide to Artificial Intelligence

*Elizabeth Kearney, MS, LCGC, MBA*

Robots are taking over genetics! Or are they? Separate fact from fiction with a basic overview of AI for genetic counselors. Learn how technology is used in genetic testing and how technology may influence genetic counseling practice in the not-to-distant future.

## Wednesday, November 6

Sponsored by:



6:00 pm – 6:15 pm

### Implications of Early Diagnosis of Genetic Disease Through Carrier Testing and Newborn Screening

*Karen Grinzaid, MS, LCGC, CCRC, Emory University School of Medicine*

Discuss the impact that early diagnosis of genetic diseases has had on the health of patients with lysosomal storage diseases, and updates on carrier testing and newborn screening.

6:30 pm – 6:45 pm

### Taking Care of Ourselves so We Can Serve Others

*Colleen Caleshu, MS, LCGC*

Genetic counselors spend much of their time oriented towards the needs of others. Yet we cannot serve others well if we are not taking care of ourselves. We need a professional culture that prioritizes and values self-care. We'll talk through self-care strategies and evidence that supports their efficacy.

7:00 pm – 7:15 pm

### To Post or Not to Post: Establishing a Professional Social Media Presence

*Rebecca L. McClellan, MGC, CGC*

The age-old question in our modern world. Disclosure has always been a challenge in patient-provider relationships, but in today's world patient's have ever-increasing access to our online personal identities. Many institutional policies outline privacy, legal and ethical considerations, but also allow their providers freedom to act responsibly. But how is the question.

## Thursday, November 7

Sponsored by:



12:00 pm – 12:15 pm

### NIH All of US Research Program Genetic Counseling Resource (GCR)

*Brad Ozenberger, PhD*

Learn about the All of Us GCR powered by Color, future delivery of genomic results and integration into the GC community. Leadership from All of Us, Color and the GCR Advisory Board will be there to answer your questions.

12:30 pm – 12:45 pm

### The First Combined Carrier Screen and Single Gene NIPT That Identifies High-Risk Pregnancies

*Sara Riordan, MS, LCGC*

ACOG recommends all pregnant women be offered carrier screening for cystic fibrosis, spinal muscular atrophy and hemoglobinopathies. UNITY™ identifies carriers and reflexes to single gene NIPT (sgNIPT), allowing for early identification of high-risk pregnancies. Utilizing molecular counting technology, UNITY™ is the only sgNIPT that does not require paternal DNA.

1:00 pm – 1:15 pm

### Hanging out on Your Own Shingle: Genetic Counseling Consulting

*Linda Robinson, MS, CGC; Debra Collins, MS, CGC*

Have you ever thought about consulting, whether as a full-time job or to make extra money on the side? If you have been asked to be on an advisory board or paid to give a lecture, you are a consultant. We will give you an introduction to the world of consulting. Examples and practical considerations such as contracts, resources, money, taxes, etc. will be covered.

1:30 pm – 1:45 pm

### How to Perform a Single-Gene NIPT Without the Father's DNA

*Brian Landry, PhD*

UNITY™ conducts single-gene NIPTs for cystic fibrosis, spinal muscular atrophy, and hemoglobinopathies without requiring the father's DNA. Screening of these recessively inherited disorders in the fetus from cell-free DNA is a complex problem. This talk explains the novel cell-free DNA counting technology and bioinformatic analysis that powers the UNITY™ screen.

2:00 pm – 2:15 pm

### Tools for Us by Us: Genetic Counselors Informing the Development of Technology for Our Profession

*Jill Davies, MS, CCGC*

Learn how genetic counselors can (and do!) guide and lead the development of technology solutions aimed at increasing access to our services and improving efficiency in the delivery of genomic medicine.

# NSGC Awards

## Fellowships and Special Project Awards

### JANE ENGELBERG MEMORIAL FELLOWSHIP AWARD (JEMF)

Katherine Helbig, MS, LCGC

### AUDREY HEIMLER SPECIAL PROJECT AWARD (AHSPA)

Jessica Hartley, MS, CGC

Angela Krutish, MSc, MSc

## NSGC Leadership Awards

### NATALIE WEISSBERGER PAUL NATIONAL ACHIEVEMENT AWARD

Vickie Venne, MS, LCGC

### NEW LEADER AWARD

Katelynn Sagaser, MS, CGC

### OUTSTANDING VOLUNTEER AWARD

Melanie Hardy, MS, MS, LCGC

### CULTURAL ADVOCACY AWARD

Charité Ricker, MS, LCGC

### STRATEGIC LEADER AWARD

Tara Schmidlen, MS, LGC

### DIVERSITY AND INCLUSION LEADER AWARD

Gayun Chan-Smutko, MS, CGC

## Best Abstract Awards

### BEST FULL MEMBER ABSTRACT AWARD

Sienna Aguilar, MS, LCGC

### BETH FINE KAPLAN STUDENT ABSTRACT AWARD

Franceska Hinkamp, MS

## Scholarship and Journal Awards

### JOURNAL OF GENETIC COUNSELING BEST PAPER TRAINEE ONLY CATEGORY

#### Development and Validation of the Genetic Counseling Self-Efficacy Scale

Sarah Caldwell, University of Cincinnati/Cincinnati Children's Hospital Medical Center

#### The Impact of Cardiovascular Genetic Counseling on Patient Empowerment

Hannah E. Ison, Indiana University School of Medicine

#### Genetic Counselors' and Genetic Counseling Students' Implicit and Explicit Attitudes Toward Homosexuality

Megan Nathan, Stanford University

#### Evolving Decisions: Perspectives of Active and Athletic Individuals With Inherited Heart Disease Who Exercise Against Recommendations

Trishna Subas, Stanford University

### STUDENT ANNUAL CONFERENCE SCHOLARSHIP

Joseph Liu

Hebbah Sayed-Ahmad

## Award Schedule

Make sure you are in the Grand Ballroom during the following times to see the award presentations:

### NATALIE WEISSBERGER PAUL NATIONAL ACHIEVEMENT AWARD

Tuesday, November 5 | 3:45 pm

### NEW LEADER AWARD

Wednesday, November 6 | 8:00 am

### DIVERSITY AND INCLUSION LEADER AWARD

Wednesday, November 6 | 4:15 pm

### AUDREY HEIMLER SPECIAL PROJECTS AWARD

Wednesday, November 6 | 5:20 pm

### OUTSTANDING VOLUNTEER AWARD

Thursday, November 7 | 8:00 am

### CULTURAL ADVOCACY LEADER AWARD

Thursday, November 7 | 5:00 pm

### BEST FULL MEMBER ABSTRACT AWARD

Thursday, November 7 | 5:35 pm

### BETH FINE KAPLAN ABSTRACT AWARD

Thursday, November 7 | 5:50 pm

### JANE ENGELBERG MEMORIAL FELLOWSHIP AWARD

Thursday, November 7 | 6:05 pm

### STRATEGIC LEADER AWARD

Friday, November 8 | 10:00 am

# Networking Activities + Meetings

## Welcome to the Annual Conference First-Time Attendee Orientation

**TUESDAY, NOVEMBER 5**

**1:30 pm – 2:30 pm**

*Room 251*

Are you a first-time Annual Conference attendee? Make your way to this event to network with other new attendees and learn about the Annual Conference.

## Welcome Reception

**TUESDAY, NOVEMBER 5**

**5:00 pm – 8:00 pm**

*Exhibit Halls A-B, Level 1*

Make new contacts and greet your friends as you preview the vendors and their services in the Exhibitor Suite. Join your colleagues for this special kickoff to the Annual Conference. Light hors d'oeuvres and a cash bar will be available.

Sponsored by:



## Tour Myriad Genetic Laboratories

**WEDNESDAY, NOVEMBER 6**

**8:00 pm – 8:45 pm**

**8:50 pm – 9:35 pm**

*Shuttles to Myriad will depart from the South Foyer of Salt Palace Convention Center on the First Level near Exhibit Hall E.*

Ever wonder what happens to a patient's sample once it arrives at Myriad Genetic Laboratories in Salt Lake City? Join Myriad for a personal tour of their labs to learn more about their commitment to precision medicine and genetic testing.

You will be guided by team members who collaborate daily with world-class scientists. The tour will provide a general introduction to Myriad's mission, history and research. Tours will be approximately 45 minutes long.

Register at <https://myriadlabtournsgc.rsvpify.com>

RSVP is required for tour access. Only confirmed guests will be allowed in.

