PERSPECTIVES in genetic counseling

Volume 23 Number 4 Winter 2001/02

national society of genetic counselors, inc.

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

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NSGC gratefully acknowledges Athena Diagnostics, Worcester, Massachusetts

for a generous grant to support this newsletter.

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athena diagnostics

The Genaissance Agreement

A LOOK BEHIND THE SCENES

Liz Stierman, MS

At the open mike session at the Annual Education Conference, several members expressed concern about NSGC's business relationship with Genaissance, an emerging, publicly-traded pharmacogenetics company. Some commented that the process had been shrouded in secrecy. To help address this matter, here is a timeline of the events leading up to the agreement.

February 2001: NSGC Executive Director, Bea Leopold, was contacted by a Genaissance representative exploring possible alternate roles for genetic counselors (GCs) in conjunction with a new product they are developing. Given the competitive nature of pharmacogenetics technology, they asked Bea and NSGC President, Vivian Weinblatt, to sign confidentiality agreements before they would disclose any details about the product and the process. This standard agreement allows us to share privileged information without the fear that either party would use that information to compete with the other.

March 2001: Genaissance asked to present more details to the Board of Directors (BoD) at the interim meeting in April. The treasurer conducted a background-check on the firm and its financial standing. The President-elect toured the facility and reviewed the company's scientific basis.

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LICENSURE: SIMPLE SOLUTION OR PANDORA'S BOX?

Angie Trepanier, MS

Licensure has been a topic of considerable interest and discussion amongst genetic counselors over the last several years. With the passing of genetic counselor licensure legislation in two states, the momentum is building. But what exactly is licensure? What are the pros of establishing a professional license? …and the cons? How will it help us do our jobs?

To address some of these questions and to stimulate discussions between geneticists and genetic counselors, Dr. Howard Smith was invited to speak on licensure at the joint Southern Genetics Group and Southeast Regional Genetics Group (SERGG) conference in Hilton Head this summer. Dr. Smith, Senior Director for Professional Affairs, American Counseling Association (ACA), has watched and participated in the nationwide licensure

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President's Beat

A new year has begun; always a good time for reflection and new resolve.

My term as President began with the wonderfully successful Annual Education Conference in Washington DC in November. Despite all the fear and violence in the news this past Fall, over 1000 people attended our meeting, breaking all previous attendance records, truly a testament to the dedication of our membership — and the very strong program that had been planned and executed.

There is always a special kind of energy at our Conference, but this year seemed to be especially poignant as we talked shop with colleagues, listened thoughtfully to excellent speakers and reconnected with old friends. Informal conference discussions also reaffirmed the strong personal commitment and passion each of us has for and about NSGC. I believe that passion is what makes our organization so special and ensures that our successes will continue.

Goals and Challenges

Board members provide the president with lists of goals that they hope to accomplish over the next year. Here are the projects I am working on:

- Strengthening our presence and clout in Washington DC.
- Identifying new strategies for increasing our membership.
- Increasing our visibility among consumers, hospitals and insurers.
- Exploring ways of standardizing our educational and counseling efforts.

Thanks in large part to our members' activities and voice on behalf of NSGC, your Board of Directors was able to approve an ambitious budget of nearly $1 million for next year, another landmark event in the history of our organization! We also approved acceptance of credit cards online. As we go to press, our webmaster is working on making that happen. Activation will be announced on our listserv, or you can check our website periodically for the link.

Being President is proving to be both challenging and rewarding. With the help of the Board, the Executive Office and each of you, I look forward to working with you and to all we can accomplish together this year! ❖

Katherine A. Schneider, MPH
President, 2001-2002

NSGC - Genaissance Contract Details

The final Genaissance contract approved by the Board included these provisions:

- Genaissance donates $25,000 to NSGC's conference as a corporate sponsor.
- NSGC appoints a working group to meet with Genaissance up to three times a year to "share ideas and information about various avenues for using GCs to provide counseling services to consumers relating to the results of tests and for educating the public and physicians about the availability of such opportunities."
- Genaissance owns the intellectual property expected to come from the working group sessions: feedback on the business model, an outline for developing educational materials and guidelines for using GCs as service providers.
- NSGC does not endorse the product nor authorize use of its name in promoting the product.
- For one year, the BoD and working group members agree not to disclose any confidential or proprietary details to other parties. NSGC agrees not to provide input to Genaissance competitors developing a similar product. ❖

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The opinions expressed herein are those of the authors and do not necessarily reflect those of the editorial staff or NSGC.

