PERSPECTIVES
in genetic counseling

Volume 17 Number 4 Winter 1995/1996

Mentors: Shaping Our Future

by Kristin Kruger Sanden, MS, Children's Hospital of Wisconsin; Kristin Baker, BS, University of Wisconsin

"I am a genetic counselor today because of her. I think what was most important was that she was so excited herself about genetic counseling—it was contagious. Although we are now friends and colleagues, she will always be a role model to me."

Most genetic counselors can name someone who inspired or encouraged them along their professional journey: perhaps by boosting confidence during graduate school, easing the transition from student to practicing counselor or guiding professional growth by sharing insight and experience. Such a helper is a mentor, defined by Webster's Dictionary as "a trusted counselor or guide." Mentoring passes on the wisdom of the past and present to positively shape the future.

For some, the relationship with a mentor begins even before entering the field. A student remembers, "As an undergraduate, I explored the field of genetic counseling with the help of a clinical geneticist at my university. Graciously and selflessly, she spent time teaching and providing me with many wonderful clinical experiences even before I entered my graduate program."

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On the Horizon: A CPT Code Specific to Genetic Counseling?

by Debra Lochner Doyle, MS, Chair, Professional Issues Committee

For the past two years, Barbara Bernhardt and I have served on the American College of Medical Genetics Committee on Economics of Genetic Services. The committee's activities include efforts to revise the existing CPT manual to incorporate new codes better reflecting the myriad of genetic services. I am pleased to announce that on October 20, a formal request was submitted to the American Medical Association (AMA) CPT Editorial Panel proposing numerous CPT code changes, including one specifically for genetic counseling. In fact, all the proposed changes were related to laboratory procedures except one—the code for genetic counseling!

Why should you care? CPT codes are used by nearly all fee-for-service payors (insurance companies, health plans, and Medicaid/MediCal). Combined with ICD-9 codes, they are intended to easily identify for the payor exactly what services were rendered and why; in fact, most payors base their reimbursement level on the service descriptions in the CPT manual.

For those providing genetic services, these codes have always proved problematic, since many of the laboratory or genetic counseling

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national society of genetic counselors, inc.

nsgc

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

On the Inside

Women's Health

NSGC acknowledges Women's Health Care Services, Wichita KS, providers of late abortion care for fetal anomalies, George R. Tiller, MD, Medical Director, for a grant to support this newsletter.

Presidential Address

Positioning Genetic Counseling for the 21st Century

I cannot imagine not being a genetic counselor. The variety of jobs that currently exist and the future opportunities make it a field consistently included in "Future Trends" articles.

But how will our profession look in the next decade? Will we shape the future of genetic counseling or will we allow others do it for us? I wouldn't be president if I didn't believe that to be a rhetorical question. I *know* we have the creativity and ability to shape our own future. Watching the future unfold is like putting puzzle pieces together and watching the picture emerge.

The Job Paradox

One key issue is jobs. You've read that not enough genetic counselors will be available to provide needed services in the future. But some new grads have difficulty finding jobs, colleagues have been laid off and openings are being filled by non-counselors. This is a paradox—how can we have not enough positions for counselors, yet not enough counselors to fill positions? The reasons are complex, but it is a survival issue—for our profession, for our organization and for each of our jobs.

Three Goals for the Year

The following goals will help ensure continuing and expanding employment opportunities for genetic counselors:

■ **See that genetic counseling positions are filled by qualified genetic counselors.** We can accomplish this by:

- creating practice guidelines
- identifying CPT codes for reimbursing our services
- developing/funding positions in innovative ways
- promoting undergraduate interest in our profession.

■ **Successfully implement Special Interest Groups (SIGs) to bridge the diverse needs of our members.** As our professional roles expand, we need a mechanism to assure that we continue growing together. SIGs—a new membership benefit—support all of us wanting to:

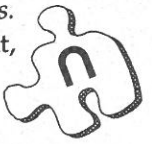
- increase our competency in a specialized area
- take advantage of internal expertise to learn about a new aspect of our field
- continue as generalists but be competent in all areas.

■ **Position genetic counseling through marketing and public relations.** Identified as important in our original strategic plan, the need for marketing was again mandated at the Board of Directors' meeting. A global strategic marketing plan is necessary to focus our energies. NSGC will hire a consultant to outline the steps each of us needs to take to inform the world of the value of genetic counselors. Initial target groups will be:

- managed health care providers
- insurance companies
- health care professionals
- the public
- future genetic counselors.

You Hold a Piece of the Puzzle

How is this going to happen? *It takes all of us.* On becoming president, I purchased a 3000 piece puzzle: a metaphor for the work we all need to do to accomplish our goals.



During this year, many of you will receive puzzle pieces acknowledging your contributions—if you deserve one, let me know. Bring them to the Education Conference in San Francisco where we will assemble the puzzle. We will once again demonstrate that it takes energy from all of us, all the time to move us toward our vision—to be the leading voice, authority and advocate for the genetic counseling profession.

I look forward to this year. I anticipate celebrating milestones we have achieved when we meet again in San Francisco. I hope I will regret then not buying that 5000 piece puzzle.

Vickie Venne, MS
President

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Send articles, reviews, correspondence to the Editor-in-Chief; address changes, subscription inquiries, advertisements and classifieds to the Executive Director. Contact any Editorial Board member with ideas or suggestions.

Publication date, next issue: March 15
Deadline for submissions: February 10

Board Meeting Highlights...

Board of Directors Meet in Minneapolis

The 1995 Board of Directors' meeting revealed once again the energy, enthusiasm and dedication of NSGC's leadership. Incoming President Vickie Venne split the meeting in two sessions—one encouraging creative brainstorming about NSGC's future, the other devoted to current issues requiring votes.

Board members engaged in strategic planning, examining NSGC's internal strengths and weaknesses, identifying external opportunities and threats. Targeted issues included:

- job opportunities & recruitment
- expanded roles for counselors
- education
- board reorganization.

The Board created a list of priorities and determined which groups or committees would work on each. Specific ideas for pursuing goals were outlined and developed further in NSGC committee meetings later in the week.

Strategic Positioning

One priority is developing **practice guidelines** formally outlining the specialized skills and training possessed by genetic counselors. These guidelines will help us position ourselves in the health care reform process.

As fiscal awareness becomes increasingly imperative, NSGC is carefully studying **billing, reimbursement and licensure**. These may hold the key to creating opportunities for genetic counselors amidst health care transitions.

This depends in part on promoting ourselves among professionals and consumers. We discussed developing a **marketing** plan, investing in the expertise of a public relations consultant.

Research and Education

Genetic counselors need to become increasingly involved in **research projects** that define and expand our profession. Two committees—Education and Professional Issues—are working on ways to encourage and assist genetic counselors who want to develop such research projects.

Continuing education units (CEUs) are coming, and will help ensure genetic counselors remain current and proficient in the field. The Education Committee is planning to implement CEUs for participants in a wide range of educational activities.

NSGC will co-sponsor the University of Pittsburgh's Board Review Course offered May, 1996 (*see article, page 4*). In the future, NSGC hopes to "take the show on the road," and offer the board review course locally.

