

2009 NSGC Annual Business Meeting

November 14, 2009

**Steven Keiles, MS, CGC
NSGC President**

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Overview

- Welcome
- NSGC 2009 Membership Survey
- Progress on Strategic Initiatives
- 2009 Financial Report
- NSGC Operations
- Genetic Counseling Foundation
- Open Microphone Q&A
- Volunteer Recognition

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NSGC 2009 Membership Survey

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Methodology

- Survey was administered between July 6, 2009 and August 7, 2009
- 2,397 members of NSGC were sent a link to the online survey
- 1,094 members completed at least part of the survey
 - 83% Full members
 - 10% New Genetic Counselor Members
 - 5% Student Members
 - 2% Other
- 45% response rate

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Who completed the survey?

- Age/Ethnicity/Gender fits the profile seen in other NSGC surveys such as the PSS
- Majority of respondents are:
 - White or Caucasian, female and under 40 years old
- Majority of respondents:
 - Have been a member of NSGC for under 10 years
 - Have been in the genetic counseling profession under 15 year
- Specialty Areas/Practice Settings reflect those seen in the 2008 PSS

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Overall, how satisfied are you with your NSGC Membership?

76% of respondents indicate they are satisfied or very satisfied with their NSGC Membership

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When thinking about your NSGC membership, what is most important to you?

Response	Percent %
Educational offerings	54%
Initiatives to promote the profession, e.g. billing and reimbursement or collaborations/liaison positions	21%
Networking opportunities	18%
Leadership opportunities	2%
Other	1%

Thinking about the benefits NSGC provides to its members, how important are the following member benefits to you personally?

(Top ten ranked from most important to least important)

1. Obtaining CEUs through education
2. Access to and opportunity to complete the Professional Status Survey
3. Free access to the *Journal of Genetic Counseling*
4. Access to general email listserv
5. Access to “Members Only” area of NSGC Website
6. Job Connection service and Job Eblasts
7. Opportunity to participate in Special Interest Groups (SIGs)
8. Access to SIG email listservs
9. Expanded access to/being listed in the Find a Counselor section of the NSGC Website
10. Membership Directory

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How important is it to you, personally, for NSGC to do the following?

Response (check all that apply)	Not at all important	Of little importance	Moderately important	Important	Very Important
Represent my professional interests and views	1%	2%	12%	38%	47%
Serve as an advocate for my profession	0%	1%	4%	26%	69%
Provide PR/marketing for my profession	1%	1%	9%	28%	60%
Give me an opportunity to have a voice in my profession	1%	4%	20%	35%	40%

How effective is NSGC in doing the following?

Response	Not effective at all	Minimally effective	Somewhat effective	Effective	Very effective
Representing my professional interest and views	6%	21%	29%	34%	10%
Serving as an advocate for my profession	10%	19%	22%	33%	16%
Providing PR/marketing for my profession	7%	20%	35%	29%	10%
Giving me an opportunity to have a voice in my profession	7%	19%	34%	31%	9%

We asked you about new forms of communication and here's what you told us you would like...

Response (check all that apply)	> once per week	Weekly	1-2 times per month	3-4 times per year	Once or twice per year	< once per year	Never
Text Messages	0%	3%	5%	3%	2%	1%	85%
Social or professional networking websites - i.e. Facebook, LinkedIn, Plaxo, Twitter	2%	8%	14%	7%	4%	3%	63%
Online message boards/discussion forums	5%	17%	23%	12%	5%	3%	35%
Podcasts	1%	6%	14%	20%	13%	4%	42%
NSGC blogs	2%	16%	28%	15%	6%	4%	29%

How satisfied are you with the following NSGC educational programs?



Volunteer Experience

- Most members involved as volunteers became involved as an opportunity for professional development and to network with other members
- Members are looking for additional information about the estimated time commitment and the desired qualifications and expectations for volunteer opportunities
- 89% of members are interested in short-term, defined tasks (i.e. task force, short-term project, workgroup)
- 29% of members are interested in long-term involvement (i.e. committees, subcommittees)

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Overall, how do you feel about the governance changes that were initiated in 2007-2008?