Sponsored by:



## Mindful Yoga

**THURSDAY, NOVEMBER 7**

**7:00 am – 8:00 am**

*Marriott Hotel, Deer Valley Room*

Balance your mind and body before conference sessions begin! Join Progenity for a yoga session at the Marriott headquarters hotel on Thursday morning. Pre-registration is required; to register, visit booth #729 on Tuesday or Wednesday.

Sponsored by:



## NSGC State of the Society Address

**THURSDAY, NOVEMBER 7**

**8:00 am – 9:15 am**

*Grand Ballroom*

Join NSGC President Amy Sturm, MS, CGC, LGC, as she shares NSGC activities and accomplishments over the past year, reviews NSGC's 2019 advocacy efforts and provides an update on NSGC's strategic initiatives.

## Incoming Presidential Address

**THURSDAY, NOVEMBER 7**

**9:15 am – 9:45 am**

*Grand Ballroom*

Welcome NSGC President-Elect Gillian Hooker as she introduces herself to NSGC members and outlines her vision for NSGC and the genetic counseling profession in 2020.

## 2019 Code Talker Award Ceremony

**THURSDAY, NOVEMBER 7**

**7:00 pm – 9:00 pm**

*Room 251*

Join us for an evening of food, drinks, and amazing stories at the 2019 Code Talker Award Ceremony, honoring genetic counselors nominated by the families they serve

Registration is required, check at the registration desk for availability.

Presented by:



INVITAE and



## Unwind at Keys on Main

**THURSDAY, NOVEMBER 7**

**7:00 pm – 10:00 pm**

*Keys on Main, 242 South Main St.*

Hosted by ARUP Laboratories, this official event of the NSGC Annual Conference features an open bar, unique Utah food offerings, and the best all-request dueling piano show in the state. Bring your favorite song selections and be ready to party!

Sponsored by:



## Headshot Lounge

**During Exhibitor Suite Hours**

*Exhibit Halls A-B, Level 1*

Take your career to the next level with a complimentary professional headshot, sponsored by Myriad Women's Health. When the Exhibitor Suite is open, visit booth #711 to take advantage of this opportunity to update your LinkedIn profile picture.

Sponsored by:



# Annual Conference Program Committee

## NSGC EXPRESSES ITS GRATITUDE TO THESE VOLUNTEERS FOR THEIR HARD WORK AND DEDICATION:

### **Program Committee Chair**

Katherine Lafferty, MS, CGC

### **Program Committee Vice-Chair**

Rachel Mills, MS, CGC

### **Program Committee Members**

Carrie Blout, MS, CGC  
Colleen Caleshu, MS, LCGC  
Melanie Hardy, MS, MS, LCGC  
Katie Krepkovich, MS, MS, CGC  
Lauren Lichten, MS, CGC  
Margaret Sheehan, MS, CGC  
Barry Tong, MS, CGC  
Tara Hart, MS, CGC  
Carolyn Applegate, MGC, CGC  
Sandy Woo, MS, LCGC

### **Abstract Workgroup**

#### **Abstract Workgroup Chair**

Courtney Berrios, MSc, ScM, CGC

#### **Abstract Workgroup Vice Chair**

Chris Tan, MS, LCGC

#### **Abstract Workgroup Members**

Meg Bradbury, MS, CGC, MSHS (*Past Chair*)  
Kathleen Aaron, MS  
Carrie Atzinger, MS, CGC  
Danielle Azzariti, MS, CGC  
Riyana Babul-Hirji, MSc, CGC  
Karlla Brigatti, MS, LCGC  
Carrie Castonguay, MS, CGC  
Emily Fassi, MS, LGC  
Sara Fitzgerald-Butt, MS, LGC  
Caitlin Grabarits, MGC, LCGC  
Tracey Grant, MS  
Katherine Helbig, MS, LCGC  
Jodie Ingles, GDCC, MPH, PhD,  
Yelena Kemel, MS, ScM, CGC  
Jessica Laprise, MS, CGC  
Gabriel Lazarin, MS, CGC  
Meghan Lundy, MS, LCGC  
Megan Marshall, MS, LCGC  
Jessica Mester, MS, LCGC  
Erin Miller, MS, CGC  
Ashley Parrott, MS, LGC  
Betsy Peach, MS, CGC  
Andrea Procko, PhD, LCGC

Gretchen Schneider, MS, LCGC  
Jennifer Schwab, MS, CGC  
Morgan Similuk, ScM, CGC  
Jill Slamon, MA, MS, LCGC  
Katie Wusik, MS, LGC  
Sarah Yarnall, MS, CGC  
Sharon Aufox, MS, CGC  
Kyle W. Davis, ScM, LCGC  
Kate Foreman, MS, CGC  
Maria Gyure, MS, LCGC  
Meadow Heiman, MS, LCGC  
Michelle Jacobs, MS, CGC  
Sara Knapke, MS, LCGC  
Amy Lemke, PhD, MS, CGC  
Katie Lewis, ScM, CGC  
Khalida Liaquat, MS, LCGC  
Chinmayee Nagaraj, LGC  
Sarah Noblin, MS, CGC  
Kailey Owens, MS, CGC  
Vivian Pan, CGC  
Zöe Powis, MS, CGC  
Lauren Propst, MS, CGC  
Chloe Reuter, MS, CGC  
Katherine Skora, MS, MPH, CGC  
Alicia Scocchia, MS, CGC, LGC  
Caitlin Mauer, MA, MS, CGC  
Carolyn Haskins, MS, CGC  
Erica Bednar, MS, CGC  
Emily Suskin, MS, CGC  
Karen Hurley, PhD  
Jennifer Leonhard, MS, LCGC  
Jennifer Brzosowicz, MS, CGC  
Kyla Patek, MS, CGC  
Kunal Sanghavi, MBBS, MS, LCGC  
Lauren Westerfield, MS, CGC  
Laura Godfrey Hendon, MA, MS, CGC  
Melanie Baxter, ScM, CGC  
Randa Newman, MS, LCGC  
Sarah Bannon, MS, CGC  
Katelynn Sagaser, MS, CGC  
Shifra Krinshpun, MS, CGC, LCGC  
Sheila Solomon, MS, LCGC  
Haley Streff, MS, CGC  
Lara Sucheston-Campbell, MS, Ph.D.  
Susan Christian, MSc, PhD, CGC  
Victoria Wagner, MS, CGC  
Wendy McKinnon, MS, CGC

# Meals + Refreshments

Continental breakfast will be served Wednesday – Friday in the Grand Ballroom Foyer and in the 155, 255 and 355 foyers on Tuesday from 7:00 am – 8:00 am for pre-conference symposia attendees.

## Refreshment Breaks

### TUESDAY, NOVEMBER 5\*

10:00 am – 10:30 am 155 Foyer, 255 Foyer and 355 Foyer

\*Pre-conference attendees only

### WEDNESDAY, NOVEMBER 6

9:30 am – 10:15 am Exhibit Hall A-B, Level 1

3:45 pm – 4:15 pm Exhibit Hall A-B, Level 1

### THURSDAY, NOVEMBER 7

9:45 am – 10:20 am Exhibit Hall A-B, Level 1

4:40 pm – 5:00 pm Grand Ballroom Foyer

### FRIDAY, NOVEMBER 8

9:50 am – 10:10 am 155 Foyer, 255 Foyer and 355 Foyer

## Wine Down Tasting

### TUESDAY, NOVEMBER 5

5:00 pm – 8:00 pm

Booth #423  Ambry Genetics  
A Konica Minolta Company



## Join Us at the Booths Below for a Special Treat

The following generous vendors are serving snacks at their booth at the following times. Be sure to stop by while supplies last.

### TUESDAY, NOVEMBER 5

5:00 pm – 8:00 pm

Booth #301  INVITAE

Booth #423  Ambry Genetics  
A Konica Minolta Company

Booth #711  myriad®

### WEDNESDAY, NOVEMBER 6

9:30 am – 10:15 am

Booth #711  myriad®

11:45 am – 1:30 pm

Booth #307  BOULDER ABORTION CLINIC

Booth #116  UNITY  
POWERED BY  Billion

3:45 pm – 4:15 pm

Booth #301  INVITAE

Booth #116  UNITY  
POWERED BY  Billion

Booth #729  progenity®  
Prepare for life.

5:30 pm – 7:30 pm

Booth #423  Ambry Genetics  
A Konica Minolta Company

### THURSDAY, NOVEMBER 7

9:45 am – 10:20 am

Booth #301  INVITAE

Booth #423  Ambry Genetics  
A Konica Minolta Company

11:35 am – 3:00 pm

Booth #108  variantyx

Booth #711  myriad®

Booth #729  progenity®  
Prepare for life.