Get Involved!

Your voice and energy are needed. To work on these or other issues, contact the committee chairs listed below. Other ideas? Comments? Concerns? Contact your Regional Representative.

- **Practice guidelines:** Rebecca Rae Anderson, Genetic Services
- **Billing, reimbursement, licensure:** Debra Lochner Doyle, Professional Issues, Rebecca Rae Anderson, Genetic Services or your Regional Representative
- **Marketing:** Ann Happ Boldt
- **Research projects:** Jill Fischer, Education, or Debra Lochner Doyle, Professional Issues
- **Continuing education units:** Jill Fischer, Education

Jill Stopfer, MS
Secretary

Legislative Update

The week of October 30, the US House of Representatives passed HR 1833, making it a crime for doctors to perform "intact dilation and extraction" abortion procedures. This was followed by a vote on the Senate version of the bill, S939, which passed on December 7. This procedure is performed in the third trimester for cases of fetal abnormality or when the mother's life is endangered.

Differences in House and Senate versions need to be resolved before the bill is sent to President Clinton. The President has indicated he will veto the current version. At this time, it is doubtful a presidential veto would be overridden.

Write Your Elected Officials Today

Please contact President Clinton and your legislators as soon as possible to express your opinion on this bill. See the Spring 1995 issue of *Perspectives* (Vol. 17, No. 1) for tips on effective letter writing.

President Bill Clinton
The White House
Washington DC 20500
202-456-1111
EM: http://www.whitehouse.gov

Senator (name)
Senate Office Building
Washington DC 20510
202-224-3121

Representative (name)
House Office Building
Washington DC 20510
202-225-3121

Cindy Soliday, MS
Legislative Issues Subcommittee

Bound for the Boards? NSGC Co-Sponsors Review Course

NSGC recently negotiated with the University of Pittsburgh to co-sponsor a genetics board review course, scheduled for May 3-5, 1996. This course, first offered by NIH, is now in its fifth cycle. It is one of two courses offered to individuals sitting for the American Board of Genetic Counseling or American Board of Medical Genetics exams.

This win-win opportunity benefits both the University of Pittsburgh and NSGC. We supply expertise in conference management and enhance the course with our reputation. In return, NSGC receives a share of the profits and becomes a national player in a review course. The alliance also directly benefits members, who receive a registration discount.

Since planning for the course was largely complete by the time we signed the contract, our collaboration in this exam cycle will be primarily administrative. We anticipate an active role in the course's organization and content in coming years. It may even be possible to transport the program and offer the course regionally in the future.

By the time you read this, those sitting for the Board exams have submitted logbooks and will soon receive an information/registration brochure. Good luck with your preparation, whatever form it takes.

The NSGC Board of Directors extends thanks (and a puzzle piece) to Betsy Gettig, whose foresight and vision seized this remarkable opportunity for our organization.

Vickie Venne, MS
President

NSGC Notes

■ 1995 NSGC award winners were announced in Minneapolis:

Special Projects Fund: Diane Baker for a patient letter writing project

Natalie Weissberger Paul Award: Ann P. Walker

Regional Service Awards:
Region 1: Ed Kloza
Region 2: Elsa Reich
Region 3: Stephanie Smith
Region 4: Amy Lemke
Region 5: Pat Ward
Region 6: Robin Bennett

■ NSGC endorsed a position statement by the ELSI Working Group critiquing *The Bell Curve (at right).*

■ The Membership Committee has developed a colorful poster *(right)* to entice college students to consider genetic counseling careers.

■ The Social Issues Committee finished its position paper on folic acid supplementation, to appear in the *Journal of Genetic Counseling.*

■ Liaison Rosalie Goldberg attended a recent NCHGR meeting where director Francis Collins reported on the ELSI Working Group's National Action Plan on Breast Cancer.

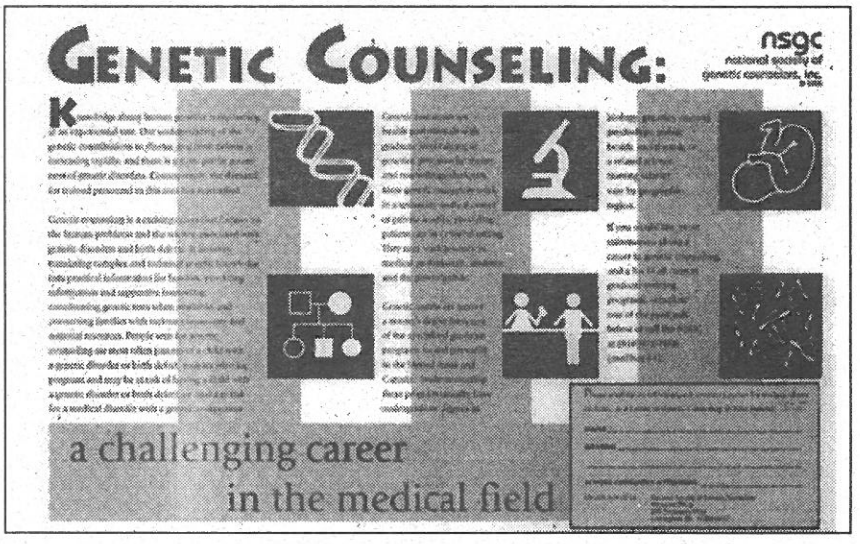
The Bell Curve

This statement was developed by the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of Human Genome Research and is endorsed by NSGC.

In 1994, a highly publicized book, Richard Hernstein and Charles Murray's *The Bell Curve*, claimed that IQ is largely genetically determined and that the differences in IQ between ethnic groups are substantially explained by genetic factors. We are especially concerned about the impact of *The Bell Curve*, and books developing similar themes, because we believe that the legitimate successes of the Human Genome Project in identifying genes associated with human disease should not be used to foster an environment in which mistaken claims for genetic determination of other human traits gain undeserved credibility.

Hernstein and Murray suggest that IQ explains social problems such as crime, welfare dependence, and single parenting...

For a copy of the entire position statement, contact ELSI liaison Vivian Weinblatt, 215-955-4295, EM: vivian@genetics1.jmp.tju.edu



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CPT Codes Proposed for Genetic Counseling

services we provide cannot easily be found in the existing codes. I challenge you to find a CPT code in the current manual that can be used for FISH studies!

Our research revealed most genetic counselors bill for their services using either consultation codes (#99202-99205), office visit codes (#99242-99244) or counseling and risk reduction/intervention codes (#99401-99404).

Code Distinctions

Each code is distinguished by subtle yet distinct nuances. For example, consultation codes are limited to services provided to a patient referred by another physician and should not be used for those who are self-referred. The CPT manual restricts billing services for a self-referred patient to an office visit code, typically generating a much lower level of reimbursement. All these codes pertain to services provided by a physician, not by an allied health care provider.

Existing Codes Incomplete

Three reasons were noted when asked to describe why the current codes are inadequate:

- they assume the presence of a medical condition,
- they include elements outside the scope of genetic counseling,
- they fail to include elements integral to genetic counseling.