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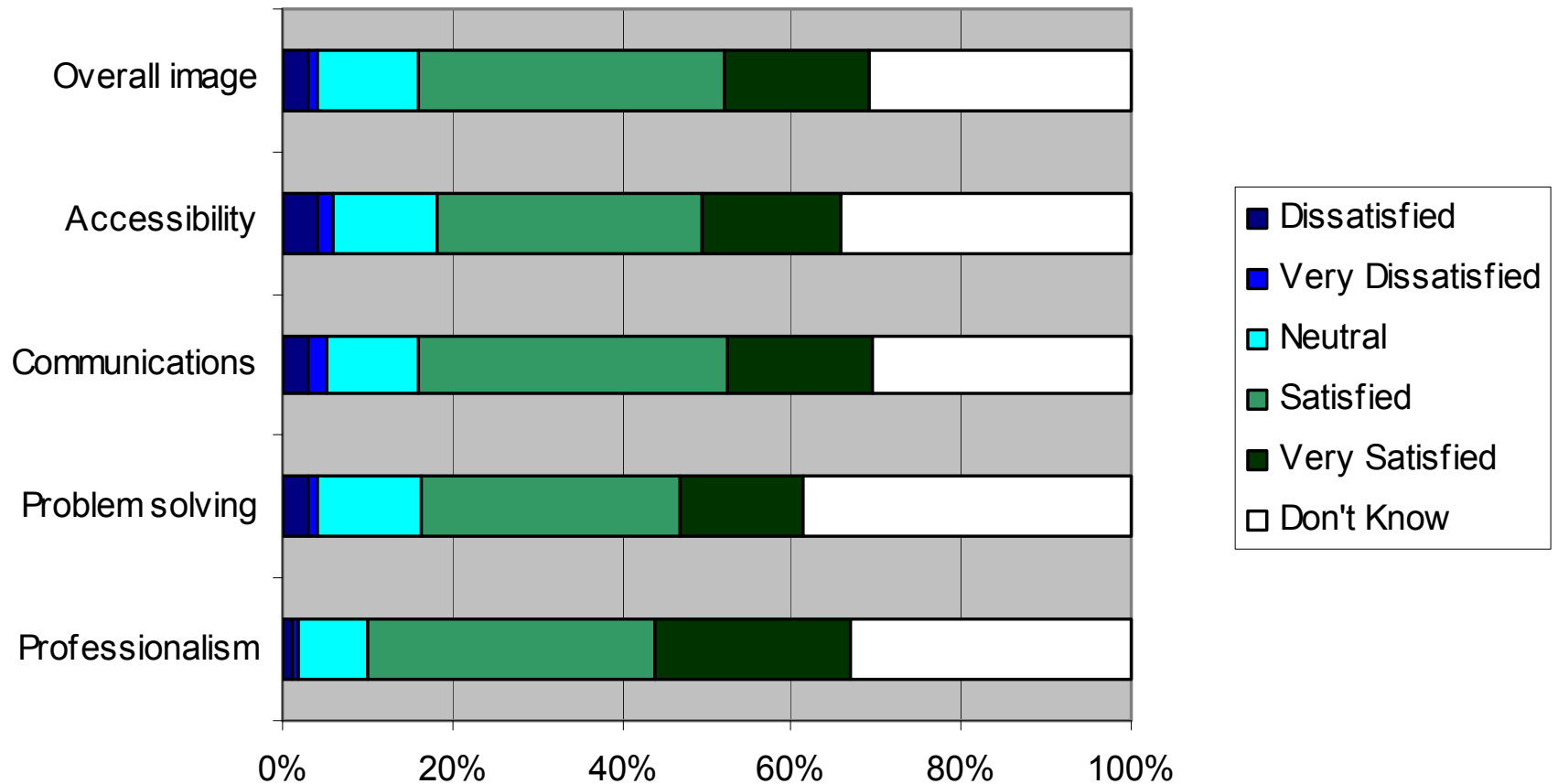
How has your involvement in NSGC changed since the governance changes were initiated in 2007-2008?

Response	Percent %
Remained the same	55%
I was not aware of any governance changes	24%
Decreased	10%
Unsure	7%
Increased	5%

Overall, how satisfied are you with your experience in dealing with the NSGC Executive Office in the last 6 months?

Response	Percent %
Very Satisfied	15%
Satisfied	21%
Neutral	8%
Dissatisfied	4%
Very Dissatisfied	2%
Not Applicable	51%

How would you rate the Executive Office on the following?



Progress on 2007-2009 Strategic Initiatives

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NSGC's Strategic Initiatives

- **Strategic Initiative #1 - Expand access to genetic counseling services by actively pursuing reimbursement for Certified Genetic Counselors**
- **Strategic Initiative #2 – To promote and organizational culture that will enable NSGC to adapt to the evolving needs of Genetic Counselors**
- **Strategic Initiative #3 - Position Genetic Counselors as key players in the integration of genetics across the healthcare spectrum**

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Strategic Initiative #1

- Federal effort
- State licensure
- GINA – We Did It!