# Exhibitor Directory by Company Name

Exhibitor Name	Booth Number	Exhibitor Name	Booth Number
23andMe	831	Johns Hopkins Genomics	231
AbortionClinics.Org, Inc.	200	JScreen at Emory University	601
Acer Therapeutics	109	Kaiser Genetics – Northern California	206
Admera Health	528	Le Bonheur Children's Hospital	119
Agios Pharmaceuticals, Inc.	121	Lettercase: National Center for Prenatal and Postnatal Resources	104
AiLife Diagnostics, Inc.	106	MNG Laboratories	225
Alexion Pharmaceuticals, Inc.	120	Myriad Genetic Laboratories	711
AliveAndKickn	701	Natera	429
Allele Diagnostics	330	National Coordinating Center for the Regional Genetic Networks	103
Ambry Genetics, A Konica Minolta Company	423	National Down Syndrome Congress (NDSC)	925
American Board of Genetic Counseling (ABGC)	130	Nationwide Children's Hospital	924
American Society of Human Genetics	815	NIH Genetic Testing Registry/MedGen/ClinVar	817
Amicus Therapeutics	406	Northside Hospital	433
Ancestry.com Operations, Inc.	101	Norton & Elaine Sarnoff Center for Jewish Genetics	806
ArcherDX, Inc.	632	Norton Genetic Specialists, Part of Norton Healthcare	102
ARUP Laboratories	323	Now I Lay Me Down To Sleep	126
Association for Creatine Deficiencies (ACD)	918	NSGC Central	415
AstraZeneca	802	NSGC Job Board	319
Atlantic Fetal Medicine	916	NTD Eurofins	209
AveXis, Inc.	232	NxGen MDx	830
AveXis, Inc.	233	Parent Project Muscular Dystrophy/Decode Duchenne	923
AXYS	927	Partners Personalized Medicine Laboratory for Molecular Medicine	107
Basser Center for BRCA	204	PerkinElmer	523
Batten Disease Support & Research Association	531	Pfizer Oncology	530
Baylor Genetics	201	Phoenix Children's	921
BillionToOne, Inc. (UNITY screen)	116	Prevention Genetics	605
Biogen	728	Progenity	729
BioMarin Pharmaceutical, Inc.	707	PTC Therapeutics, Inc.	920
Blueprint Genetics Inc.	629	PWN Health	131
Boulder Abortion Clinic, PC	307	Quest Diagnostics	113
Capital Women's Services	832	RARE Science, Inc. – RARE Bear Sponsor	803
Center for Fetal Diagnosis and Treatment (CHOP)	308	Recordati Rare Diseases	623
Center for Genomic Interpretation	229	Retrophin, Inc.	430
Centogene AG	821	Retrophin Medical Affairs	431
Clear Genetics	133	Rhythm Pharmaceuticals	633
Clinical Genome Resource	827	Roche Diagnostics	202
Clovis Oncology, Inc.	929	Sanford Health	800
Color	630	Sanford Research – CORDS Registry	122
Connective Tissue Gene Tests	703	Sanofi Genzyme	211
Cord Blood Registry	215	Sarepta Therapeutics	628
Department of Veterans Affairs	917	Seattle Children's Hospital – PLUGS Program	329
DNA ALLY, Inc.	532	Sema4	724
Down Syndrome Diagnosis Network	928	Sharsheret	213
EGL Genetics	310	Simons Searchlight	926
FamHis, Inc.	428	Southwestern Women's Options	819
FORCE: Facing Our Risk of Cancer Empowered	919	Spark Therapeutics	625
Fulgent Diagnostics	825	Special Angels Adoption	228
Geisinger Health System	829	Specialist TeleMed	432
Gene42, Inc.	813	Stealth BioTherapeutics	700
GeneDx	501	Texas Children's Pavilion for Women – Fetal Center	332
GeneMatters	811	UAB Medical Genomics Lab	627
Genome Medical	208	UCLA Health Sciences	218
GenPath Women's Health	611	UCSF Health	533
Glut1 Deficiency Foundation	118	Ultragenyx	833
Greenwood Genetic Center	704	Undiagnosed Diseases Network	105
IGENOMIX	124	University of Chicago Genetic Services Laboratories	309
InformedDNA	732	University of Washington	331
InformedDNA	733	UNMC Human Genetics Laboratory	529
Integrated Genetics	322	Valley Children's Healthcare	328
Invitae	301	Varietyx, Inc.	108
Invitae Photobooth	100	Women's Care Florida	128
Johns Hopkins Center for Fetal Therapy	230	YourDNA.com	333







# Who Will Be Named Code Talker of the Year?

Honoring genetic counselors who interpret complexity with compassion.

Come celebrate your profession with the emotional stories of what excellent care feels like to patients and find out who will be the 2019 Code Talker. This year's essay book will be available to all. You don't want to miss it!

**Thursday, November 7**  
**7:00pm to 9:00pm**

Doors open at 6:45pm.



**Featuring guest speaker,  
Amylynn Santiago Volker**

Rare disease advocate and mother of Nic Volker, the first child saved by DNA sequencing.

PRESENTED BY



National Society of  
**Genetic  
Counselors**

# Exhibitor Index

## 23andMe

### Booth 831

650.938.6300

customer@23andme.com

www.23andme.com

Founded in 2006, 23andMe is the only genetic testing company to receive FDA authorization to provide carrier status, genetic health risks, cancer predisposition and pharmacogenetic information directly to consumers.

## AbortionClinics.Org

### Booth 200

402.292.4164 or 888.684.3599

info@arhc.online

www.abortionclinics.org

Specializing in 2nd and 3rd trimester abortion care. For over 45 years we have been providing abortion care with kindness, courtesy, justice, love and respect.

## Acer Therapeutics

### Booth 109

## Admera Health

### Booth 528

908.222.0533

clientcare@admerahealth.com

www.admerahealth.com

Admera Health's CLIA-certified, CAP-accredited diagnostic testing laboratory utilizes Next-Generation Sequencing technology to advance personalized medicine. Our expertise includes pharmacogenomics, cardiovascular disease, and oncology. Physicians and patients receive test results to make more informed treatment decisions.

## Agios Pharmaceuticals, Inc.

### Booth 121

## AiLife Diagnostics, Inc.

### Booth 106

## Alexion

### Booth 120

475.230.2596

gretchen.prins@alexion.com

www.alexion.com

Alexion has delivered life-changing therapies to patients suffering from rare diseases and has a highly innovative enzyme replacement therapy for patients with a ultra-rare metabolic disorder, hypophosphatasia (HPP).

## AliveAndKickn

### Booth 701

201.774.1843

dave@aliveandkickn.org

www.aliveandkickn.org

AliveAndKickn is a patient advocacy organization whose mission is to improve the lives of individuals and families affected by Lynch Syndrome through research, education, and screening. Ask us about The HEROIC Registry.

## Allele Diagnostics

### Booth 330

844.255.3532

kleiser@allelediagnosics.com

www.allelediagnosics.com

Allele Diagnostics provides high-quality genetic testing and reporting services. Specializing in rapid microarray, we offer a unique test menu focused on neonatal/pediatric patients.

## Ambry Genetics, A Konica Minolta Company

### Booth 423

714.788.2540

zjensen@ambrygen.com

www.ambrygen.com

Ambry Genetics is a leader in clinical diagnostic and software solutions, combining both to offer comprehensive and high-quality genetic testing. As part of the Konica Minolta family, Ambry Genetics is responsibly applying new technologies to the molecular diagnostics market to bring about precision medicine.

## American Board of Genetic Counseling

### Booth 130

913.222.8661

info@abgc.net

www.abgc.net

The American Board of Genetic Counseling (ABGC) is the credentialing organization for the genetic counseling profession in the US and Canada. ABGC works to protect the public and promotes the growth and development of the profession.

## American Society of Human Genetics

### Booth 815

301.634.7300

society@ashg.org

www.ashg.org

The American Society of Human Genetics is the primary professional organization for human genetics specialists worldwide. Our mission is to advance human genetics in science, health, and society through excellence in research, education and advocacy.

# Exhibitor Index continued

## Amicus Therapeutics

**Booth 406**

609.662.3897

[msorrentino@amicusrx.com](mailto:msorrentino@amicusrx.com)

[www.amicusrx.com](http://www.amicusrx.com)

## Ancestry

**Booth 101**

801.762.7372

[lwagner@ancestry.com](mailto:lwagner@ancestry.com)

Ancestry, the global leader in family history and consumer genomics, brings together science and self-discovery to help everyone, everywhere discover the story of what led to them.