Consultation and office visit codes refer to "existing medical conditions." But patients seen for genetic counseling may not have existing conditions or symptoms of an illness: ethnicity, family history and advanced maternal age are common reasons for referral.

Both consultation and office visit codes include a review of body systems and physical exam; neither are part of the genetic counseling process. And existing codes all fail to capture all the required components for genetic counseling *(see box)*.

Who Provides Services?

When asked which physicians and specialties will provide the service, the proposal states: "Genetic counseling is typically provided by health care professionals who are certified by the American Board of Medical Genetics or by the American Board of Genetic Counseling. In addition, genetic counseling may be provided by physicians who have additional training in human genetics and who are boarded in specialties including, but not limited to, pediatrics, internal medicine, obstetrics and gynecology and family practice."

What's Next?

The AMA CPT Editorial Panel will meet in February to review the proposal. Two physicians selected by ACMG will be present to defend the request; I will be available to answer questions about the genetic counseling part of the proposal.

The CPT Editorial Panel may choose to select some or all of the proposal. If the genetic counseling portion is selected, the Relative Value Uptake Committee process will proceed through March and April. This process documents the impact of proposed changes in terms of cost effectiveness and/or utility.

If all goes well, the new genetic counseling CPT code would be published and available for use in 1997!

Genetic Counseling Services Defined

The request to add a genetic counseling CPT code described the service as follows:

Genetic counseling has been defined by the American Society of Human Genetics as a "communication process which deals with the human problems associated with the occurrence, or the risk of occurrence, of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family (1) comprehend the medical facts, including the diagnosis, the probable course of the disorder and the available management; (2) appreciate the way heredity contributes to the disorder, and the risk of recurrence in specified relatives; (3) understand the options for dealing with the risk of recurrence; (4) choose the course of action which seems appropriate..., and (5) make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder."

In order to fulfill these objectives, the genetic counseling process contains the following elements: (1) eliciting a complete individual and family social, reproductive and health history; (2) risk assessment; (3) consulting with the individual and family about available clinical evaluation and testing options including risks, benefits, limitations, interpretation and possible psychological and economic consequences of genetic testing and diagnosis; (4) a psychosocial assessment and intervention; (5) facilitating medical and reproductive decision making in a non-directive fashion; (6) anticipatory grief and crisis counseling; and (7) facilitating medical screening, testing, or management options as requested by the individual or family.

1996 Education Conference

San Francisco is the site of NSGC's 15th Annual Education Conference, to be held October 26-29, 1996. The meeting will have no single theme, representing instead genetic counseling's diversity. More information will be mailed in Spring, or call 610-872-7608, #6.

Your Help is Needed!

Can you share some time, energy or enthusiasm? Contact one of the following to participate in conference planning:

Conference Chairs	Lisa Amacker North 704-355-3159	Robert Resta 206-386-2101 bc928@scn.org
Program	Barbara Biesecker 301-496-3979 barbarab@nchgr.nih.gov	Janice Palumbos 801-581-8943 JPALUMBOS@ped.med.utah.edu
Workshops	Lavanya Misra 212-523-3103	Joyce Bradburn 606-323-5558 jbr@pop.uky.edu
Abstracts	Kathy Steinhaus 714-456-6873 kasteinh@uci.edu	Juliann Stevens 716-878-7530 justeven@ubmedf.buffalo.edu
Communications	Cathy Wuchenich 404-297-1521	
Resource Center	Vivian Weinblatt 215-955-4295 vivian@genetics1.jmp.tju.edu	

Unlock the Secrets of Neurogenetics

A 1 ½ day short course, to be held October 25-26, will provide clinical information about neurogenetic disorders such as ataxias, phacomatoses, neuromuscular and muscular dystrophies, peripheral neuropathies, epilepsy, Alzheimer disease and familial dementias. It will also review terminology, neuroanatomy and neurodiagnostic procedures. For more information, contact:

Chantelle Wolpert	Sharon Smith
919-684-6515	614-722-3540
chantell@dnadoc.mc.duke.edu	SMITH%Genetics%CHI@ALOHA.CHI.OHIO-State.edu

Call for Abstracts

We are please to announce an award program for abstracts. A $250 prize will be awarded for best paper, and a $100 award will be given for best paper based on research carried out while a student.

Members of NSGC, the Canadian Association of Genetic Counselors and the International Society of Nurses in Genetics are invited to submit abstracts for consideration as poster or platform presentations. Students and non-members may submit abstracts with sponsorship. Research on genetic counseling will be given high priority. For more information or assistance in developing an abstract, contact Committee Co-Chairs Juliann Stevens or Kathy Steinhaus (*see above*).

Education Conference Survey

Members Vote . . .

The annual educational conference (AEC) is our one opportunity each year to meet for education and networking. We recently polled the entire membership—including those not attending conferences—to evaluate educational needs and to learn where, when and how the AEC should be held.

Respondent Attributes

Of the 1249 surveys mailed, 46% were returned: 54% of full members completed surveys, 19% of associates and 18% of students. The majority of respondents work full time (78%). The primary area of focus was prenatal genetics for 53%, pediatrics for 16% and specific diseases for 8%.

Among those responding, 30% had 0-4 years experience, 20% had 5-9 years and 31% had worked for 10 or more years. Although veteran and novice counselors are equally represented, these two groups have different educational needs and may have different financial and logistical concerns as well.

Meeting Attendance

NSGC held independent conferences in 1990, 1992, 1993 and 1994. Other than 1993, when NSGC and ASHG met in a different sites, members attended both meetings in similar numbers *(see graph)*.

10% of respondents attended the ACMG conference in 1994 and 12% in 1995. Participants found that conference more clinical and more applicable to their counseling practices. Among those not attending, main reasons cited were lack of funding and not being an ACMG member.

Most respondents (59%) do not plan to change the conferences they typically attend.

. . . to Continue Meeting with ASHG

Funding

For most, funding is a major factor in determining which conferences they attend. Financial reasons kept 41.5% from attending the AEC. 31% of those who did not attend had funding for only one meeting and chose another.

Only 7% of full members had no funding for meetings. A higher number of associate and student members did not have funding. Many noted they must rotate conferences with co-workers or had budgets so limited (under $1000) that they attend meetings only in their geographic areas.

Among those with conference funding, budgets were determined by the number of meetings per year (26%), on an ad hoc basis (16%) or based on their discretion (36%). 4.5% are allowed to attend conferences only if they present.

Conference Logistics

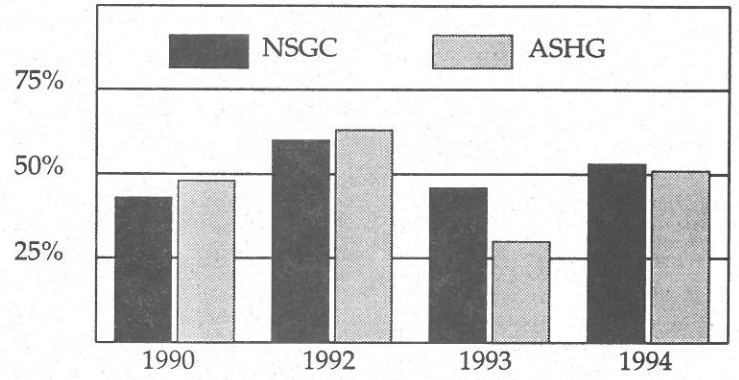
Traditionally, the AEC is held prior to ASHG's annual conference. The survey explained NSGC's increasing difficulties in securing hotel conference and sleeping space for these dates and presented several alternatives.