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Strategic Initiative #1: Federal Effort

- Drafted federal legislation and sent through US House of Representatives legislative counsel
- Leadership and members have met with various members of House and Senate throughout the year to pursue sponsorship of our bill
- House sponsor imminent
- Organized NSGC Day on the Hill and Participated in Genetic Alliance “Hill Day”
 - Provided information on genetic counselors
 - Actively promoted NSGC legislation

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Strategic Initiative #1: State Licensure

- 2009 was the most successful year to date – 5 states passed bills
- NSGC has provided ongoing guidance to states pursuing licensure and writing licensure rules and regulations.
- Issuing licenses: IL, MA, NM, OK, TN, UT
- Passed bills/in rulemaking: CA, HI, IN, NJ, SD, WA
- Bill introduced, held hearings: NY, PA, TX,
- Preparing to introduce bills: CT, FL, KS, MD, MI, MN, NE, NH, OH, OR, RI, VA, WI

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Strategic Initiative #1: GINA – We Did It!



- Genetic Information Nondiscrimination Act passed after 13 years and the bill will be fully effective this week!
- NSGC worked as a member of the Coalition for Genetic Fairness in educating legislators and advocating through our own grassroots network
- Thank you for your support and strong participation – NSGC members and the NSGC Grassroots network answered the call to action and made a difference!

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Strategic Initiative #1: Building on GINA...

- NSGC Grassroots support was critical to this success
- We have established a strong platform for support and advocacy that can be replicated for the NSGC federal bill
- Look for “calls to action” from NSGC as we introduce our bill
- We will need everyone to participate again to ensure success!

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Strategic Initiative #2

- Governance changes
- Education
- Membership enhancements
- External education and partnerships

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Strategic Initiative #2: Governance

- The Board, Nominations Committee and Membership Committee continues to evaluate and make governance improvements
- Assessed impact of the 2008 governance changes on the membership through the 2009 Membership Survey
 - 56% of members responding experienced little or no impact as a result of the changes
 - 21% of members responding are supportive of the changes
 - 4% preferred the previous governance model
- Committees, Task Forces, Workgroups and SIGs serve in key leadership roles, so we will support development of new leaders and continue to work to improve communication between all of these important groups

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Strategic Initiative #2: Governance

Volunteer Database a success, but still room for growth:

- Accessed for 24 distinct projects/appointments to date in 2009
- Some projects involved appointing multiple volunteers
- 2010 Committee Chairs currently using database to help make appointments for next year's committees and workgroups
- We are actively using this as a source of volunteers for both long-term projects and short-term, defined tasks as many members indicated they wanted through the membership survey - make sure we have your information!
- If you want to get involved or need guidance on how, reach out by phone to an NSGC leader (Board, staff, Committee, Chair, SIG Chair)

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Strategic Initiative #2: Nominations and Elections

- Fewer nominations than in 2009, but percentage of nominees willing to be considered for the ballot increased for a second year
- 50% more members participated in ratification of the slate in 2009 than in 2008
- We will continue to evaluate the process:
 - Annual survey of nominees
 - Assessing membership participation in the nominations and elections process
 - Evaluating our ability to engage and develop new leaders
 - Monitoring progress toward achieving our strategic initiatives

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Strategic Initiative #2: Membership Enhancements

- Two new SIGs were initiated in late 2008/early 2009 to meet the needs of members interested in Fetal Intervention Therapy and Personalized Medicine.
- Organizational Cultural Competency Task Force recommendations recently approved by the Board
- NSGC launched Facebook group, Facebook page for AEC and Twitter to increase our avenues of communication with members, although the membership survey indicates most members not yet excited about social media

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Strategic Initiative #2: Education

- Regional Conferences held in Chicago and DC.
- Online course developed in 2009 for all members, building on the success of the course in 2008
- Conference recordings, providing alternative method of accessing AEC and Short Course content, offered again in 2009
- Coding course offered for first time in 2009, providing education for members and coding/billing specialists about coding for genetic counseling services
- 2010 Regional Meetings

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Strategic Initiative #2: Education Ethics Advisory Group

- Members completing terms – Sonja Eubanks (chair), Karin Dent, Nancy Warren and Janet Williams. Current members Laura Hercher, Sarah Noblin and Kimberly King-Spohn.
- 5 formal consults this year on a range of topics
- Reviewed recently created Alzheimer's Disease Practice Guidelines
- Want to increase visibility and use of this member resource. Will be posting monthly reminders to the listserv about our services. Info also available on NSGC website.
- Thanks to Dianne Bartels, Univ. of Minn. – bioethicist consultant to group for past 8 years (retiring)
- 4 new members joining next year (Dawn Allain, Curtis Coughlin II, Nancy Hanson, Carin Lea Yates)

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Strategic Initiative #2: External Education and Partnerships

