

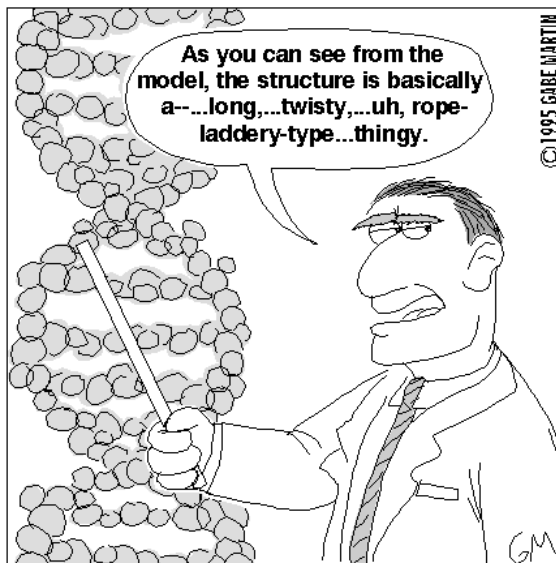
Genetic Counseling in the 21st Century: Expanding Roles and Redefining the Scope of Practice

national society
of genetic
counselors, inc.



Kelly E Ormond, MS, CGC
on behalf of the
National Society of Genetic Counselors

the leading voice, authority and advocate for the genetic counseling profession



1953: The structure of the DNA molecule is first described.

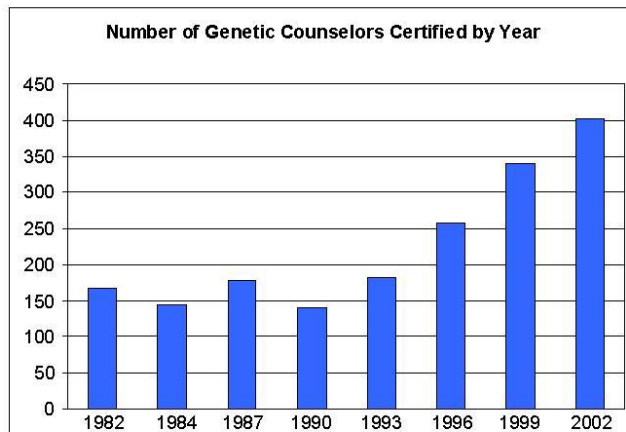


Growth

- Professional milestones of NSGC, ABGC
- Currently 27 GC training programs nationally, and ~15 internationally
 - Australia (4), Netherlands, Britain, Japan (3), Taiwan, Cuba, S Africa, Israel, Norway
- Approximately 175 graduates/year in US and Canada alone, with >600 applicants for those positions (*source AGCPD*)



Certified Genetic Counselors



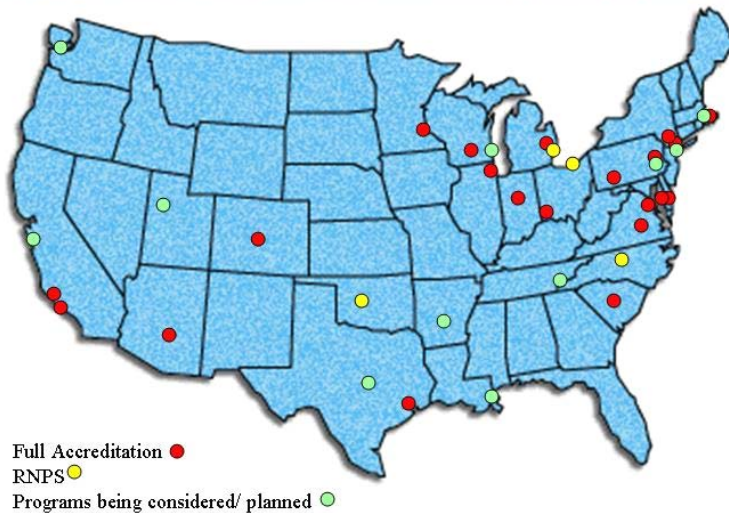
Data from ABGC

** 466 individuals sitting for 2005 examination

Genetic Counselors (full members only) By State (data from NSGC 3/05)

State	Number	State	Number	State	Number
AK	1	KS	8	NV	7
AL	4	KY	7	NY	111
AR	11	LA	5	OH	68
AZ	18	MA	79	OK	6
CA*	236	MD	68	OR	21
CO	17	ME	10	PA	99
CT	29	MI	46	RI	10
DC	12	MN	35	SC	20
DE	9	MO	24	SD	0
FL	42	MS	0	TN	19
GA	33	MT	5	TX	70
HI	11	NC	77	UT*	21
IA	8	ND	0	VA	42
ID	3	NE	6	VT	6
IL*	69	NH	1	WA	40
IN	23	NJ	55	WI	44
		NM	9	WV	2
PR	2			WY	1

Geographic Distribution of Genetic Counseling Graduate Programs





NSGC: Highlights as a Professional organization

- Journal of Genetic Counseling
- Position Statements and Practice Guidelines
- Liaisons to other organizations
- Marketing and PR of genetic counseling services
- Impact on policy decisions

- Code of Ethics (recently updated)