Most chose to continue meeting with ASHG *(see graph)*. Many cited a financial advantage; among the drawbacks were time needed to attend both meetings, and NSGC's lack of control in negotiating for conference sites. Many expressed interest in rotating between the ASHG and ACMG conferences.

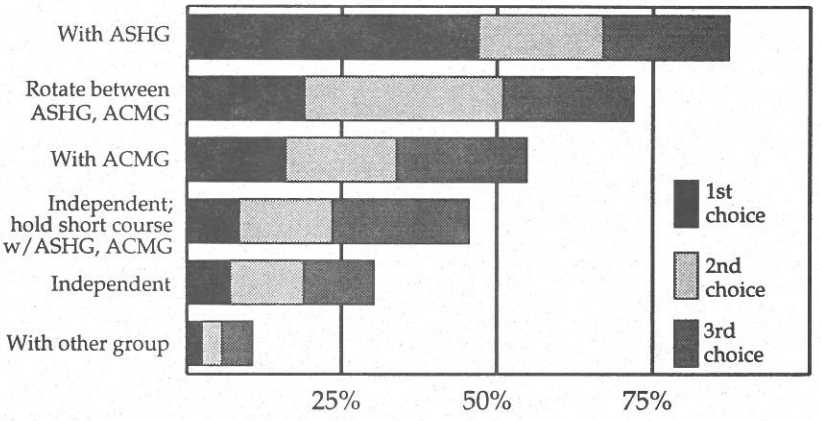
If NSGC continues to meet with ASHG, 40% are willing to convene in a nearby city to defray costs.

This is the first year the AEC has been held following the ASHG meeting. 32% preferred having NSGC's meeting first; 65% had no preference. The greatest concerns were "meeting burnout" and conflicts with holidays.

Meeting Attendance Among NSGC Members



Meeting Preferences



Educational Preferences

The majority attend the AEC for education (72% of full members, 63% of students and 56% of associates). 52% prefer the meeting have a theme—many feel it helps them decide whether to attend, but do not want strict adherence to the theme to exclude other topics.

Most prefer a variety of learning methods. For optimum learning, 43% rated single-topic intensive symposia their top choice, 28% chose didactic lectures and 21% chose workshops.

Short Courses

94% of respondents wanted NSGC to offer short courses, 56% preferring them in conjunction with the AEC and 16% desiring that they be offered in conjunction with regional meetings. A variety of topics were suggested. 46% are interested in the neurogenetics short course be offered prior to the 1996 AEC in San Francisco.

This membership poll provided crucial guidance as NSGC negotiated hotel and meeting space for the 1997 AEC. In addition, we gained valuable insight about how members choose conferences to attend, their learning styles, logistic preferences and interest in short courses. Thanks to all of you who took the time to complete the survey.

Maureen Smith, MS
Chair, AEC Subcommittee

The Prenatal and Childhood Testing Resolution...

A Resolution is Born

Imagine you've been assigned to author an NSGC resolution. You'd thoroughly research the topic and discuss the issue with others well-versed in the subject. As you draft the resolution, you'd try to reflect the point of view of the majority of NSGC members. Hopefully, your desk would be piled high with their comments and opinions.

Three years ago, the Genetic Research Issues Subcommittee of the Social Issues Committee received such an assignment: to develop a resolution about prenatal and childhood testing for adult-onset disorders.

After in-depth research, the working group drafted a statement. Written for genetic counselors, it was intended to encourage families to seek genetic counseling to discuss their needs and the issues surrounding testing.

After incorporating feedback from the Board of Directors, the proposed resolution was presented in the Winter 1994/95 issue of *Perspectives* (Vol. 16, No. 4) accompanied by an article outlining testing pros and cons and inviting member response.

The working group considered the comments received—input from two members—and wrote the final draft. The revised resolution and ballot appeared in *Perspectives* Fall 1995 (Vol. 17, No. 3).

NSGC Members Vote

252 of 1,027 (24.5%) ballots sent to full members were returned: 199 voted to approve the resolution, 29 voted against it and 24 ballots were disqualified because they were postmarked after the October 23 deadline, were torn in the mail or had comments on them.

At October's Annual Education Conference, several members complained they had not received or read *Perspectives* before leaving for Minneapolis. Reviewing the bylaws, the Board of Directors concluded that the narrow time window did not invalidate the vote. (Timing will be carefully considered for future votes, however.)

On a Parallel Track

In September, the NSGC Board of Directors was asked to review the ASHG/ACMG's "Points to Consider" position paper on childhood testing for adult-onset conditions. Comparing the two statements, the Board found no contradictions and voted to endorse ASHG/ACMG's document.

Controversy Erupts

At the Education Conference, a panel symposium about testing children for late onset disorders turned into a forum for discussing NSGC's resolution, with two of the three panelists presenting their criticisms. It was not known in advance that the resolution would be addressed.

Ellen Wright Clayton, MD, JD
The Vanderbilt Clinic, Nashville TN
Education Meeting Panel Symposium Member

I applaud NSGC's interest in defining conditions under which to offer prenatal and childhood testing for adult onset diseases. These are important issues on which the genetics community should speak out. Nonetheless, I have serious concerns about NSGC's resolution, which I outline here in hopes of encouraging further discussion.

My main point is the interests of children receive far too little protection.

- All health care providers have an affirmative duty to avoid harm, which is a real possibility with these tests.
- It cannot be assumed that prospective parents must be informed about and/or offered prenatal diagnosis and testing of children for adult-onset disorders. This sort of conversation is not value-neutral but rather implies that testing is acceptable. Non-directiveness is neither possible nor appropriate in this setting.
- It is difficult and potentially dangerous to talk about prenatal diagnosis and testing of children in the same document because the interests at stake and the choices available to the decision makers are so different.
- Informed consent means making decisions for oneself based on one's own values. Parents necessarily give permission for testing of their children, not informed consent. Children also have a role to play in making choices, which increases as they become more mature.
- One has to wonder why parents who decline testing for themselves may desire testing for their children. There is almost certainly trouble afoot when that occurs.
- The document states "attempts should be made to contact, counsel and obtain permission" from family members whose carrier status would be revealed by testing a child, with consultation by an ethics committee in the event of conflict. That children have no such safeguards demonstrates how little protection they receive in this document.

...Expert Opinions Spark Debate

Without the resolution in front of them, those attending the symposium could neither fully debate the panelists' remarks, nor compare the NSGC resolution to the then unpublished "Points to Consider" document (*American Journal of Human Genetics*, 67:1233, Nov. 1995).

Resolution Revisited

Given the heated discussion generated in Minneapolis, and the limited time members had to review and vote on the resolution, the Board of Directors and the Social Issues Committee are revisiting the prenatal and childhood testing issue.