- NSGC represented on IOM Roundtable on Translating Genomic-Based Research for Health
- NSGC represented and advocated for GC's at key meetings in 2009:
 - **Consumer Genetics Show**
 - **NHGRI meeting on Genetics Education for PCP's**
 - **State of the Science Family History Conference**
 - **ISONG Annual Meeting**
 - **NHGRI meeting for population screening for SMA**
 - **Genetic Alliance Annual Conference/Genetics Day on the Hill**
 - **American College of Surgeons Commission on Cancer Conference**
 - **Parent Project DMD**
 - **ACMG Board of Directors Meeting**
- NSGC's liaisons attended meetings/conferences to build relationships and further promote the value of genetic counselors

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Strategic Initiative #2: External Education and Partnerships

- Practice Guidelines Subcommittee under the leadership of Susan Hahn implemented the new process for soliciting and approving guidelines
 - 5 guidelines currently in process:
 - Colorectal Cancer
 - Alzheimer's
 - Cancer Referral
 - Down Syndrome
 - Fabry Disease (under revision)
- Goal is to increase the availability and use of NSGC as a source for genetic counseling practice information
- Actively seeking opportunities to collaborate with other organizations to expand our impact

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Strategic Initiative #3

- Public Relations
- Partnerships
- Advocacy

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Strategic Initiative #3: Public Relations

- 6 National, 5 Regional and 16 online media placements in 2009. Numerous other interviews and media contacts established for future
- Developed key talking points and press releases around:
 - DTC Testing
 - Breast Cancer Myths
 - Genetic Counseling as a growing profession
- The Board is assessing how best to use PR to further NSGC's strategic goals and brand moving forward

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Strategic Initiative #3: Advocacy

- Provided comment to the IOM regarding comparative effectiveness research priorities
- The Public Policy Committee created a blog
- Commented on the EARLY Act - successfully added genetic counselors to the bill. NSGC will work to strengthen the bill by emphasizing awareness of the hereditary aspects of breast cancer
- Reviewing NSGC policy statements to ensure they are current
- Significant headway has been made with payors:
 - Noridian – After NSGC contact, Noridian clarified their testing policy to reflect current practice
 - United Healthcare – Issued “*BRCA Genetic Testing Notification and Expanded Access to Genetic Counseling*” encouraging the utilization of certified genetic counselors. NSGC continues to work with the national medical director to increase access to our services.

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Strategic Initiative #3: Research to support the value of genetic counseling

- NSGC Research Technical Expert Panel established to make short and long term recommendations for development of evidence-based quantitative research to demonstrate the value of genetic counseling
- Panel is working with NSGC members working in laboratories, Samantha Baxter, Brittany Thomas and Lisa Susswein to obtain data that demonstrates the value of genetic counselors
- Data will be used in our legislative and advocacy efforts to support expanding access to genetic counselors

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Strategic Initiative #3: Core Skills of Genetic Counselors

- Task Force created
- Document available on website

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Looking Ahead to 2010

- The NSGC Board of Directors approved a revised branding platform and member value proposition in late summer
- We are using this as a framework for some exciting new changes that you will see in 2010:
 - New logo and...
 - Redesigned Website!

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Branding – why?

- Why brand an association?
 - Helps ensure consistency and adherence to mission
 - Increases member retention, recruitment and participation
 - Defines the unique place we want to occupy in target audience's mind
 - Builds credibility for individual members
 - Helps vendors, sponsors, funders, exhibitors understand who you are and what you are about
 - Can help streamline decision making in expenditures, marketing, new product development

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Who is our target?

Target: *Physicians whose patient care would benefit from comprehensive genetic and genomic services*

- Why target physicians?
 - 2008 vision survey indicated that promotion/advocacy of profession is an important benefit to members
 - Physicians (primary care, OB/Gyn, oncologists) are critical to genetic counselors' access to patients.
 - Time/cost efficiencies and decreased liabilities are real issues for physicians that genetic counselors can help solve.
 - Genetic counselors (especially those who are NSGC members) are not just knowledgeable and up-to-date on genetic science, but are trained to translate and communicate the science into practical, understandable information that allows patients to make better decisions about their health

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Strategic Planning: 2010 - 2012

- NSGC Board of Directors held our 2010 - 2012 strategic planning session in late February 2009
- Planning involved input from membership gathered through various sources:
 - 2008 PSS
 - Vision 2039 focus groups
 - 2008 Vision Survey
 - 2007 Education Summit
 - AEC Evaluations
- 2010 – 2012 Strategic Plan was approved in June 2009