## ArcherDX, Inc.

**Booth 632**

303.357.9001

[sales@archerdx.com](mailto:sales@archerdx.com)

[www.archerdx.com](http://www.archerdx.com)

ArcherDX addresses the bottlenecks associated with using next-generation sequencing in translational research by offering a robust platform for targeted sequencing applications.

## ARUP Laboratories

**Booth 323**

801.583.2787

[info@aruplab.com](mailto:info@aruplab.com)

[www.aruplab.com](http://www.aruplab.com)

ARUP Laboratories offers high quality testing in molecular genetics, cytogenetics, biochemical genetics and maternal serum screening. Accurate testing, timely results, and on-demand consultation with our experts translates to optimal patient outcomes.

## Association for Creatine Deficiencies

**Booth 918**

[info@creatineinfo.org](mailto:info@creatineinfo.org)

[www.creatineinfo.org](http://www.creatineinfo.org)

The Association for Creatine Deficiencies (ACD) is a nonprofit organization dedicated to the three Cerebral Creatine Deficiency Syndromes (CCDS): CTD, AGAT and GAMT. Our mission is to provide patient, family, and public education, to advocate for early diagnoses, and to promote and fund medical research for treatments and cures for CCDS.

## AstraZeneca

**Booth 802**

301.398.0000

[alyssa.u@astrazeneca.com](mailto:alyssa.u@astrazeneca.com)

[www.astrazeneca-us.com](http://www.astrazeneca-us.com)

AstraZeneca is a global, science-led biopharmaceutical company that focuses on the discovery, development and commercialization of prescription medicines, primarily for the treatment of diseases in three main therapy areas – Oncology, Cardiovascular & Metabolic Diseases and Respiratory. The Company also is selectively active in the areas of autoimmunity, neuroscience and infection. AstraZeneca operates in over 100 countries and its innovative medicines are used by millions of patients worldwide. Follow us on Twitter @AstraZenecaUS.

## Atlantic Fetal Medicine

**Booth 916**

910.667.7451

[Kathy.Gresham@nhrmc.org](mailto:Kathy.Gresham@nhrmc.org)

[www.nhrmc.org](http://www.nhrmc.org)

Atlantic Fetal Medicine is part of the New Hanover Regional Medical Center located in beautiful coastal Wilmington, North Carolina. We seek to add a genetic counselor to our growing team.

## AveXis, Inc.

**Booth 232 & 233**

844.428.3947

[info@avexis.com](mailto:info@avexis.com)

[www.avexis.com](http://www.avexis.com)

AveXis is the world's leading gene therapy company, reimagining the treatment of genetic diseases. We are focused on developing and delivering transformational gene therapies for patients and families devastated by rare and life-threatening neurological genetic diseases.

## AXYS

**Booth 927**

888.999.9428

[info@genetic.org](mailto:info@genetic.org)

[www.genetic.org](http://www.genetic.org)

AXYS, the Association for X and Y Variations, is an advocacy, education and support organization for individuals with X and Y chromosome variations and their families. AXYS improves the lives of those impacted by the X and Y chromosome aneuploidies including Klinefelter syndrome (47,XXY), Trisomy X (47,XXX), 47,XYY, 48,XXYY, and related genetic conditions through support, education, research and treatment.

## Basser Center for BRCA

### Booth 204

215.662.2748

basserinfo@uphs.upenn.edu

www.basser.org

The Basser Center for BRCA is the first comprehensive center for the research, treatment, and prevention of BRCA-related cancers. These hereditary mutations can increase lifetime risk for cancers including breast, ovarian, pancreatic, prostate and melanoma.

## Batten Disease Support and Research Association

### Booth 531

614.768.1159

info@bdsra.org

www.bdsra.org

Our long term vision is a world without Batten disease. Our mission is to support Batten families, fund and Facilitate research, and advocate for action. BDSRA is the largest support organization dedicated to Batten disease in North America

## Baylor Genetics

### Booth 201

800.411.4363

help@baylorgenetics.com

www.baylorgenetics.com

A pioneer of precision medicine for nearly 40 years, Baylor Genetics now offers a full spectrum of clinically relevant genetic testing, access to world-renowned experts, and the confidence to provide patients with the best care.

## BillionToOne Inc.

### Booth 116

617.602.0277

shan@billiontoone.com

www.unitiescreen.com

BillionToOne is a precision diagnostics company behind UNITY test, the first and only carrier screen with reflex single-gene NIPT for CF, SMA and hemoglobinopathies.

## Biogen

### Booth 728

781.464.2000

www.biogen.com

At Biogen, our mission is clear: we are pioneers in neuroscience. Biogen discovers, develops and delivers worldwide innovative therapies for people living with serious neurological and neurodegenerative diseases as well as related therapeutic adjacencies.

## BioMarin Pharmaceutical Inc.

### Booth 707

415.506.6700

www.biomarin.com

BioMarin develops innovative biopharmaceuticals. Approved products include therapies for PKU, LEMS, MPS I, MPS VI, MPS IVA, and CLN2 disease. Development programs include investigational therapies for Hemophilia A, Achondroplasia, MPS IIIB, Friedreich's Ataxia.

## Blueprint Genetics

### Booth 629

650.452.9340

joe.jacher@blueprintgenetics.com

www.blueprintgenetics.com

Blueprint Genetics is one of the fastest growing genetics laboratories globally. We provide world-class genetic testing and clinical interpretation for rare inherited diseases in 14 medical specialties with a customer-base spanning over 40 countries.

## Boulder Abortion Clinic, PC

### Booth 307

303.447.1361

bac.conf@gmail.com

www.drhern.com

Boulder Abortion Clinic's Dr. Warren Hern provides services to select patients beyond 30 menstrual weeks for fetal anomaly and maternal indications. Assistance with genetic testing and grievance services is available.

## Capital Women's Services

### Booth 832

202.400.0235

molly@capitalwomensservices.com

www.capitalwomensservices.com

Capital Women's Services is dedicated to providing women with quality reproductive healthcare.

## Center for Fetal Diagnosis and Treatment (CHOP)

### Booth 308

800.IN UTERO (468.8376)

www.fetalsurgery.chop.edu

Celebrating twenty five years of dedication to advances, excellence and hope, the world's largest prenatal therapy program has welcomed more than 24,000 families from around the world. Team members pioneered the surgical techniques and protocols that today define the field. A leader of the landmark Management of Myelomeningocele Study proving the efficacy of fetal surgery for MMC. Since 2008, CHOP remains the world's first delivery unit dedicated exclusively to delivering pregnancies complicated by birth defects.

# Exhibitor Index continued

## Center for Genomic Interpretation

### Booth 229

801.810.4097

[contact@genomicinterpretation.org](mailto:contact@genomicinterpretation.org)

[www.genomicinterpretation.org](http://www.genomicinterpretation.org)

Center for Genomic Interpretation (CGI) is an independent nonprofit with the mission to drive quality in clinical genetics and genomics. Clinicians can compare lab test quality by asking labs for their CGI ELEVATEGenetics quality scores.

## Centogene AG

### Booth 821

617.580.2102

[customer.support-us@centogene.com](mailto:customer.support-us@centogene.com)

[www.centogene.com/](http://www.centogene.com/)

CENTOGENE – Worldwide leader in the field of genetic diagnostics for rare hereditary diseases. Our mutation database (CentoMD®) is the world's largest for and is pivotal to our high-quality diagnostic reporting and comprehensive medical interpretation.

## Clinical Genome Resource

### Booth 827

[clingen@clinicalgenome.org](mailto:clingen@clinicalgenome.org)

[www.clinicalgenome.org](http://www.clinicalgenome.org)

The Clinical Genome Resource (ClinGen) is an NIH-funded initiative dedicated to identifying genes and variants of clinical relevance for use in precision medicine and research.

## Color

### Booth 630

650.743.0657

[pam@color.com](mailto:pam@color.com)

[www.color.com](http://www.color.com)

Color is a health service that helps you understand your genetic risk for common hereditary cancers and hereditary high cholesterol, and use this knowledge to create a personalized healthcare plan.

## Connective Tissue Gene Tests

### Booth 703

484.244.2900

[inquiries@ctgt.net](mailto:inquiries@ctgt.net)

[www.ctgt.net](http://www.ctgt.net)

Connective Tissue Gene Tests (CTGT) specializes in molecular diagnostic testing for inherited genetic disorders. CTGT offers over 1,000 tests and serves hundreds of leading healthcare providers and institutions from the US and around the world.