What do we want to say? Does our resolution express this? Should this be a resolution or a policy paper? If there is enough member support, the resolution can be amended.

To recreate some of the Minneapolis debate, three experts on the childhood testing issue were invited to comment on the resolution. Read their remarks *(pages 8-10)* and share your own opinions. In the next issue, we will publish NSGC members' viewpoints. Let us know what you think!

☛ Send opinions to *Perspectives*, c/o Liz Stierman, 3780 Wilshire Blvd, #410, Los Angeles CA 90010, FAX 213-380-7344, EM: LStierman@aol.com

☛ For a copy of the resolution, call 610-872-7608, #8.

Benjamin S. Wilfond, MD
University of Arizona Pediatrics Department & The Arizona Bioethics Program
Chair, ASHG/ACMG Subcommittee on Genetic Testing in Children

The ASHG/ACMG statement on genetic testing in children was developed by a diverse group participants including pediatricians, geneticists, genetic counselors, social scientists and lawyers. It was endorsed by several other organizations including NSGC, ISONG, CORN, AAP, and AGSG.

NSGC's resolution has much in common with the ASHG/ACMG statement. The congruity between the documents is not surprising considering the input of genetic counselors to the ASHG/ACMG statement. Two of the NSGC statement's authors were consultants to the ASHG/ACMG paper.

Both documents acknowledge that the benefits and risks of such testing are primarily psychosocial and extensive counseling is necessary. Both advocate an individualized approach and recommend such decisions be considered within the context of the family environment. The documents also urge caution in considering such testing and point out providers are not obligated to provide testing just because it is requested.

The NSGC statement differs in two regards. First, different justifications are used to advocate restraint in childhood testing. The NSGC resolution used an argument put forth initially in the context of Huntington disease, based on the preemption of future autonomous decision making when children become adults.

The ASHG/ACMG committee rejected the future autonomy argument because it would restrict too many actions which parents might consider for their children. There may be many things that a child might choose not to do as an adult, but which parents still pursue because they believe it is in the child's interest, such as education, religious training, exercise, diet and visiting relatives. Instead of focusing on future autonomy, the ASHG/ACMG committee based its argument more comprehensively on the child's physical and emotional well-being.

Secondly, while the ASHG/ACMG statement focuses on children, NSGC includes issues related to prenatal diagnosis. The document correctly points to the problem created by making prenatal testing contingent on intent to abort. However, because the moral status of fetuses and children are not considered equivalent by many it is difficult to link them in one document.

Because of our lack of philosophical clarity, it is difficult to address these policy issues jointly. For example, the NSGC document seems to imply that parents should be informed of all prenatal tests that are available, yet simultaneously urges caution for childhood testing. I don't think the authors intend to, on one hand, urge caution for apolipoprotein E4 testing for Alzheimer's in childhood, but, on the other hand, to inform all parents that this test could be done prenatally and then tell them that they should decide if they want to test their fetus.

The point of my comments to is draw attention to the complexity of the philosophical and policy issues and, as a member of NSGC, to ask that the resolution be considered a starting place for further analysis and discussion, in which I would eagerly participate.

LYNN D. FLEISHER, PHD, JD, FACMG
Sidley & Austin, Chicago IL
Chair, ASHG Social Issues Committee 1993-95
Chair, ACMG Social, Ethical and Legal Issues Committee

The NSGC resolution is the most recent of a number of similar statements by professional genetic/medical groups. This fact alone is encouraging, as it bespeaks the serious attention given to this significant issue. Nor do I find it troubling that each group has found its own harmony, different as it may be from the others. Physicians, geneticists and genetic counselors often approach counseling from different perspectives. The lack of absolute consensus is surely no greater than that which must have existed among contributing members of each group. (I speak from experience.)

I find myself agreeing with most of the recommendations in the NSGC resolution. That is not to say that I would not suggest some changes:

- I believe it is inappropriate to consider prenatal testing in the same context as childhood testing. The interests of the parents are different with respect to prenatal testing and the child's interest in autonomy—in my mind a significant (but not necessarily determinative) argument against childhood testing—is moot if prenatal testing is to be followed by termination of positive pregnancies. Testing of adolescents also deserves separate discussion.
- I would delete the first sentence of recommendation #2, which focuses on parental "informed consent" for testing. It sets the wrong tone and provides the wrong emphasis on a critical point—that is, that a decision by the parents to test obviates the right of the child-turned-adult to not be tested.
- I am opposed to the idea of contacting relatives whose carrier status might be revealed by childhood testing and obtaining their "permission" to test—or, for that matter, to consultation by an outside review body in these circumstances. The issue of inadvertent disclosure of a third party's genetic status is not unique to childhood testing, and the duties, if any, that a geneticist may have to such individuals is far from clear.

Let me now address the recommendation that has generated—and will continue to generate—the most debate. The resolution states "It is the role of the genetic counselor to educate and counsel clients about testing, but the decision about whether to proceed must be the parents to make." In the final analysis, I must agree. To take any other position would fly in the face of cumulated years of counseling experience.

We must inform patients about all available options and educate them as to the ramifications those options may have in their families' circumstances. We must assist parents in making decisions that benefit their children and families. But we cannot make those decisions for them. Except in the most egregious circumstances, the law continues to recognize that parents are the most appropriate decision makers for their minor children. This is based on the presumption that parents' love and concern for their children's well-being will inform and guide their decisions. Similarly, we must presume that, if properly informed, parents will make appropriate decisions for their children. As professionals, our obligation is to provide information and facilitate understanding—not take the easy way out by failing to raise the issue. Above all, we must refrain from indulging in the hubris that would lead us to believe that we always know best.

CYBERGENES

LISTSERV

We are starting an NSGC listserv, which should be up and running in early 1996.

A listserv is a program that operates a mailing list. A user sends an e-mail message to the listserv, which then forwards it to everyone subscribing to the list.

SO WHAT I AM SUPPOSED TO DO WITH A LISTSERV?

Once it is operational, everyone will receive a special e-mailing with instructions about how to use the listserv, correct addresses and type of messages that can be sent.

Messages received each day will be combined and broadcast as one daily digest message. The digest will contains only messages—you won't have to scroll through a list of recipients' names. Messages should be concise, succinct, pithy, laconic and direct (it would also help if they weren't too wordy) to make it easier for recipients to determine if a message is relevant.

Any NSGC member can subscribe to the listserv. If you wish to be removed from the list, you can "unsubscribe," sending a message deleting your name. You can also unsubscribe temporarily—this prevents a flood of mail when you return to the office after an extended absence.

E-MAIL UPDATE

We now have 240 members with e-mail. If you want to receive NSGC e-mail, send a message to Jeff Shaw (JShaw@wln.com).

Also, we are looking for individuals to help work on our World Wide Web home page—no experience is necessary. Contact me if you're interested.