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2009 Financial Report

**Peter Levonian, MS, CGC
NSGC Secretary/Treasurer**

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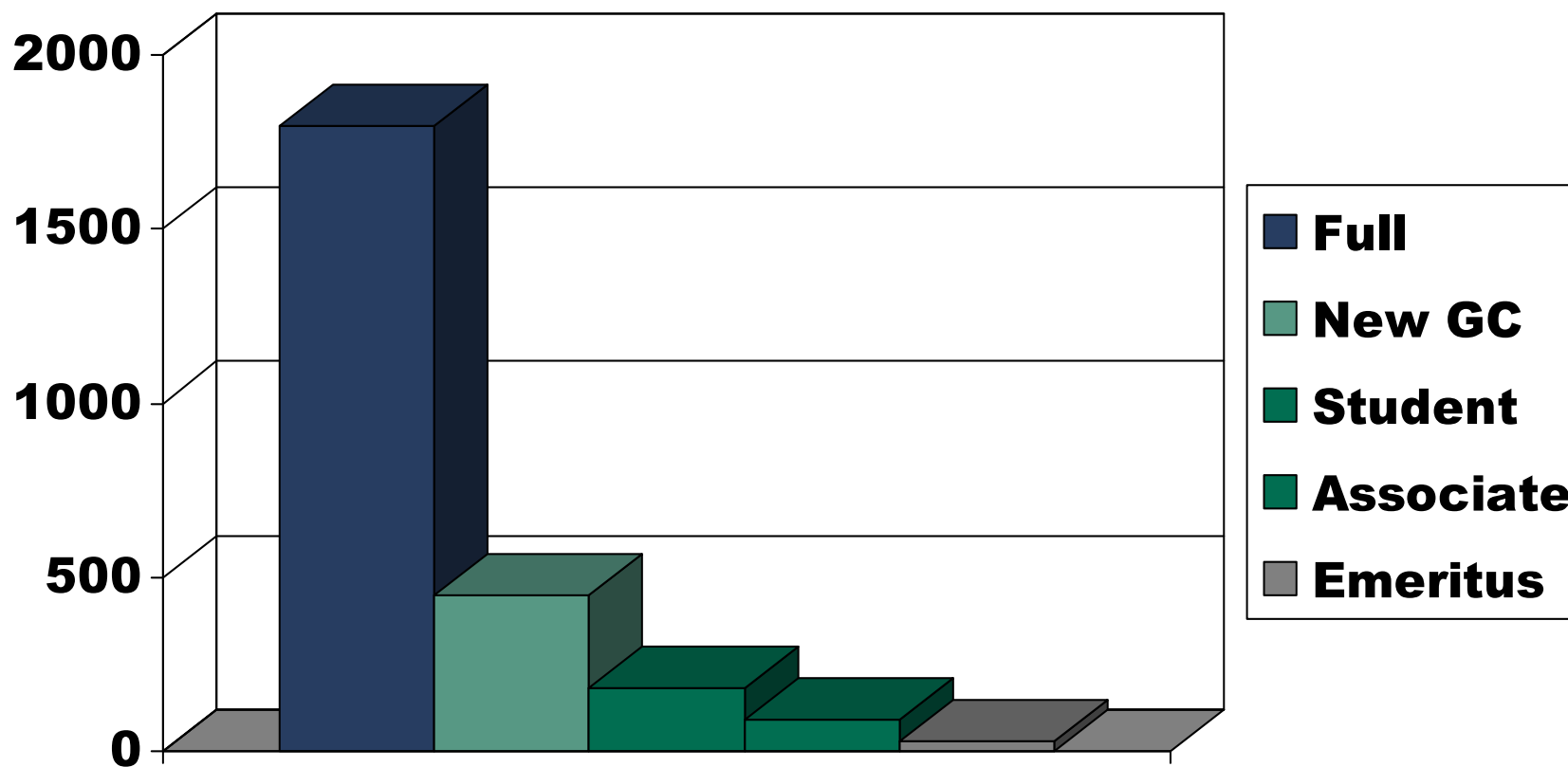
Financial Objectives in 2009

- Funding strategic initiatives through our operating revenue
- Continuing to focus on new sources of revenue
- Holding steady in a tough economic year
- Mitigating the impact of the economy through contingency planning

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NSGC Membership: 2,549 Members and Growing!