## Cord Blood Registry

### Booth 215

415.517.2404

[njaffar@cordblood.com](mailto:njaffar@cordblood.com)

[www.cordblood.com](http://www.cordblood.com)

Cord Blood Registry® (CBR®) is the world's largest and most experienced newborn stem cell company. Since 1992, families have entrusted CBR to store more than 875,000 cord blood and cord tissue samples. As part of their commitment to advancing the clinical applications of newborn stem cells, CBR has helped over 500 families use their cord blood samples for current and investigational treatments.

## DNA ALLY, Inc.

### Booth 532

408.204.6922

[karl.gundal@dnaally.com](mailto:karl.gundal@dnaally.com)

[www.dnaally.com](http://www.dnaally.com)

We're hiring!!! If you have an extra 5 hours per week and want to increase your income, come visit our booth. DNA ALLY is a national telegenetics company providing on demand genetic counseling services.

## EGL Genetics

### Booth 310

470.378.2200

[eglmarketing@egl-eurofins.com](mailto:eglmarketing@egl-eurofins.com)

[www.egl-eurofins.com](http://www.egl-eurofins.com)

With over 50 years of experience, EGL Genetics is an established leader in genetic diagnostic testing. EGL is one of the few labs in the country to offer molecular genetics, biochemical, and cytogenetics tests under one roof.

## FamHis, Inc.

### Booth 428

561.631.9171

[info@famhis.net](mailto:info@famhis.net)

[www.famhis.net](http://www.famhis.net)

FamHis is the developer of FamGenix, an App built for patients to record their family health histories, share with other family members, and ultimately share with a clinician. It identifies patients who meet referral criteria.

## FORCE: Facing Our Risk of Cancer Empowered

### Booth 919

866.288.7475

[sandrac@facingourrisk.org](mailto:sandrac@facingourrisk.org)

[www.facingourrisk.org](http://www.facingourrisk.org)

FORCE improves the lives of individuals and families affected by hereditary cancers by providing support, education, advocacy, awareness and research.

## Fulgent Genetics

### Booth 825

626.350.0537

info@fulgentgenetics.com

www.fulgentgenetics.com

Fulgent Genetics is a clinical genetic testing laboratory offering an extensive and flexible test menu, with a goal to increase the accessibility and affordability of personalized genomic care for both patients and clinicians.

## Geisinger Health Science

### Booth 829

717.251.4197

bjhicks@geisinger.edu

www.geisinger.org

Geisinger is a physician-led health system comprised of approximately 30,000 employees, including 1,600 physicians, 13 hospital campuses, two research centers, medical school, and a 583,000-member health plan. Geisinger is nationally recognized for innovative practices and quality care.

## Gene42 Inc.

### Booth 813

888.682.5252

info@gene42.com

www.gene42.com

Gene42 helps clinicians and researchers diagnose more confidently through better patient phenotyping. Our flagship product, PhenoTips®, is used around the world by leading hospitals and institutions for deep phenotyping, pedigree drawing and phenotype-based genomic analysis.

## GeneDx

### Booth 501

301.519.2100

zebras@genedx.com

www.genedx.com

GeneDx was founded in 2000 to diagnose patients with rare disorders and assist clinicians responsible for treating these patients. GeneDx has cutting-edge diagnostic testing for a majority of inherited genetic disorders.

## GeneMatters

### Booth 811

612.314.7482

info@gene-matters.com

www.gene-matters.com

GeneMatters provides telehealth genetic counseling, working alongside your internal team or serving all genetic counseling needs. We provide deep expertise, immediate access, cost-effectiveness and easy, flexible integration through our customized platform.

## Genome Medical

### Booth 208

877.688.0992

info@genomemedical.com

www.genomemedical.com

Telegenomics technology and services company. Comprehensive clinical genetics services. Telehealth consultations and genomic care delivery platform. Help practices integrate reproductive health genetics – patient education/informed consent, selection/ordering of tests, interpretation of/counseling on results.

## GenPath Women's Health

### Booth 611

800.229.5227

eventsmarketing@bioreference.com

www.genpathdiagnostics.com/womens-health

GenPath Women's Health, division of BioReference Laboratories, an OPKO Health Company, offers a full-service test menu including cytology, pathology, infectious disease, prenatal/maternal risk assessment, pregnancy thrombophilia, carrier testing and more.

## Glut1 Deficiency Foundation

### Booth 118

859.585.2538

info@g1dfoundation.org

www.g1dfoundation.org

The Glut1 Deficiency Foundation is dedicated to improving the lives of those in the G1D community through its mission of increased awareness, improved education, advocacy for patients and families, and support and funding for research.

## Greenwood Genetic Center

### Booth 704

864.941.8100

labgc@ggc.org

www.ggc.org

The Greenwood Genetic Center is a nonprofit institute organized to provide clinical genetic services, diagnostic laboratory testing, educational programs and resources and research in the field of medical genetics. Our laboratory offers biochemical, cytogenetic and molecular testing.

## Igenomix

### Booth 124

305.501.4948

marketingusa@igenomix.com

www.igenomix.us

A reproductive genetics company whose experience and research capabilities have placed them among the world leaders in the field, enabling them to provide effective solutions tailored to different infertility problems, with 24 laboratory affiliates worldwide.

# Exhibitor Index continued

## InformedDNA

**Booth 732 & 733**

800.975.4819

[info@informeddna.com](mailto:info@informeddna.com)

[www.informeddna.com](http://www.informeddna.com)

InformedDNA is the authority on the appropriate use of genetic testing. We leverage the largest staff of board-certified genetics specialists in the U.S. to counsel and advise health systems, payers, pharmaceutical companies, providers and patients.

## Integrated Genetics

**Booth 322**

800.848.4436

[www.integratedgenetics.com](http://www.integratedgenetics.com)

With over 1,700 patient service centers, the largest commercial genetic counseling network, and an online cost estimator, Integrated Genetics, a member of the LabCorp Specialty Testing Group, offers one of the most comprehensive genetic testing menus.

## Invitae

**Booth**

800.436.3037

[clientservices@invite.com](mailto:clientservices@invite.com)

[www.invitae.com](http://www.invitae.com)

Invitae's mission is to bring comprehensive genetic information into mainstream medical practice to improve the quality of healthcare for billions of people. Our goal is to aggregate most of the world's genetic tests into a single service with higher quality, faster turnaround time and lower prices.

## Johns Hopkins Center for Fetal Therapy

**Booth 230**

410.502.6561

[fetaltherapy@jhmi.edu](mailto:fetaltherapy@jhmi.edu)

[www.hopkinsmedicine.org/gynecology\\_obstetrics/specialty\\_areas/fetal\\_therapy/index.html](http://www.hopkinsmedicine.org/gynecology_obstetrics/specialty_areas/fetal_therapy/index.html)

The Johns Hopkins Center for Fetal Therapy provides state-of-the-art treatment for complex fetal conditions including twin-twin-transfusion syndrome, spina bifida, congenital diaphragmatic hernia, urinary tract obstruction and fetal tumors. Our multidisciplinary care approach integrates expertise in open and closed fetal interventions, fetoscopic surgery, maternal, neonatology, pediatric, genetic and social services located at one of the leading medical institutions in the nation. Our fetal therapy physician hotline – 1-844-JH-FETAL – provides 24/7 access to care.

## Johns Hopkins Genomics

**Booth 231**

410.614.1075

[www.jhgenomics.jhmi.edu](http://www.jhgenomics.jhmi.edu)

Integrating expertise, enabling data discovery, informing patient care.

## JScreen at Emory University

**Booth 601**

404.778.8640

[info@jscreen.org](mailto:info@jscreen.org)

[www.JScreen.org](http://www.JScreen.org)

National, at-home genetic disease screening program offering affordable saliva-based expanded carrier screening and genetic counseling.

## Kaiser NCAL Genetics

**Booth 206**

708.972.3300

[jazmine.jung@kp.org](mailto:jazmine.jung@kp.org)

[www.genetics.kp.org](http://www.genetics.kp.org)

Practice what you believe, practice at Kaiser Permanente! Kaiser Genetics is the employer of choice for over 70 genetic counselors in Northern California. Stop by our booth to meet some of our genetic counselors, learn about employment opportunities and talk to us about our rewarding positions.

## Le Bonheur Children's Hospital

**Booth 119**

901.287.5080

[www.lebonheur.org](http://www.lebonheur.org)

Le Bonheur is a free standing pediatric acute care facility located in Memphis, TN. Recognized among the nation's "Best Children's Hospital" by US News & World Report for seven consecutive years.