Steven Keiles, MS
Steven.Keiles@kp.org

Bulletin Board

Summer Institute

The University of Puget Sound will conduct a Summer Institute, "Scientific, Ethical and Social Challenges of Contemporary Genetic Technology," July 7-Aug 2. Lab exercises will complement discussions about issues raised by genetic technology. Supported by the National Endowment for the Humanities and the National Science Foundation, 25 participants will receive a stipend of $1000 and an allowance for room, board and travel. Application deadline is **March 1, 1996.**

☛ Contact: David Magnus, Institute Director, Phibbs Prof. of Ethics and Science, Univ of Puget Sound, Tacoma, WA 98416, 206-756-3508, EM: dmagnus@ups.edu

Genetics Web Site

If you can access the World Wide Web, visit the new home page for genetic professionals created by Debra Collins. Type the address exactly; letters are case sensitive:

http://www.kumc.edu/GEC/prof/geneprof.html

Cancer Video

Videotapes of OncorMed's recent conference "Applying Molecular Genetics to Cancer Detection & Management: An Update for Clinicians," are available for viewing at no charge. The conference covered BRCA1, melanoma, HNPCC and presymptomatic testing issues.

☛ Contact Joan Scott, MS, OncorMed, 205 Perry Parkway, Gaithersburg MD 20877.

Developmental Disabilities Guide

Rainbow of Hope, a 192 page resource guide, was developed for parents and caregivers of children with developmental disabilities. Normally selling for $12.95, it is available to NSGC members for $5 shipping and handling.

☛ Write Toby Levin, 4000 Island Blvd, N. Miami Beach FL 33160.

Calendars Available

The Indiana Down Syndrome Foundation is selling a 1996 calendar, "Down Right Beautiful"—proceeds will benefit organizations serving families. The wonderfully photographed calendar includes accurate information about Down syndrome.

☛ Cost: $14.95 + 5% tax + $3 S&H. To order, call 1-800-792-6099.

Hang a Poster!

Help distribute the new genetic counseling recruitment poster *(see page 4)*. Display them in college biology departments, career offices or other sites where undergraduates potentially interested in genetic counseling may see them.

☛For copies, contact Troy Becker, 402-559-7560, EM: tbecker@unmc.edu

Study Group Forming

Anyone in the Baltimore/Washington Metro area interested in forming a study group to prepare for the boards? We have flexible schedules and are willing to rotate meeting sites.

☛ Contact Carmella Sarneso, 202-884-4167, EM ctifft@gwis2.circ.gwu.edu

Upcoming Meetings

February 16-17	CORN Conference, "Genetic Services: Developing Guidelines for the Public's Health," Washington DC. Contact Cynthia Hinton, 404-727-4549.
March 11-14	Joint Clinical Genetics Meeting of the American College of Medical Genetics and March of Dimes, San Antonio TX. Contact: 301-530-7127.
March 27-30	Region VI Education Conference, Asilomar CA. Contact: Karen Wcislo, 408-972-3306.
March 28-30	Region IV Meeting and Great Lakes Regional Genetics Group Annual Meeting, Kansas City MO. Contact: 309-695-7436.
March 29	Region I Conference, "Religious and Spiritual Influences on the Genetic Counseling Encounter," Waltham MA. Contact: Kathryn Spitzer Kim 617-736-3108.
April 28-30	Human Teratogens Course sponsored by Harvard Medical School & Massachusetts General Hospital, Boston MA. Contact: 617-432-1525.

NSGC Goodies for Sale

Did you get cash as a holiday gift? Here are some ways to spend it:

- **Job Search Manuals** developed by the Professional Issues Committee are available for $2 plus 75¢ P&H. Discount on larger orders.
- **Syllabus Binders** from the Minneapolis Conference are $15; $20 including conference tote bag.
- ***Perspectives* Binders** for organizing back issues are $20 a set. They aren't dated, so you can begin your collection with any year.
- ***Perspectives* Index:** Those who already own binder sets will soon receive the index for Volume 17.

☛ To order, call 610-872-7608, #8.

FAX/E-mail poll

For Inspiration, Guidance, Support: Thank You Mentors

Last fall, we asked about your mentors. The response was overwhelming—so many stories we couldn't print them all in this issue. Here is a sampling:

■ I am the only genetic counselor ever trained by the University of Virginia. Two counselors there, **Pat Schnatterly** and **Mary Anne Shires**, gave me very different insights into the field and showed how different styles of counseling can be effective. They gave me the background and courage to go to a community hospital where I was the first genetic counselor.

Working alone, I looked statewide for peers and advice. **Marna Barrett** introduced me to the wider genetic counseling community. She encouraged me to get involved in NSGC, even signing me up for the Education Conference planning committee. Thanks Marna—ten years later, I am Co-Chair of the '96 meeting. Now I follow Marna's example and mentor others to become involved in our field.

Lisa Amacker North, MS
Charlotte NC

■ I still think of the lessons **Elsa Reich** taught me as a Sarah Lawrence student almost 12 years ago. She helped me learn the art of listening and valuing each family as having unique concerns. I remember being particularly sad about the fate of one family I saw and asking Elsa when you no longer feel like crying as a genetic counselor. She told me the day you no longer feel like crying is the day you should leave the field. Her words have helped prevent me from burning out and maintain my enthusiasm for genetic counseling.

Robin L. Bennett, MS
Seattle WA

■ My mentor was **Gladys Rosenthal** at Strang Cancer Prevention Center in New York. Gladys taught me the ropes of cancer counseling, the politics of large institutions and the need to be very diplomatic and flexible. This spring I applied for a cancer counseling position—with the help of Gladys' glowing recommendation I got the job. I will be forever grateful to a lovely woman who gave me a chance to learn the ropes. Thanks Gladys!

Jamie L. Dann, MSc
Kingston, Ontario

■ We both met **Tillie Young** when we were students, and chose to return and work with her as soon as the opportunity arose. Tillie is a wonderful teacher, role model and, more than anything else, a treasured friend. She is extremely dedicated to her patients, her colleagues and genetic counseling.

Caroline Lieber, MS
Robin Wolf, MS
Hackensack NJ

■ I offer heartfelt thanks to **Seymour Kessler** for being able to "see more" in me: that he recognized my flaws made his praise more credible; that he had faith in me despite my weaknesses helped me build confidence in my strengths. He taught me to trust my instincts but also to examine them, to better understand why and how genetic counseling works.

My current boss, mentor and dear friend, **Sonja Bentley**, is a wise woman in all regards—she's guided me through difficult times both at work and in my personal life. A born diplomat, she's given me valuable, practical insight into dealing with others. Most important, she taught me it's okay to make mistakes, as long as you recognize and learn from them, and work to make matters right.

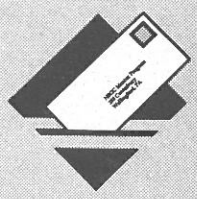
Liz Stierman, MS
Los Angeles CA

More commendations for our mentors will appear in future issues.

New Mentoring Program Links Experienced and Novice Counselors

NSGC's Membership Committee is developing a Mentorship Program to connect practicing professionals with students and recent graduates. Participants in the program are asked to make at least four contacts over six months. The program is flexible, with the content determined largely by individual personalities and interests. Mentors and students may exchange ideas and information ranging from common personal background to recent topics in genetics. Mentors can help make contacts within the field, provide insight into different employment situations and offer support and guidance in the job search process.