Cash Assets as of September 30, 2009

- Cash Assets
 - NSGC: \$260,553
 - JEMF: \$84,902
 - Rollnick: \$48,459

 - AHSPA (*now under GCF*): \$18,037

- Budgeted Revenue: \$1,444,248
- Forecasted Revenue: \$1,381,404

- Budgeted Expenses: \$1,464,106
- Forecasted Expenses: \$1,421,171

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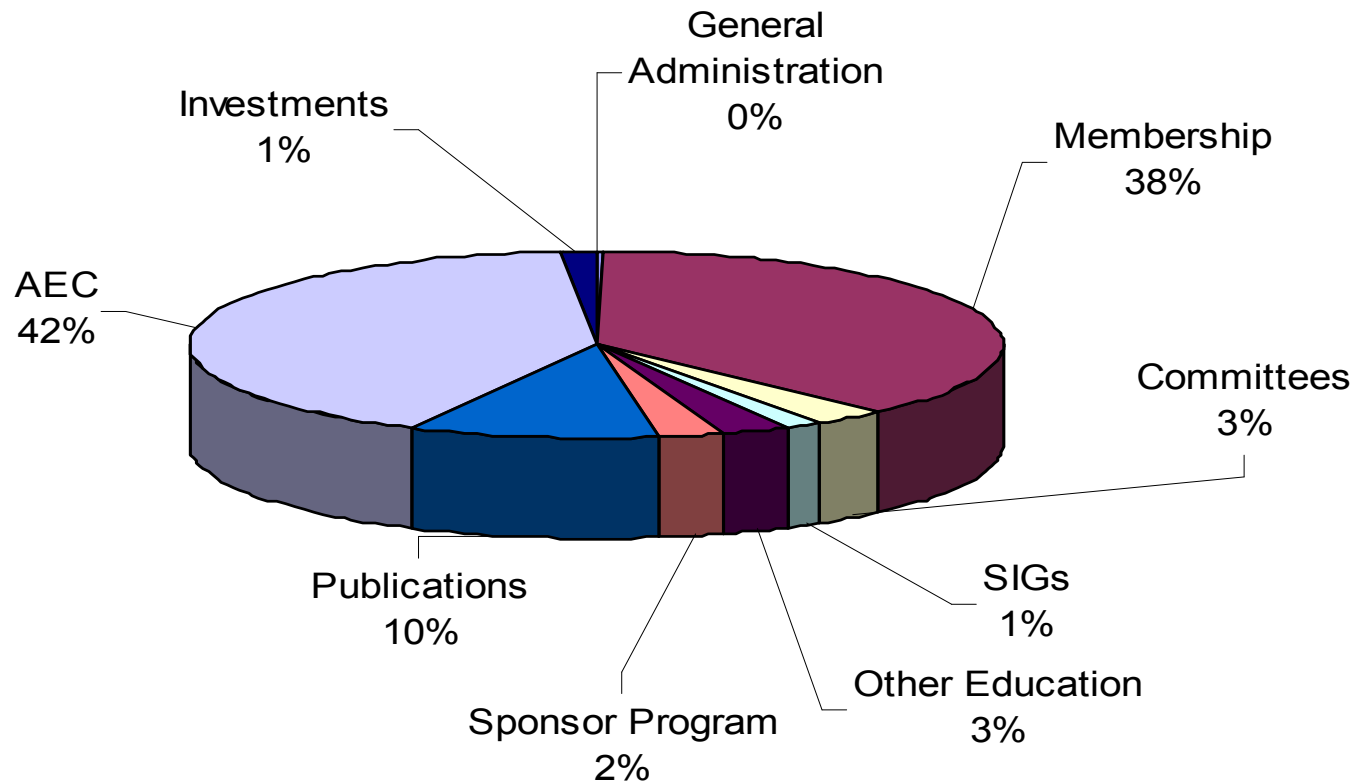
Investment Account Balances as of September 30, 2009

- Short Term Account: \$45,090
- Long Term Account: \$893,230
- Other Investments: \$2,794
- TOTAL Investments: \$941,114