## Lettercase National Center for Prenatal & Postnatal Resources

**Booth 104**

770.310.3885

[stephanie.meredith@uky.edu](mailto:stephanie.meredith@uky.edu)

[www.lettercase.org](http://www.lettercase.org)

The Lettercase National Center for Prenatal and Postnatal Resources offers patient-friendly, accurate, balanced, and up-to-date resources about multiple genetic conditions, which are reviewed by representatives of the national medical and advocacy organizations.

## MNG Laboratories

**Booth 225**

470.419.5606

[alaimod@labcorp.com](mailto:alaimod@labcorp.com)

[www.mnglabs.com](http://www.mnglabs.com)

MNG Laboratories, a LabCorp Company, strives to be your global partner in the diagnosis of inherited disease. MNG utilizes complex biochemical testing, next-generation sequencing, and RNA analysis to deliver results that drive patient-centered decisions.



## Myriad Genetics

### Booth 711

800.469.7423

[cscomments@myriad.com](mailto:cscomments@myriad.com)

[www.myriad.com](http://www.myriad.com)

Myriad Genetics Inc., a leading personalized medicine company dedicated to being a trusted advisor is transforming patient lives worldwide with pioneering molecular diagnostics.

## Natera, Inc.

### Booth 429

650.249.9090

[lhuynh@natera.com](mailto:lhuynh@natera.com)

[www.natera.com](http://www.natera.com)

Natera is a global leader in cell-free DNA testing. The company is driven to harness the power of DNA from a single blood sample to improve the management of reproductive health, oncology, and organ transplantation.

## National Coordinating Center for the Regional Genetics Networks (NCC)

### Booth 103

301.718.9603

[ncc@nccrcg.org](mailto:ncc@nccrcg.org)

[www.nccrcg.org](http://www.nccrcg.org)

The mission of the seven HRSA Regional Genetics Networks (RGNs), their National Coordinating Center (NCC), and the National Genetics Education and Family Support Center (NGEFSC) is to improve access to quality genetic services for medically underserved populations. The NCC is funded by a cooperative agreement to ACMG from the Health Resources and Services Administration, Maternal and Child Health Bureau, Genetic Services Branch (HRSA/MCHB/GSB).

## National Down Syndrome Congress

### Booth 925

770.604.9500

[tamara@ndscenter.org](mailto:tamara@ndscenter.org)

[www.ndscenter.org](http://www.ndscenter.org)

The NDSC promotes the interests of people with Down syndrome and their families through advocacy, public awareness, and information. We reshape the way people understand and experience Down syndrome. We educate, advocate, empower and inspire.

## Nationwide Children's Hospital

### Booth 924

[talent@nationwidechildrens.org](mailto:talent@nationwidechildrens.org)

[www.nationwidechildrens.org](http://www.nationwidechildrens.org)

Nationwide Children's Hospital is a destination academic pediatric medical center designed to manage the most complex of diseases. We treat the sickest of patients from across the country and around the world. We build research programs to assure tomorrow's breakthroughs help children everywhere. And we train the next generation of physicians, scientists and healthcare professionals. Beyond our walls, we invest in building social equity in our communities, address the social determinants of health, and develop payment models to better serve unique populations of children. Our unparalleled investment in Behavioral Health services and research further cements our role as an ambitious champion for the well-being of children everywhere.

## NIH Genetic Testing Registry/ MedGen/ClinVar

### Booth 817

The National Center for Biotechnology Information (NCBI, <https://www.ncbi.nlm.nih.gov/variation/>) at NIH advances science and health by providing access to biomedical and genomic information. NCBI will highlight resources for clinical genetics including GeneReviews®, MedGen, NIH Genetic Testing Registry (GTR®), ClinVar and the Medical Genetics Summaries, as well as important human variation tools and resources such as dbSNP, dbGaP, OSIRIS and SPDI.

## Northside Hospital

### Booth 433

404.851.8696

[jennifer.gilbert@northside.com](mailto:jennifer.gilbert@northside.com)

[www.northside.com](http://www.northside.com)

Northside is so much more than just a hospital. It's an extensive network of state-of-the-art facilities staffed with skilled, caring professionals who are dedicated to the health and wellness of the communities they serve.

## Norton & Elaine Sarnoff Center for Jewish Genetics

### Booth 806

312.357.4718

[jewishgenetics@juf.org](mailto:jewishgenetics@juf.org)

[www.jewishgenetics.org](http://www.jewishgenetics.org)

For more than a century, the residents of Kentucky and Southern Indiana have trusted the Norton Healthcare name for dedicated and compassionate care. With a network of five hospitals in Louisville, Norton Healthcare is a leader in serving adult and pediatric patients.

# Exhibitor Index continued

## Norton Genetic Specialists

### Booth 102

502.550.9625

[amanda.keller@nortonhealthcare.org](mailto:amanda.keller@nortonhealthcare.org)

[www.nortonhealthcare.com](http://www.nortonhealthcare.com)

Norton Healthcare is a leader in serving adult and pediatric patients in Louisville, Kentucky. Five hospitals provide inpatient and outpatient general care as well as specialty care.

## Now I Lay Me Down to Sleep (NILMDTS)

### Booth 126

720.583.3339

[headquarters@nilmdts.org](mailto:headquarters@nilmdts.org)

[www.nowilaymedowntosleep.org](http://www.nowilaymedowntosleep.org)

NILMDTS offers the gift of healing, hope and honor to parents experiencing the death of a baby through the overwhelming power of remembrance portraits.

## NTD Eurofins

### Booth 209

888.683.5227

[stephaniezichi@eurofins.com](mailto:stephaniezichi@eurofins.com)

[www.ntd-eurofins.com](http://www.ntd-eurofins.com)

For more than 30 years, NTD Eurofins has pioneered the research and development of prenatal screening protocols for open neural tube defects, Down syndrome, Trisomy 18/13 and early onset preeclampsia. Our laboratory network focuses on responding to your needs while enabling earlier, more accurate results, and our quality screening tests and services provide numerous benefits to healthcare providers and patients.

## NxGen MDx

### Booth 830

855.776.9436

[info@nxgenmdx.com](mailto:info@nxgenmdx.com)

[www.nxgenmdx.com](http://www.nxgenmdx.com)

NxGen MDx is a women's health care company providing precise genetic testing combined with best-in-class science, unrivaled accuracy, and personal genetic counselors to help you make informed decisions about your health and reproductive journey.

## Parent Project Muscular Dystrophy/ Decode Duchenne

### Booth 923

917.273.5020

[jen@parentprojectmd.org](mailto:jen@parentprojectmd.org)

[www.parentprojectmd.org](http://www.parentprojectmd.org)

Parent Project Muscular Dystrophy fights every single battle necessary to end Duchenne. Decode Duchenne provides free genetic testing and counseling to people with Duchenne or Becker muscular dystrophy who have been unable to access genetic testing.

## Partners Personalized Medicine Laboratory for Molecular Medicine

### Booth 107

617.768.8500

[Imm@partners.org](mailto:Imm@partners.org)

[www.personalizedmedicine.partners.org/laboratory-for-molecular-medicine/default.aspx](http://www.personalizedmedicine.partners.org/laboratory-for-molecular-medicine/default.aspx)

The Laboratory for Molecular Medicine (LMM) is a CLIA-certified molecular diagnostic laboratory, operated by Partners HealthCare Personalized Medicine and is led by a group of Harvard Medical School-affiliated faculty, geneticists, clinicians and researchers.

## PerkinElmer

### Booth 523

800.762.4000

[www.perkinelmer.com](http://www.perkinelmer.com)

Pairing our decades of experience in newborn screening with a state-of-the-art clinical genomics program, PerkinElmer Genomics provides one of the world's most comprehensive programs for detecting clinically significant genomic changes. Our high-quality, fast, affordable results allow clinicians to offer patients the answers they need to determine their path forward.

## Pfizer Oncology

### Booth 530

800.879.3477

[www.pfizer.com](http://www.pfizer.com)

Pfizer is a leading research-based biopharmaceutical company. We apply science and our global resources to deliver innovative therapies that extend and significantly improve lives. For more than 150 years, we have worked to make a difference for all who rely on us.

## Phoenix Childrens

### Booth 921

602.933.5638

[jpilka@phoenixchildrens.com](mailto:jpilka@phoenixchildrens.com)

[www.phoenixchildrens.com](http://www.phoenixchildrens.com)

With a medical staff of nearly 1,000 specialists, Phoenix Children's is one of the largest pediatric healthcare systems in the country, and the most comprehensive children's care facility in the state. We provide inpatient, outpatient, trauma and emergency care across more than 75 subspecialties.