☛ To be a part NSGC's mentorship program, fill out and return the enclosed postcard by **January 22**. Those expressing interest will be sent a questionnaire later to assist in making the best possible match.



continued from page 1

Mentors

Mentors may assist new graduates in their transformation to full professionals. Students of the University of Wisconsin-Madison training program recently participated in a pilot mentorship project in which they were paired with program graduates. All students chose to participate, looking for help seeking jobs and information about unique work settings.

But benefits go beyond locating jobs. Says one counselor, "I was fortunate to develop a relationship with someone outside my program who provided me with insight and connections to opportunities in the part of the country where I was interested in working. She did a great deal to boost my confidence in my developing skills. Even though I was a student, she always treated me like a colleague."

Benefits For Mentors

Although motivated by a desire to nurture fledgling counselors preparing for the "real world," mentors reap rewards as well. They keep up-to-date on topics being taught in training programs, refine their teaching skills and develop friendships with future colleagues. Mentoring may rekindle their own excitement for the field.

"It is gratifying to share my experience with others in hopes of making their road to becoming a genetic counselor a little easier," says one mentor. "On those days when the paperwork is backing up and hospital politics seem to have gotten the best of me, a future colleague's enthusiastic question reminds me again of all the reasons why I love this field."

Genetic counseling is a profession rich in history and expertise. Mentoring will help shape its future.

Resources

■ Pamphlet ■

An Abortion For Love: Notes from a Friend

By Susan E. Hodge. Omaha NE: Centering Corporation (phone 402-553-1200), 1995. 16 pages. $3.10.

Working as a prenatal genetic counselor for over 11 years, I have seen many families go through the experience Susan Hodge describes in her very personal pamphlet, *An Abortion for Love.* Dr. Hodge, a geneticist, uses excerpts from her journal to describe the inner process before, during and after an abortion due to prenatally diagnosed abnormalities. Interspersed with the journal entries are the author's present day comments emphazing the potential for hope and growth through this experience.

Dr. Hodge gives an open, honest account of her responses yet also stresses the uniqueness and validity of other reactions. As she takes the reader through the days, weeks, months and years following her abortion, you begin to grasp the breadth and depth of the impact this tragedy makes on a woman and her family.

Those new to prenatal genetics or any medical professional whose patients undergo prenatal testing would do well to read this booklet before giving an abnormal result. It is also a useful resource for patients. Most of the emotions and reactions Dr. Hodge describes have been noted by my patients over the years as well. Sometimes, just knowing someone else has the same thought or fear can be helpful to a person in emotional pain. A woman could share this pamphlet with her partner to help explain her thoughts when words themselves are too difficult.

A Patient's Viewpoint

I asked a woman who has been down this same path to review the pamphlet. She started a pregnancy termination support group and wrote a patient pamphlet several years ago to fill the void she found following her experience. She was more hesitant in her recommendation; her comments follow:

"Well, I had difficulty reading *An Abortion for Love.* Ah yes, it must be time for my own grief to recycle. Although it is much less intense, it nevertheless requires my attention from time to time.

"I think it is beneficial for geneticists and genetic counselors to read—to be confronted with the depth of grief and anguish. I have some ambivalence about distributing it to patients. For some, it may be helpful to know that one is not alone. For me, I found it too wordy. When I am in intense grief, I can't sit and read a lot—after all, my eyes are pretty irritated already.

Terminology Troubling

"On a personal note, I had a negative response to the use of the word 'abortion' rather than 'termination'— it conjures up all the conflict and confrontation of the anti-abortionists. 'Abortion' seems to emphasize the process—which can occur intentionally or spontaneously—whereas 'termination' seems to focus on the outcome and occurs as the result of a deliberate decision."

Perhaps genetic counselors should provide patients a variety of resources in this sensitive area, allowing them to use those which are most personally helpful.

Karen Copeland, MS
Austin TX

Resources continue on page 16

Student Page

Student Workshop: Advice, Mentors, Jobs

Nearly 70 students from 15 programs attended a workshop designed by and for students at October's NSGC conference.

Participants heard words of advice from five professionals representing different counseling careers: Barbara Bowles Biesecker, Nancy Adams, Ken Loud, Beth Balkite and Chantelle Wolpert.

They also learned about the new NSGC mentor program, following the University of Wisconsin's successful model (*see articles on pages 1 and 12*). Almost unanimously, students thought mentors would be beneficial, especially if in geographical areas where they hoped to move. A mentor could answer questions about cost of living, patient populations and help the student begin networking with other counselors in that area.

During the second hour, students voiced their opinions and concerns. In particular, students felt confused about the American Board of Genetic Counseling examination; many are undecided about taking the 1996 exam. Genetic counselors and program directors vary about whether the test should be taken so close to graduation. Students with questions about the exam should speak to other genetic counselors, program directors, other students and the ABGC.

The current job market was another main topic of discussion. Many feel today's market is reminiscent of years ago, when genetic counseling first began to grow. We realize we must be innovative in our search for jobs, marketing our profession as well as our personal skills. Kelly Connerton-Moyer and Kirstin Finn presented their thesis project on issues students face when searching for a new position.

We found a need for better communication between students, as well as between students and NSGC. We encourage those in their second year to talk to new students about NSGC, as many were unaware of the organization and its membership benefits. We suggest student liaisons from each program work with the NSGC to ensure exchange of information and ideas.

The workshop was a successful start for student networking. We hope next year's students will plan a similar workshop for the meeting in San Francisco.

Ann Brauti
University of Minnesota

Therese Kessel
Sarah Lawrence College

Summer Internship

The North Carolina Medical Genetics Association offers a summer internship in one NC medical center each year. Funded by a $500 stipend, the 6-week internship is open to students with one year of genetic counseling training. This year's placement, at East Carolina Univ School of Medicine in Greenville, includes pediatrics/clinical genetics, prenatal diagnosis and outreach clinics in eastern NC. Interested students should contact:

Ginny Vickery, MS
Jean Hood, MD
919-816-2525

ECU School of Medicine
3E-140 Broady Building
Greenville NC 27858

ABGC Update

At its annual Business Meeting in Minneapolis, the American Board of Genetic Counseling announced the election of Janice Edwards and Patricia Ward to the Board of Directors. They will replace Ann Walker and Ann Smith, who complete their terms of office December 31. The following officers were elected by the Board to begin terms on January 1, 1996:

- Virginia Corson, President
- Beth Fine, Vice President
- Judith Benkendorf, Secretary
- Patricia Ward, Treasurer.

The Accreditation Committee approved two additional programs for Recognized New Program Status:

- Mt. Sinai School of Medicine
- University of Arizona.

The Credentials Committee has been reviewing applications for the 1996 examination. Postmark deadline was December 31.

ABGC
Administrative Office
9650 Rockville Pike
Bethesda MD 20814-3998
301-571-1825

E-mail Discussion Group

To subscribe to the genetic counseling students' e-mail discussion group, send an e-mail message to:

list serv@indycms.iupui.edu

Leave the subject line blank. In the body of the message type:

subscribe pzandqz your name

Put your first and last name in the message; do not type in your user address.