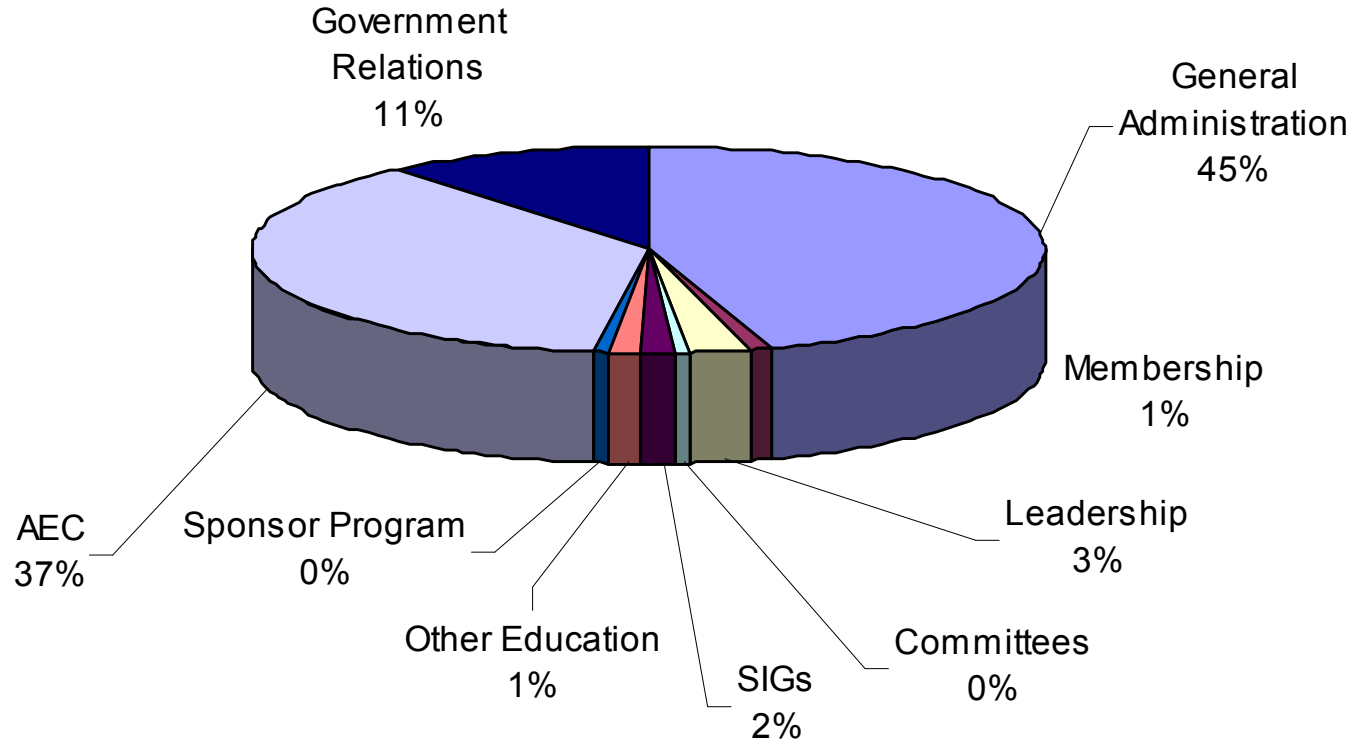
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Sources of Revenue



Expense Distribution



*Note that general administration includes staff, legal fees, IT, website, public relations, accounting, insurance, bank and credit card fees, office services and postage

Progress toward Financial Goals

- Operations are in the black by \$141,702
- Still using reserves to fund approximately 28% of strategic initiatives
- Goal in 2010 is to fully fund operations and strategic initiatives from operating revenue
- Will require continued non-dues revenue growth and prioritization of initiatives

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NSGC Publications

- Journal of Genetic Counseling
- Perspectives in Genetic Counseling

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Journal of Genetic Counseling

Editor-in-Chief

Bonnie LeRoy, MS, CGC



Assistant Editor

Pat McCarthy Veach, PhD



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Journal of Genetic Counseling Important Achievement

- The JOGC **has been** accepted for coverage by Thomson Reuters, effective 18:1 (Feb 09)!!
- It will get an Impact Factor in 2011, but in the meantime it will be indexed and abstracted in Science Citation Index Expanded (SciSearch), Journal Citation Reports/Science Edition (this is the Impact Factor section), and Current Contents/Clinical Medicine.
- An impact factor provides one indication of the extent to which the *Journal of Genetic Counseling* is being read and cited in current research.
- Impact factor is important because some funding agencies and academic institutions require authors to publish in journals that have achieved an impact factor.
- These services will be added to the website and the print Table of Contents with Springer.

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Journal of Genetic Counseling Data

From January 1, 2008 and October 15 2008

- Manuscript submission and processing has remained stable.
 - Over the past 12 months, JOGC editorial office received:
 - 106 new submissions; 8.8 per month average (original research and professional issue manuscripts)
 - 120 manuscripts were sent out for revision
 - 111 revised manuscripts were received and sent out for a second review
 - Average # of days from submission to first decision is 25 (*time to publication varies dependent upon time taken to revise*)
 - Approximately $\frac{1}{2}$ of manuscripts were submitted by USA authors; $\frac{1}{4}$ were from Canada, Australia and UK; $\frac{1}{4}$ from other countries.

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Additional Journal of Genetic Counseling Highlights

- In June of 2009, we published the ABGC practice analysis of the profession.
- The Breast Cancer News picked up the Somers article on ***Cancer Genetics Service Interest in Women with a Limited Family History of Breast Cancer published in the Journal.***
- ❖ Since 1996 **The BCN News** goes out to nearly every major cancer and health organization, *all* the major breast cancer organizations, and major research laboratories and universities around the world. In addition, we provide custom news for both the California Breast Cancer Research Program and the National Breast Cancer Coalition.
- The abstracts from this meeting will be in the December issue

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***New Perspectives* Editor and Associate Editor in 2009!**

Deepti Babu, MS, CGC, Editor

Kirsty McWalter, MS, CGC, Associate Editor

- Built on the success of Jessica Mandell
- Continually seeking new content of interest to NSGC members
- Contact editors if you would like to contribute!

