

NSGC REPORT

Genetic counselor training programs: capacities and needs

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Past-President I, NSGC

**NSGC—The leading voice, authority and advocate for
the genetic counseling profession**

SACGHS Request

“Develop a plan for gathering data on what is needed to increase the number, diversity and quality of training of genetic counselors.”

June 2003

Methods

- Information collected: July -October 2003
- Survey/meeting—Association of Genetic Counseling Program Directors (AGCPD)
- Interviews/meeting—American Board of Genetic Counseling (ABGC)
- Consultation: Judith Cooksey, MD, MPH
 - Illinois Center for Health Workforce Studies

Methods: NSGC Data

- Membership: 2100 individuals
 - Expertise/training in genetic counseling
 - North America and abroad
 - ~85% of genetic counselors are members
- Query: NSGC Industry SIG
- Review: Professional Status surveys (96-02)
- Review: Executive Office data

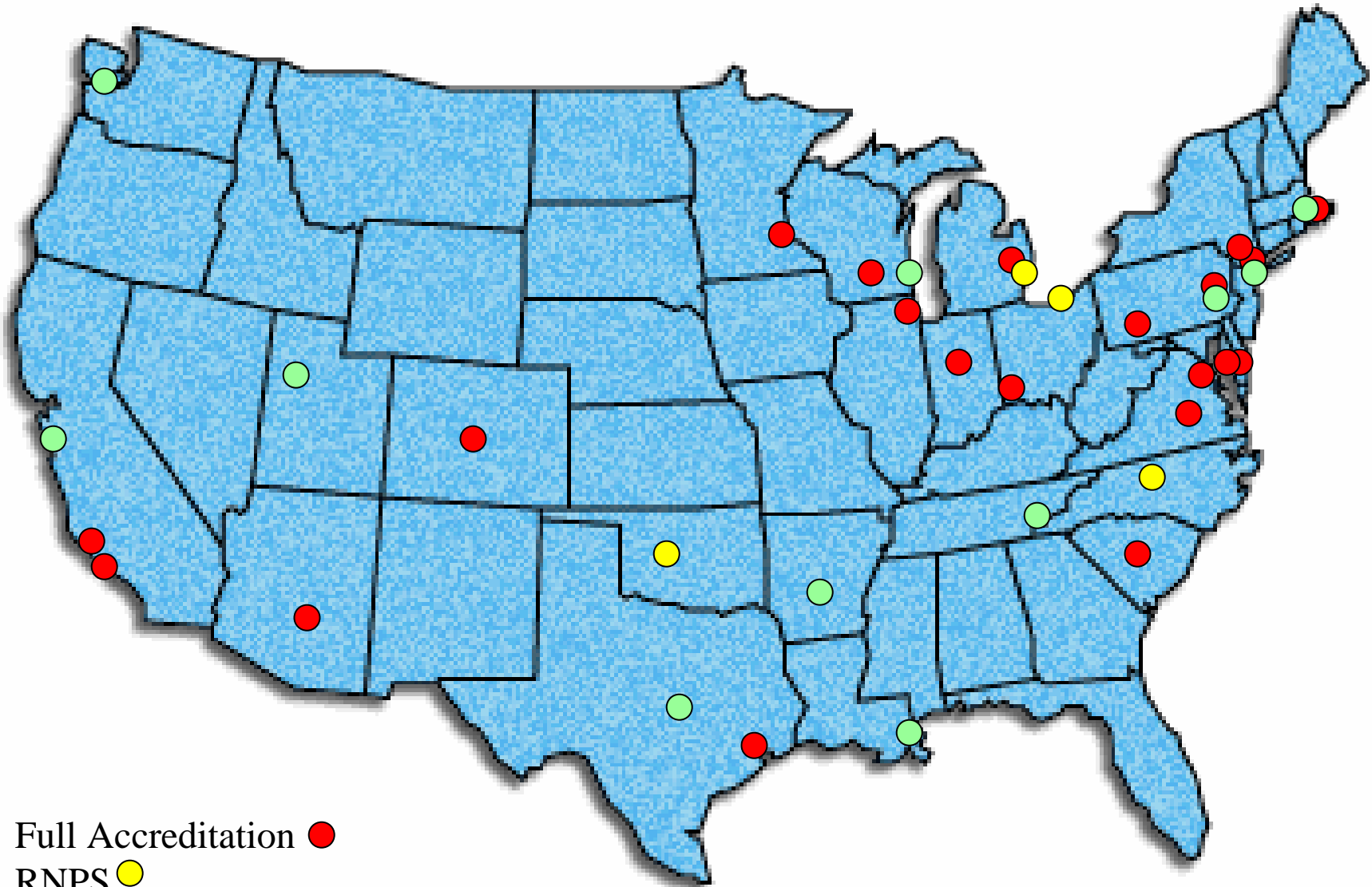
NSGC Report

- Brief review of field of genetic counseling and workforce (focus on U.S.)
- Current status of GC training programs
- Suggestions for expanding existing programs while maintaining high quality
- Suggestions for developing new programs
- Enhancement of diversity of GC profession