■ EMPLOYMENT OPPORTUNITIES ■

■ *These classified listings represent the most recent additions to the NSGC JobConnection service. Members and students interested in complete or regional information may receive a computerized printout, at no charge, by calling 610-872-7608 Mailbox #2. Printouts are mailed on the first and third Monday of each month. This service is strictly confidential.*

NEW HAVEN CT: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Varied PN counseling & consultation with patients & physicians.
CONTACT: Miriam S. DiMaio, MSW, Dept Genetics, Yale Univ School of Medicine, 333 Cedar St, New Haven CT 06510; 203-785-2661. EOE/AA.

BOSTON MA: Immediate opening for Genetic Associate with Masters in GC or related field; exp pref, not required.
RESPONSIBILITIES: Busy PNDx program: molecular DNA diagnostic program, involvement in MSAFP; research oppty available.
CONTACT: Aubrey Milunsky, MD, Center for Human Genetics, Boston Univ School of Medicine, 80 E. Concord St, Boston MA 02118; 617-638-7083. EOE/AA.

HELENA MT: Immediate opening for BC/BE Genetic Counselor in Dept of Medical Genetics.
RESPONSIBILITIES: Pediatric & adult general genetics; outreach clinics, incl svcs to Native Americans. Fetal pathology, PN screening & diagnosis. Approx 50% time in clinical & educational aspects of FAS program. Oppty for professional & public education & contribution to program development.
CONTACT: Rick Harden, Human Resources, Shodair Hospital, PO Box 5539, Helena MT 59604; Phone 800-447-6614; Fax: 406-444-7536. EOE/AA.

BUFFALO NY: Immediate opening for BC/BE Genetic Counselor with demonstrated exp in cancer genetics & familiarity with computers.
RESPONSIBILITIES: Join active clinical, research, cytogenetic & DNA diagnosis expanding group: identify cancer families, describe cancer genes and phenotypes for diagnosing disease, organize registries & databases, counsel CA patients & families; conduct genetic studies.
CONTACT: Nicholas J. Petrelli, MD, Dept Surgical Oncology, Roswell Park Cancer Institute, Elm & Carlton Streets, Buffalo NY 14263; 716-845-8983. EOE/AA.

GLENS FALLS NY: Immediate opening for full or part-time Genetic Counselor.
RESPONSIBILITIES: Join multi-disciplinary cancer team: development & implementation of cancer genetics program; GC services, assist in community behavioral research re: genetic testing; Center associated with Vermont Cancer Ctr.
CONTACT: Patricia Gavin, RN, MS, The Cancer Center at Glens Falls Hospital, 100 Park St, Glens Falls NY 12801; 518-761-5310. EOE/AA.

PITTSBURGH PA: Late '95-Early '96 opening for BC/BE Genetic Counselor. Counseling exp in adult & PN genetics, incl cancer, desirable; interest in molecular basis of disease essential.
RESPONSIBILITIES: Primary liaison to clients of large, growing Molecular Diagnostic Lab testing for inherited disease.
CONTACT: Dr. David Cooper or Ralph Anderson, Div Molecular Diagnostics, Univ Pittsburgh Medical Center, 7-Scaife, 3550 Terrace St, Pittsburgh PA 15261 DC: 412-648-8519; RA: 412-648-9113. EOE/AA.

COLUMBIA SC: Immediate opening for BC/BE Genetic Counselor. CV & 3 ltrs of recommendation req.
RESPONSIBILITIES: Coordinate SC regional NTD Prevention Initiative: PN GC for all facets of high risk pregnancy management; participate in MS GC Program & other education, research, service activities.
CONTACT: Janice Edwards, MS, University South Carolina School Medicine, Dept Obstetrics & Gynecology, Two Medical Park, Columbia SC 29203; 803-779-4928. EOE/AA.

SALT LAKE CITY UT: Immediate opening for Nurse Educator/ Genetic Counselor with BS in nursing, GC or health ed req & MS pref. Working knowledge of genetics, genetic testing, excellent communication skills req; exp in clinical oncology/ health educ pref.
RESPONSIBILITIES: Join genetics team in expanding diagnostic division.
CONTACT:Barbara Berry, Myriad Genetics, 390 Wakara Way, Salt Lake City UT 84108; Fax: 801-584-3640. EOE/AA.

SALT LAKE CITY UT: Immediate opening for BC/BE Genetic Counselor. Experience pref.
RESPONSIBILITIES: All aspects of reproductive genetics: PNDx, BR/ovarian cancer, molecular diagnostics, PN gene therapy. Oppty for research & professional development in University setting.
CONTACT: Jamie McDonald, MS, University of Utah, 50 No. Medical Drive #2B200, Salt Lake City UT84132; 801-581-7825. EOE/AA.

national society
of genetic
counselors, inc.

nsgc

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Virginia Corson MS
Johns Hopkins Hospital
CMSC 1001
Baltimore MD 21287-3914

Resources, continued

■ Book ■

MAPPING FATE

By Alice Wexler. New York: Times Books Random House, 1995. 294 pages, including notes on sources. $23.

"He knew that his fate was written in Melquiades' parchments...he began to decipher them aloud. It was the history of the family, written by Melquiades, down to the most trivial details, one hundred years ahead of time."

Interspersed with quotations from Gabriel Garcia Marquez' *One Hundred Years of Solitude*, Alice Wexler's book, *Mapping Fate*, is a nicely told tale of her family's history and how it was affected by the Huntington disease (HD) gene. Ms. Wexler has written an interesting, accessible account of a significant medical achievement.

As a historian, she states she needed to document the medical history of the HD gene and the emotional meaning of being at risk. She takes the systematic approach that biology is not fixed and unchanging in its meanings, which are partly shaped by its social, political and cultural contexts. Her book chronicles how her family's biology and the social movements of the 1950s and 60s, especially the rise of feminism, impacted the family dynamics.

Alice and Nancy Wexler are sisters whose lives are intimately tied to HD. Their mother, her four brothers and her maternal grandfather were all affected. But the diagnosis was a family secret, leaving the family unaware and unprepared when HD struck. As their mother showed early symptoms, misunderstanding about her behavior caused marital problems, alliances of the daughters with different parents and disruption of family life.

A MEDICAL BREAKTHROUGH

Telling how the HD gene was identified and the family's involvement in the project is one of the book's major strengths. Nancy and her father established the Hereditary Disease Foundation, sponsoring scientific brainstorming forums to find strategies to treat HD and then funding these strategies. Nancy was directly involved in the research with HD families in Venezuela.

Ms. Wexler offers a clear, understandable explanation of classic and molecular genetics. She presents a very readable account of her family and the distortion caused by HD although she does not always deliver on her promise to tie in the feminist angle or her own psychological adjustments. She makes good arguments for society to develop a more comprehensive, supportive system for families as well as a national health care policy to address the needs of those with chronic illness.

Mapping Fate is excellent for a many audiences. For the general public, it describes the impact of chronic illness on a family. For scientists, it personalizes the disease. For other families with HD, it inspires and reinforces that they are not alone.

Judy Garza, MS
Rochester NY