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Genetic Counseling Foundation Update

**Vivian Weinblatt, MS, CGC
GCF President**

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GCF Accomplishments 2009

- New GCF Board has been appointed
 - We have an engaged, committed Board which is committed to the success of GCF!
- Development Director hired
- Fundraising goals established for 2009
- Funding priorities/cases for support developed by NSGC in collaboration with GCF and reflect NSGC's strategic priorities
- Submissions to Josiah Macy Foundation and the Agency for Healthcare Research and Quality
- Thorough review of foundations for possible "fit" with GCF vision performed

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2009 GCF Board of Directors

Vivian Weinblatt, MS, CGC, President

Susan Dickinson, MS, CGC, Secretary/Treasurer

C. Thomas Caskey, MD

Jim Evans, MD, PhD

Joan Marks, MS, CGC

Theresa Natalicchio

Ryan Phelan

William Rusconi

Angela Trepanier, MS, CGC

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Donations to GCF are investments in your future!

- GCF was founded to raise funds to support NSGC's strategic initiatives
 - Engaging other health care providers to participate as part of a team providing genetics services
 - Supporting outcomes-based research to demonstrate the value of genetic counseling
 - Supporting education for the genomics revolution
- GCF can attract tax-deductible donations from individuals, foundations and corporations
- A donation to GCF supports your profession, your patients and will help to solidify the role of genetic counseling as a critical component of quality health care
- In 2009 GCF has received both member and corporate support, and our goal is to expand this support in 2010 and beyond
- GCF cannot succeed without your support-- Foundation support is dependent upon demonstrated support by the membership. Support is measured by percent of member donors and **not** the amount of each donation!
- Currently, fewer than 10% of membership has donated to GCF.

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Volunteer Recognition

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NSGC President

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2009 Committee Chairs and Vice Chairs

Communications Committee

Elissa Levin, Chair

Lori Correia, Vice Chair

Membership Committee

Mary Freivogel, Chair

Sheetal Parmar, Vice Chair

Education Committee

Ellen Schlenker, Chair

Jen Hoskovec, Vice Chair

Public Policy Committee

Barbara Harrison, Chair

Diane Baker, Vice Chair

Genetic Counseling Access and Service Delivery Committee

Leslie Cohen, Chair

Janet Williams, Vice Chair

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2009 Task Force Chairs

Organizational Cultural Competency Task Force

Monica Alvarado, Chair

Core Skills Task Force

Kristin Niendorf, Chair

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2009 Board of Directors

Officers

- President: Steven Keiles, MS, CGC
- President-Elect: Elizabeth Kearney, MS, CGC
- Secretary/Treasurer: Peter Levonian, MS, CGC
- Secretary/Treasurer-Elect: Elizabeth Leeth, MS, CGC
- Immediate Past President: Angela Trepanier, MS, CGC

- Executive Director (ex officio): Meghan Carey

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Steve



Liz



Peter



Beth



Angie



Meghan

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2009 Board of Directors (Cont.)

Directors At Large

- Brenda Finucane, MS, CGC
- Joy Larsen Haidle, MS, CGC
- Karen Heller, MS, CGC
- Caroline Lieber, MS, CGC
- Cindy Soliday, MS, CGC
- Jennifer Sullivan, MS, CGC
- Deborah Wham, MS, CGC

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Brenda



Joy



Karen



Caroline



Jennifer



Cindy



Deb

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Welcome Incoming NSGC Board of Directors Members

- President-Elect: Karin Dent, MS, CGC
- Secretary-Treasurer Elect: Rebecca Nagy, MS, CGC
- Director At Large: Trisha Brown, MS, CGC
- Director At Large: Linda Robinson, MS, CGC
- Director At Large: Cindy Soliday, MS, CGC

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Karin



Becky



Trisha



Linda



Cindy

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Thank you to all of NSGC's dedicated volunteers!

We could not do it without you!

- Committees
- Task Forces
- SIGs
- Workgroups
- Subcommittees
- AEC
- Projects
- *Journal of Genetic Counseling*
- *Perspectives*
- All individual contributors

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Question & Answer Session

Steven Keiles, MS, CGC
NSGC President

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Leading Voices Drawing Winners – Congratulations!

We had over 150 leading voices nominations submitted this year!

- Kari Danziger Kaplan
- Jehannine Austin
- Kirsty McWalter
- Brandie Leach
- Renee Chard
- Amy Vance

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Thank You!

Steven Keiles, MS, CGC
NSGC President

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