## **PLUGS – Seattle Children’s Hospital**

**Booth 329**

206.987.5014

[plugs@seattlechildrens.org](mailto:plugs@seattlechildrens.org)

[www.schplugs.org](http://www.schplugs.org)

PLUGS is a non-profit laboratory stewardship collaboration whose mission is to improve test ordering, interpretation, retrieval and reimbursement. Genetic counselors are important advocates for appropriate genetic testing – visit us to learn about our stewardship efforts!

## **PreventionGenetics LLC**

**Booth 605**

715.387.0484

[clinicaldnatesting@preventiongenetics.com](mailto:clinicaldnatesting@preventiongenetics.com)

[www.preventiongenetics.com](http://www.preventiongenetics.com)

PreventionGenetics is a CLIA and ISO 15189:2012 accredited clinical DNA testing laboratory. PreventionGenetics provides patients with sequencing and deletion/duplication tests for nearly all clinically relevant genes, including whole exome sequencing, PGxome.

## **Progenity**

**Booth 729**

[events@progenity.com](mailto:events@progenity.com)

[www.progenity.com](http://www.progenity.com)

Progenity offers advanced diagnostic tests that include the Preparent® Carrier Test, the Innatal® Prenatal Screen, the Resura™ Prenatal Test for Monogenic Disease and the Riscovers® Hereditary Cancer Test.

## **PTC Therapeutics, Inc.**

**Booth 920**

908.912.9426

[www.ptcbio.com](http://www.ptcbio.com)

PTC Therapeutics, Inc. is a science-led, global biopharmaceutical company focused on the discovery, development and commercialization of clinically-differentiated medicines that provide benefits to patients with rare disorders. PTC’s ability to globally commercialize products is the foundation that drives investment in a robust pipeline of transformative medicines and our mission to provide access to best-in-class treatments for patients who have an unmet medical need. To learn more about PTC, please visit us on [www.ptcbio.com](http://www.ptcbio.com) and follow us on Facebook, on Twitter at @PTCBio, and on LinkedIn.

## **PWNHealth**

**Booth 131**

[www.pwnhealth.com](http://www.pwnhealth.com)

PWNHealth is transforming the way diagnostic tests are delivered, understood, and acted upon. We help to connect millions of patients to thousands of sophisticated and clinically-sound diagnostic tests, with individualized oversight and patient care. Our 50-state provider network and robust technology platform support a broad range of healthcare stakeholders.

## **Quest Diagnostics**

**Booth 113**

973.520.2700

[www.questdiagnostics.com](http://www.questdiagnostics.com)

Quest Diagnostics empowers people to take action to improve health outcomes. Derived from the world’s largest database of clinical lab results, our diagnostic insights reveal new avenues to identify and treat disease, inspire healthy behaviors and improve health care management.

## **RARE Science, Inc. – RARE Bears**

**Booth 803**

[info@rarescience.org](mailto:info@rarescience.org)

[www.rarescience.org](http://www.rarescience.org)

In partnership with RARE Science, Inc., join NSGCares’ special RARE Bear Stuff-and-Sew event in booth #803 any time the exhibit suite is open to help us reach our goal of completing 250 RARE Bears during this year’s conference. The RARE Bear program, that gifts one-of-a-kind bears to one-of-a-kind kids, brings instant joy and globally unites rare communities seeking biological understanding of rare diseases of children on the way to improve therapies.

## **Recordati Rare Diseases Inc**

**Booth 623**

908.236.0888

[info@recordatirarediseases.com](mailto:info@recordatirarediseases.com)

[www.recordatirarediseases.com/us](http://www.recordatirarediseases.com/us)

Recordati Rare Diseases is committed to providing often overlooked orphan therapies to the underserved rare disease communities. Our team works side-by-side with rare disease communities to increase awareness, improve diagnosis and expand availability of treatments.

## **Retrophin, Inc.**

**Booth 430 & 431**

888.969.7879

[www.retrophin.com](http://www.retrophin.com)

Retrophin is a biopharmaceutical company dedicated to identifying, developing and delivering life-changing therapies to people living with rare disease.

## **Rhythm Pharmaceuticals**

**Booth 633**

857.264.4280

[info@rhythmtx.com](mailto:info@rhythmtx.com)

[www.rhythmtx.com](http://www.rhythmtx.com)

Rhythm is a biopharmaceutical company aimed at developing and commercializing therapies for the treatment of rare genetic disorders of obesity. Not all obesity is the same.

# Exhibitor Index continued

## Roche Diagnostics Corporation

**Booth 202**

800.428.5074

[www.diagnostics.roche.com/us](http://www.diagnostics.roche.com/us)

Roche provides innovative diagnostic solutions to help clinicians make confident decisions for their patients' health, including the Harmony non-invasive prenatal test, a lab-developed (non-FDA approved) test to evaluate risk of Trisomy 21, 18 and 13.

## Sanford Health

**Booth 800**

701.234.6510

[sarah.julsrud@sanfordhealth.org](mailto:sarah.julsrud@sanfordhealth.org)

[www.sanfordhealth.org](http://www.sanfordhealth.org)

Sanford Health, one of the largest health systems in the United States, is dedicated to the integrated delivery of health care, genomic medicine, senior care and services, global clinics, research and affordable insurance. Headquartered in Sioux Falls, South Dakota, the organization includes 44 hospitals, 1,400 physicians and more than 200 Good Samaritan Society senior care locations in 26 states and 9 countries.

## Sanford Research – CORDS Registry

**Booth 122**

605.312.6465

[alyssa.mendel@sanfordhealth.org](mailto:alyssa.mendel@sanfordhealth.org)

[www.research.sanfordhealth.org/rare-disease-registry](http://www.research.sanfordhealth.org/rare-disease-registry)

Based at Sanford Research, a not-for-profit research institution, CoRDS is a centralized international patient registry for all rare diseases. We support patient advocacy groups, individuals, and researchers to coordinate the advancement of research into the 7,000 rare diseases.

## Sanofi Genzyme

**Booth 211**

800.745.4447

[www.sanofigenzyme.com](http://www.sanofigenzyme.com)

Sanofi Genzyme focuses on developing specialty treatments for debilitating diseases that are often difficult to diagnose and treat, providing hope to patients and their families.

## Sarepta Therapeutics

**Booth 628**

617.274.4000

[info@sarepta.com](mailto:info@sarepta.com)

[www.sarepta.com](http://www.sarepta.com)

Sarepta is at the forefront of precision genetic medicine, having built an impressive and competitive position in Duchenne muscular dystrophy (DMD) and more recently in Limb-girdle muscular dystrophy (LGMD), Charcot-Marie-Tooth (CMT) MPS IIIA, Pompe and other CNS-related disorders, totaling over 20 therapies in various stages of development.

## Sema4

**Booth 724**

[www.sema4.com](http://www.sema4.com)

Sema4 is a patient-focused health intelligence company offering genomic tests, digital tools, and clinical collaborations to deliver insights and drive better health decisions.

## Sharsheret

**Booth 213**

201.833.2341

[pcottrell@sharsheret.org](mailto:pcottrell@sharsheret.org)

[www.sharsheret.org](http://www.sharsheret.org)

Sharsheret supports young Jewish women and families facing breast and ovarian cancer – before, during, and after diagnosis – including those at high genetic risk. We provide educational resources, offer individualized support and create local awareness programs.

## Simons Searchlight

**Booth 926**

855.329.5638

[coordinator@simonssearchlight.org](mailto:coordinator@simonssearchlight.org)

[www.simonssearchlight.org](http://www.simonssearchlight.org)

Simons Searchlight is a partnership of leading scientists, doctors, and families on a mission. We are determined to accelerate genetic research related to autism and other neurodevelopmental disorders.

## Southwestern Women's Options

**Booth 819**

505.242.7512

[admin@swoptionsnm.com](mailto:admin@swoptionsnm.com)

[www.southwesternwomens.com](http://www.southwesternwomens.com)

Southwestern Women's Options offers pregnancy terminations with no gestational limit for patients whose pregnancies have been diagnosed with fetal abnormalities. Our services are designed to meet your patient's needs in an atmosphere of warmth and respect.

## Spark Therapeutics

**Booth 625**

1.855.SPARKTX

[www.sparktx.com](http://www.sparktx.com)

Spark Therapeutics, a fully integrated, commercial gene therapy company, strives to challenge the inevitability of genetic disease by working to discover, develop and deliver gene therapies that address inherited retinal diseases.