NSGC report does not address

- Training and workforce issues of other genetic specialists
- Not an independent report
 - Estimate cost of such a study
\$90,000-\$150,000

Geographic Distribution of Genetic Counseling Graduate Programs

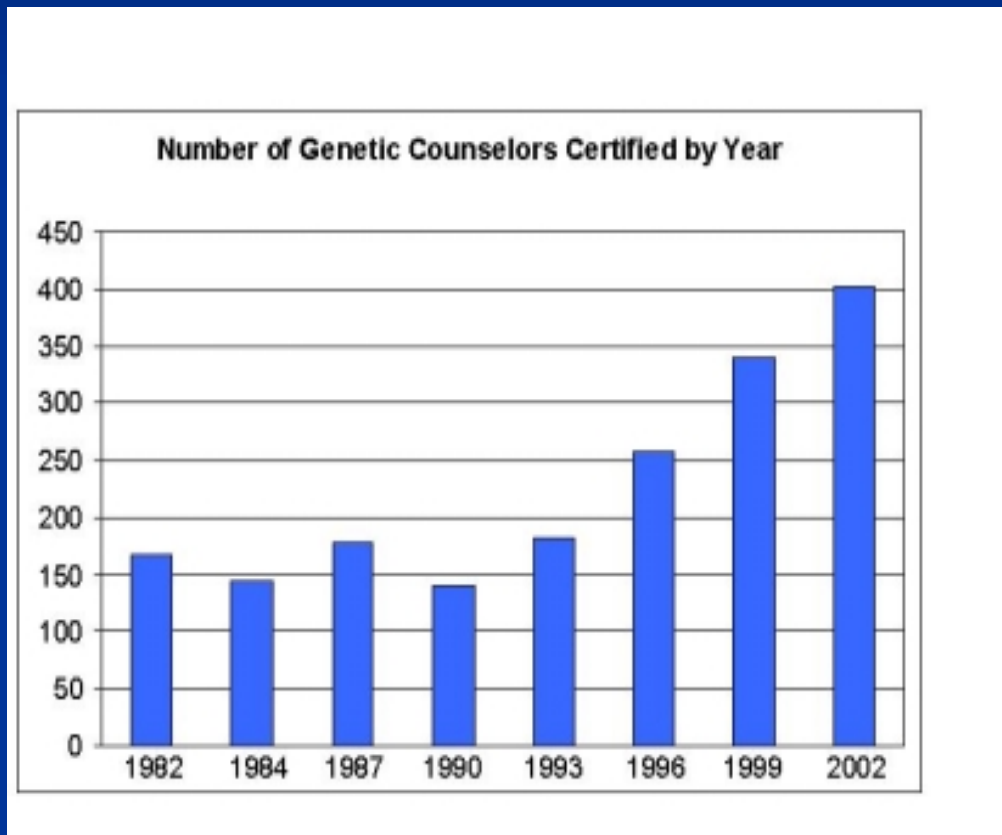


Full Accreditation ●

RNPS ●

Programs being considered/ planned ●

ABGC certifies genetic counselors & accredits programs



- 25 programs in US
- 3 programs in Canada (also certification by Canadian Association of Genetic Counselors)
- Prior to 1993 responsibility of American Board of Medical Genetics

ABGC Accreditation

- Competency in 27 areas within four critical domains
- Didactic coursework
- 800+ hours of comprehensive fieldwork
- Teaching experience
- Research experience (most with thesis requirements)
- Length 18-24 months (NIH-Hopkins-36 mo)

Demand for genetic counseling

- Difficult to predict behaviors!
- Increased sophistication of consumers
- As a profession--GC meet demands
 - Cancer genetics: NSGC
 - 42% 2002 10% 1994
 - Increase in overall annual patient load
 - ~66% increase 2000 to 2002 (345 to 572)

“To whom it may concern:

I am responding to your letter refusing genetics consultation on ___ and suggesting that we do pedigrees, etc. on her. You are forgetting who you are writing to. I am a surgeon. Remember, we are not cognitive professionals. I don't know how to do pedigrees. The only people that do pedigrees are genetic counselors and dog breeders. Since she is not a dog, I thought the geneticist would be the best fit, and thus my request.”

“Perhaps you will still refuse our small and humble request. Then, in keeping with Frank and Ernest, we will send her to you for genetic counseling.”