Next issue ***March 15***
Submission deadline ***February 10***

THE GENAISSANCE AGREEMENT, *fr p. 1*

April 2001: Major themes of the interim BoD meeting were funding for big-budget items — such as marketing and the eventual move of the Executive Office —without raising dues. Another major discussion was about partnering — collaborating with businesses to achieve complementary goals.

Representatives from Genaissance presented the company's research and ideas for delivering the new technology with the help of GCs. They invited NSGC to provide input as they develop marketing plans — including how the product would be presented to consumers and medical professionals. In particular, they wanted to explore if and how GCs might become integral in the delivery system of their product(s). The BoD voted to consider any formal offers they might make.

June 2001: Genaissance submitted its proposal offering NSGC an opportunity for input on "marketing methods which are aimed at including GCs as an important part of genetic information interpretation for consumers."

June - August 2001: Our attorney (an expert in association law) reviewed the proposal and found no conflicts with NSGC's bylaws, Code of Ethics or Business Association Guidelines. The BoD had lively, protracted discussions via email about the pros and cons of the proposal.

In addition to adding non-dues income, identified benefits were:

- Being recognized as "players at the table."
- Having the opportunity to shape a new specialty area.
- Having a chance to develop new roles — and jobs — for GCs.
- Being proactive rather than stuck cleaning up the mess later!

Many questions were also raised:

- What exactly is expected of us?
- Does this mean Genaissance can use our name in their marketing?
- Will a partnership with a biotech company tarnish our reputation?
- Does the exclusivity clause limit members from working for Genaissance's competitors?
- Are there better opportunities for partnering with other companies? In the spirit of fairness, should we approach other firms?
- Should we get input from specific members (those who work in pharmacogenetics) or the membership at large? Will this violate our confidentiality oath?
- What will our members think about this alliance?
- How much can we tell our members at this point?

Our attorney helped clarify many of the issues, and revised the contract to address our concerns. The exclusivity clause was designed to protect privileged information; in no way does it prevent NSGC from obtaining funds from other corporate sponsors nor does it mean that NSGC members cannot work for competing firms.

To educate our members, articles on partnering appeared in both Summer and Fall issues of *Perspectives*. Because of concerns about confidentiality, the name Genaissance was not mentioned and details of the alliance were kept non-specific.

August 2001: Prior to the final vote, our attorney was again asked to review the contract specifically to address conflict of interest and ethics concerns. She again saw no conflicts, commenting, "It is very common for non-profit organizations to provide consulting assistance to for-profit companies. The services are not considered unethical by the non-profit or the business communities."

August 2001: Invitations were sent to various NSGC members to participate in the Genaissance task force. Vivian Weinblatt made appointments based on profiles requested by Genaissance to get a well-rounded group representing a variety of perspectives. Genaissance agreed to reimburse participants for their time and travel expenses.

October 2001: The first task group meeting was held. A key point discussed was our discomfort with the level of secrecy involved. Genaissance clarified their position: they have no problem sharing with NSGC members their name and the nature of their business as long as no proprietary details about their business plan are divulged. Much of the meeting was spent educating Genaissance about what GCs traditionally do and our professional "culture." At the end of the meeting, Genaissance said that NSGC's obligation had been fulfilled but offered members the opportunity to continue working with them as private consultants.

In retrospect, the BoD realizes we may have been over-scrupulous in our interpretation of confidentiality and regrets that more details weren't shared with members. We learned that directives such as our Business Association Guidelines need to be reviewed and possibly updated to be relevant in today's changing business climate. At all times, however, we acted with members' best interest in mind. ❖

☞ Letters to the Editor on this issue are welcome: berlinjl@umdnj.edu

LICENSURE: PROS AND CONS, *fr. p. 1*

efforts of Master's and PhD-level counselors.

BACKGROUND

Legislators and the state licensing departments are primarily interested in protecting the public from harm when considering licensure legislation. In the absence of licensure, clients have no way of knowing if genetic counseling has been performed by an adequately trained professional.