## Special Angels Adoption

### Booth 228

740.395.3097

[jennifer@specialangelsadoption.org](mailto:jennifer@specialangelsadoption.org)

[www.specialangelsadoption.org](http://www.specialangelsadoption.org)

Special Angels Adoption handles exclusively special needs adoptions all over the United States. Working with birth and adoptive families in all states allows us to serve our mission of helping all families of children with special needs.

## Specialist TeleMed- Genetics

### Booth 432

512.402.8155

[info@specialisttelemed.com](mailto:info@specialisttelemed.com)

[www.specialisttelemed.com](http://www.specialisttelemed.com)

Specialist TeleMed-Genetics provides board certified genetic counselors & physician Geneticists to augment your current program or providers, or to initiate a full-service program in its absence. We help support or build a genetics program customized to your patient's medical needs, and your system's branding requirements.

## Stealth BioTherapeutics

### Booth 700

Stealth BioTherapeutics is an innovative biopharmaceutical company developing therapies to treat mitochondrial dysfunction associated with genetic mitochondrial diseases and common diseases of aging. Our team works with patients and advocacy organizations to better understand their journey with mitochondrial disease and raise awareness of the unmet need our programs seek to address.

## Texas Children's Pavilion for Women-Fetal Center

### Booth 332

832.822.2229

[fetal@texaschildrens.org](mailto:fetal@texaschildrens.org)

[www.women.texaschildrens.org/fetalcenter](http://www.women.texaschildrens.org/fetalcenter)

Texas Children's Fetal Center®, located in Houston, TX, is one of the nation's leaders in the diagnosis and treatment of abnormalities in unborn and newborn infants.

## UAB Medical Genomics Lab

### Booth 627

205.934.5562

[medgenomics@uabmc.edu](mailto:medgenomics@uabmc.edu)

[www.genetics.uab.edu/medgenomics](http://www.genetics.uab.edu/medgenomics)

The UAB Medical Genomics Laboratory (MGL) is a CAP-certified, nonprofit clinical laboratory, offering comprehensive testing for both common and rare genetic disorders, while specializing in the neurofibromatoses, rasopathies and tuberous sclerosis.

## UCLA Health

### Booth 218

310.267.3292

[www.uclahealthcareers.org](http://www.uclahealthcareers.org)

UCLA Health defines greatness by the quality of the patient experience we are able to deliver. Each and every time. To every single patient. If that's where your ambitions lie, UCLA is where you belong.

## UCSF Health

### Booth 533

415.353.4638

[amy.ng@ucsf.edu](mailto:amy.ng@ucsf.edu)

[www.ucsfhealth.org](http://www.ucsfhealth.org)

UCSF Health is recognized worldwide for its high-quality, innovative patient care, informed by advanced technologies and pioneering research. UCSF Health providers are leaders in virtually all specialties, including cancer, cardiology, children's health, neurology and transplant, and direct more than 1,500 clinical trials each year. UCSF Health exceeds the most widely used patient satisfaction and safety measures in the nation, and holds the highest designation for facilities that treat the most complex and specialized conditions. UCSF Health includes UCSF Medical Center, ranked among the nation's top five hospitals by U.S. News & World Report 2018-19, UCSF Benioff Children's Hospitals, and Langley Porter Psychiatric Hospital and Clinics. The health system also includes affiliations with top-tier hospitals and physician groups throughout the Bay Area to bring specialty care to patients close to home.

## Ultragenyx Pharmaceutical Inc

### Booth 833

415.483.8800

[info@ultragenyx.com](mailto:info@ultragenyx.com)

[www.ultragenyx.com](http://www.ultragenyx.com)

Ultragenyx is a biopharmaceutical company committed to bringing patients novel products for the treatment of serious rare and ultra-rare genetic diseases.

## Undiagnosed Diseases Network (UDN)

### Booth 105

844.746.4836

[udn@hms.harvard.edu](mailto:udn@hms.harvard.edu)

[www.udnconnect.org](http://www.udnconnect.org)

The UDN is a research study funded by the NIH Common Fund. It is made up of clinical and research centers across the country working to improve diagnosis and care of patients with undiagnosed diseases.

# Exhibitor Index continued

## University of Chicago Genetic Services Laboratories

**Booth 309**

773.834.2795

[mhelgeson@bsd.uchicago.edu](mailto:mhelgeson@bsd.uchicago.edu)

[www.dnatesting.uchicago.edu](http://www.dnatesting.uchicago.edu)

University of Chicago Genetic Services Laboratories is a CLIA- and CAP-certified laboratory offering cutting-edge DNA diagnostic services. We offer a wide range of tests for rare diseases including exome sequencing and panel based testing.

## University of Washington

**Booth 331**

800.713.5198

[commserv@uw.edu](mailto:commserv@uw.edu)

[www.depts.washington.edu/labweb/](http://www.depts.washington.edu/labweb/)

UW-OncoPlex is a multiplexed gene sequencing panel that detects mutations in tumor tissue in 194 cancer-related genes; BROCA genetic risk panel for 62 genes; Coloseq and Coloseq Tumor genetic test using NGS.

## UNMC Human Genetics Laboratory

**Booth 529**

402.559.5070

[humangenetics@unmc.edu](mailto:humangenetics@unmc.edu)

[www.unmc.edu/mmi/geneticslab](http://www.unmc.edu/mmi/geneticslab)

The Human Genetics Laboratory at the University of Nebraska Medical Center (UNMC) is a full-service clinical cytogenetics and molecular genetics laboratory specializing in both constitutional (prenatal and postnatal) and cancer diagnostics for over 40 years.

## VA Genomic Medicine Service

**Booth 917**

801.582.1565

[christopher.lee2@va.gov](mailto:christopher.lee2@va.gov)

[www.saltlakecity.va.gov](http://www.saltlakecity.va.gov)

Department of Veterans Affairs. VA Genomic Medicine Service. Head office is located in Salt Lake City. VA Genomic provides care nationally. Genetic Counselors function as primary providers for this service.

## Valley Children's Hospital

**Booth 328**

559.353.7058

[dyee@valleychildrens.org](mailto:dyee@valleychildrens.org)

[www.valleychildrens.org](http://www.valleychildrens.org)

Join Valley Children's Healthcare, one of the nation's ten largest pediatric hospitals located in affordable Central California. Excellent full-time Genetic Counselor opportunity in our Metabolic Genetics and Maternal Fetal Center. Come visit our booth!

## Variantyx

**Booth 108**

617.209.2090

[info@variantyx.com](mailto:info@variantyx.com)

[www.variantyx.com](http://www.variantyx.com)

Variantyx provides Genomic Unity™ whole genome testing services to clinicians for diagnosis of rare inherited disorders. We also enable hospitals and labs to profitably expand their test menu with validated genomic diagnostic solutions using our automated Genomic Intelligence® platform for simplified NGS data analysis, interpretation and clinical reporting.

## Women's Care Florida

**Booth 128**

813.286.0033

[rcuti@womenscarefl.com](mailto:rcuti@womenscarefl.com)

[www.womenscarefl.com](http://www.womenscarefl.com)


Women's Care Florida (WCF) specializes in several women's specialties including obstetrics and gynecology, gynecologic oncology, urogynecology, gynecologic pathology, breast surgery, genetic counseling, maternal fetal medicine, behavioral health, endocrinology, gastroenterology, primary care and fertility. WCF has nearly 100 locations and more than 360 providers across Central and North Florida.

## YourDNA.com

**Booth 333**

[www.yourdna.com](http://www.yourdna.com)

YourDNA is an outreach platform serving patients, practitioners and the public with resources to understand genomic health. Whether health curious, symptom serious or journey specific, we strive to help everyone answer the question.



**RYAN**  
Living with  
Duchenne Muscular Dystrophy

A NEW ERA OF MEDICINE IS UPON US

Sarepta is at the forefront of precision genetic medicine research, having built an impressive and competitive position in Duchenne muscular dystrophy (DMD) and more recently in 6 Limb-girdle muscular dystrophy diseases (LGMD), Charcot-Marie-Tooth (CMT), MPS IIIA, Pompe and other CNS-related disorders, totaling almost 30 therapies in various stages of development. Sarepta's programs and research focus span several therapeutic modalities, including RNA, gene therapy and gene editing. Sarepta is fueled by an audacious but important mission: to profoundly improve and extend the lives of patients with rare genetic-based diseases.



[#DragTomorrowIntoToday](#)

★ ★ ★ ★ ★

# RAISING OUR VOICES, SHOWING OUR STRENGTH



**Music City Center ★ Nashville, TN**

**NSGC 39TH ANNUAL CONFERENCE**  
**NOV 17-20, 2020**

National Society of  
Genetic Counselors 