Frank and Ernest



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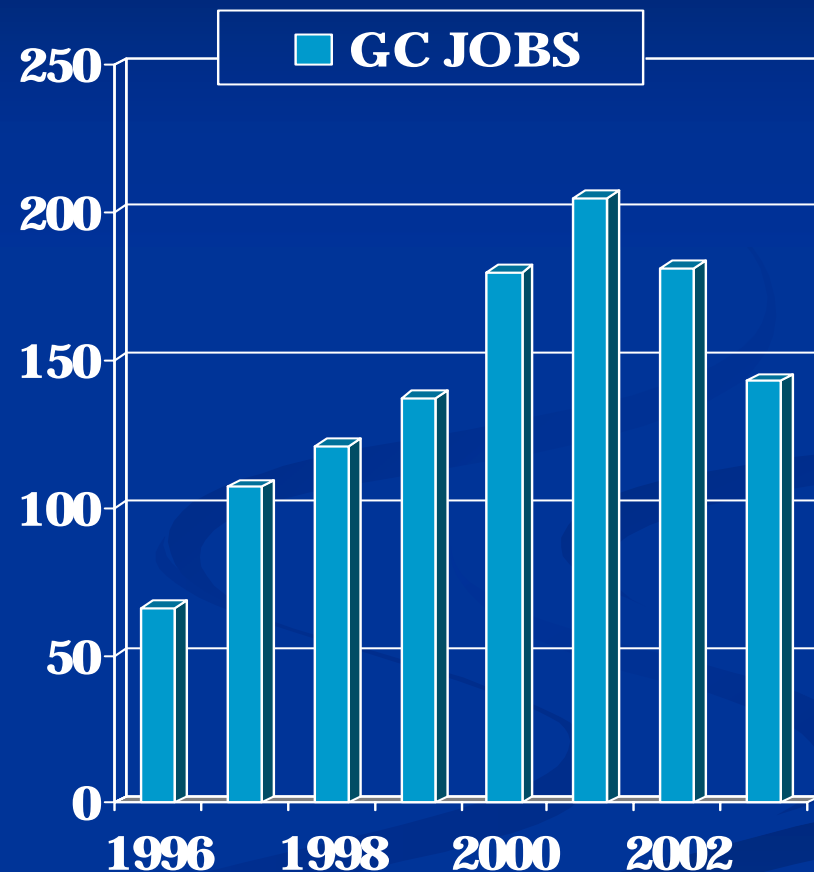
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Job Opportunities

- Steady increase in NSGC Job postings
- <75% of GC graduates employed <1 mo. from graduation
- Myriad Genetics 33 GC (1 in 1996)



Genetic counselors as a community resource

- Serve on advisory boards of consumer support groups (71%)
- Organize conferences and workshops
 - 37% for health professionals
 - 14% for consumers

Genetic counselors as teachers

- Major teaching role
 - Physician/medical students (77%)
 - Other health professionals (34%)
 - Nurses/nursing students (70%)
 - Physician assistants (10%)
 - Social workers (10%)

Current GC programs

- Usually housed in academic medical centers
- Mostly public (6 private schools)
- Total enrollment: range from 6-8 to 46 students, *average 16*
- ~550 students applied to US genetic counseling training programs in 2003
- 90% women
 - Qualified applicants– high GPA & GREs

Limits on training programs

- **Quality field placements**
- Loss of a field placement can cause reduction in program's enrollment
- **Enormous volunteer effort**
 - clinical supervision (+400 hours per year)
 - teaching
- **Lack of funding for programs & limited scholarship opportunities**

Annual costs to train GC student

- Average \$30,000
(Range \$25,000 to \$50,000)
- Does not include physical resources or in-kind contributions of many ancillary faculty and clinical supervisors

Source: Informal survey of AGCPD

Proposal: Increase Capacity of existing training programs

- Add additional training sites
 - **Student travel and living stipends** for out-of-area clinical rotations (6-9 weeks)
 - \$3000 per student per year
 - **Supervisor stipend** (~100 hours a rotation)
 - \$2600 per/student/rotation *or*
 - \$10,400 .20 FTE per student

(based on \$25 hour without benefits)

Proposal: Increase capacity of existing training programs

■ Additional faculty

- Currently limited funding of faculty for clinical and research supervision
 - limits number of students can admit
- Joint appointments, benefit other departments

Faculty FTE genetic counselor: \$80-100,000

Faculty FTE Medical Director/geneticist: \$150-175,000

Enhance existing programs:

Training grants for students

- Make training grants similar to doctoral candidates and many other types of allied health professionals
- Consider tying program support to limited obligation of practice in an underserved area

Diversity scholarships: \$50,000 per student

Student stipends: \$5,000 per student/per year

Increase number of programs

- 3-4 year start-up funds/require matching funds (?)
- **Cost estimate: \$533,200 per year** --16 students

Genetic counselor program director	\$100,000
MD/PhD geneticist	\$175,000
Program administrator	\$ 55,000
Supervisor stipends (x “32”)	\$ 83,200
Continuing education/resources	\$ 20,000
Diversity scholarships (2 @\$50,000)	\$ 100,000

Increase access to expert training

- Teaching through web casting
- Expert faculty at remote site can lecture to students at single-site or multiple sites
 - Eliminates faculty travel time & expense
- Student communication
 - Journal club, case conferences

Costs: Many medical institutions and universities have access to this equipment, though charges for land lines and tech support

Benefits of targeting funding of genetic counseling training

- Current programs express willingness to expand
 - Informal survey-- most existing programs could expand by more than 50%
- At least five programs “waiting” to exist
- Increase diversity of field
- Increase client access and diversity
- Increase access to genetic counselors by other health professionals

Just because genetic testing is more accessible, the genetic counseling issues did not become any simpler