- JEMF and Special Projects Awards (research support)

- Special Interest Groups



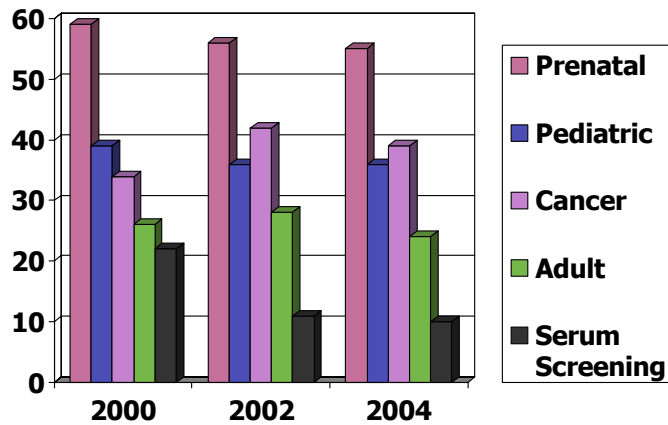
Role Diversity

- Clinical and non-clinical roles
 - Education, industry, research, administration, policy

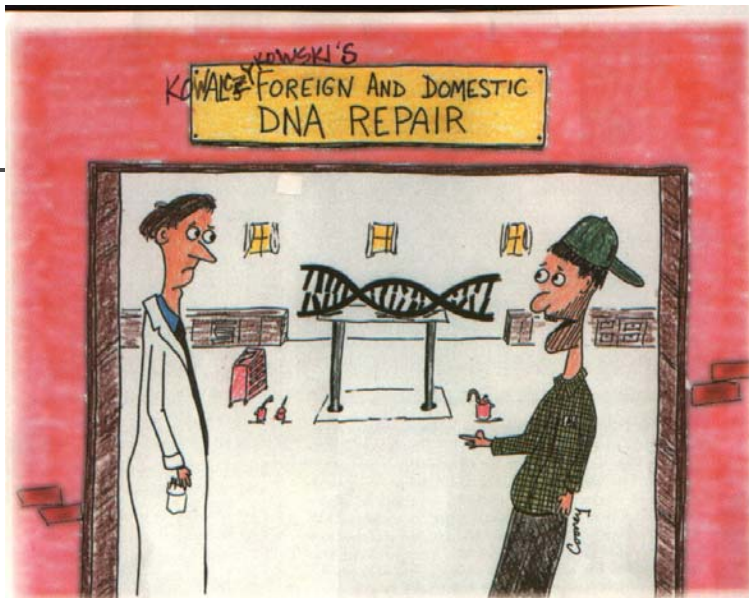
- Genetic counselors currently practice in prenatal (55%), pediatric (36%), cancer genetics (39%) and other adult specialty areas(24%).
 - neurogenetics
 - psychiatric genetics
 - infertility
 - cardiovascular genetics

- In many of these new specialty areas genetic counselors work with physician specialists who may not have clinical genetics training.

Trends: Reported Specialty Areas



Respondents could select multiple specialty areas – source NSGC 2004 PSS



"You're lucky nobody was injured. Your base pairs are out of alignment and that has your reading frames all messed up."



Defining GC roles: NSGC Strategic Plan

- Definition of genetic counseling
- Scope of Practice

- Licensure

- Attaining reimbursement and recognition as independent providers

- Working together with genetics colleagues



Draft: Definition of Genetic Counseling

Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates:

- Collection and interpretation of family and medical histories to assess the chance of disease occurrence or recurrence
- Education about inheritance, testing, management, prevention, resources and research
- Counseling to promote informed choices and adaptation to the risk or condition.

- *Definition will be reviewed by BOD and submitted to membership for vote in upcoming months*



Draft: Scope of Clinical Genetic Counseling Practice

- Focuses on clinical positions only
- Key areas in case management, psychosocial assessment and support, professional ethics
- Complements and draws from COE, Competencies, Position Statements and Practice Guidelines

- Goals to help define roles; educate others about genetic counseling; assist in developing job descriptions, licensure
 - *Ad Hoc committee: Karen Hanson (chair) Bonnie Baty, Edward Kloza, Sharon Solomon, Aimee Walter, LuAnn Weik*



Licensure of Genetic Counselors

- Utah
 - enacted
- California and Illinois
 - passed but not yet enacted

- Approximately 10 other states currently have bills in the legislature or are drafting bills at this time.
 - Colorado, Florida, Massachusetts, New York, New Jersey, Texas, Washington and Wisconsin



Billing, reimbursement and coverage

- Strategic plan initiative #1
- NSGC funded project recently completed
- Progress in various areas
 - SACGHS
 - Development of toolkit
 - Marketing plan to third party payors



Critical areas for the 21st Century

- Increasing specialization and diversification of genetic counselor roles
- Need to increase diversity in the gc workforce
- Health care disparities – access to genetic services
- Health professional and public education about genetics/ genomics



Acknowledgements

- Thanks to the current NSGC Board of Directors and many of our organization's past presidents, who contributed to the planning and development of this talk
- *NSGC's Mission: to promote the genetic counseling profession as a recognized and integral part of health care delivery, education, research and public policy.*