LICENSURE V. CERTIFICATION: SORTING OUT THE DIFFERENCE

According to Dr. Smith, licensure is based on the legal concept of 'police power' of a state. "The state has the right to pass laws and to take such other action, as it may deem necessary to protect the health, safety and welfare of its citizens."

In contrast, a certification is based on the voluntary action of a professional group to institute a system by which it can grant recognition to those practitioners who have met some defined level of training and experience. Certification is not a practice credential, it is a professional one.

PROS

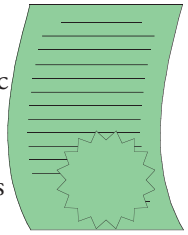
Licensure affords many benefits:

- Assures quality counseling services.
- Establishes a requirement for continuing education.
- Establishes a way to invoke disciplinary action for malpractice or unethical conduct.
- Establishes consensus practice standards.
- Sets standards for professional recognition.
- May set the stage for obtaining reimbursement for genetic counseling services.

CONS

Conversely, caution must be noted because licensure may:

- Be expensive.
- Be difficult to enforce.
- Restrict geographic mobility, as one state may not recognize another's license.



- Restrict the number of practicing genetic counselors in a given state if not all are able to obtain licensure, thus decreasing access to genetic counseling services.

An example for the genetic counseling profession: most licenses require passing an examination. Both Utah and California recognize the ABGC certification examination as the test required for licensure. If ABGC certification is the standard set by other or all states, will new graduates be unable to obtain licensure until they pass the ABGC examination, creating a delay in employability of up to three years? Probably not. Both the California and Utah licensure legislation includes provisions for issuing temporary licenses until new graduates can sit for the ABGC examination.

KEY ELEMENTS

In seeking licensure, protecting the public must be the primary stated goal when lobbying legislators to gain favor for licensure. Counselors must also be educated about the legislative process.

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CARRIER SCREENING...

Beth Rosen-Sheidley, MS

GATEKEEPERS OR EDUCATORS?

Due to recent research advances, it is now possible to determine carrier status for nine recessive conditions that occur with increased frequency among Ashkenazi Jews. Currently position statements exist for only three of the diseases.

How do we as genetic counselors decide which tests to offer to our patients? While it is true that policy should be set by the broader medical genetics community, we once again find ourselves caught between the emergence of new diagnostic capabilities and a dearth of ethically and medically sound guidelines to follow. Although many of us may have policy set by the institutions in which we work, a significant number of genetic counselors may be left to determine which tests are appropriate.

It is tempting not to offer certain tests because the carrier rate and risk for disease are relatively low. But we all have had patients who have read about the availability of tests in the newspaper or who have a friend whose child was born with a disease.

PONDERING OUR RESPONSIBILITY

- If we insist on educating patients about the "low risk" and encourage patients not to pursue testing, are we being overly directive?
- If we agree to offer testing only when patients request it, are we then providing a different standard of care?
- If we have a population that can be identified as being at higher risk, and the detection rates are over 99%, can we ethically withhold information?

...Do We Use it Just Because We Have It?

Sorting Out Our Role

Counselors who regularly see Ashkenazi patients often complain that they feel like salespeople and that their patients are overwhelmed by being offered tests that they had not anticipated. In some situations, such as the identification of a lethal fetal anomaly on ultrasound, it may not be appropriate to address the availability of screening. In most situations, however, it is possible to bring up the issue in a way that is respectful and does not leave the patient feeling assaulted with unwanted information. It is particularly important, when patients are referred for other reasons, that screening not be made the focus of the session. Counselors need to avoid providing a litany of facts, figures and excessive details about disease manifestations. In some instances, it may also be important to discuss why so many screening tests are available for Ashkenazim, many of whom may still bear the ancestral psychological scars from World War II.

Beginning the Dialogue

Ideally, patients would be referred for or would seek genetic counseling either prior to or early in pregnancy. In such situations we can raise the issue of ethnicity-based screening and offer follow-up counseling for a more in-depth discussion. Unfortunately, most patients present for counseling on the day of their amniocentesis procedure. A full bladder and high anxiety about an unknown procedure are hardly a good recipe for thoughtful decision-making about unexpected test options.

A meaningful first discussion should at least include the principles behind ethnicity-based screening; providing written materials allows patients to explore the options on their own.

In the end, it should be the patient who decides which tests to pursue. If we take this approach, we leave behind the undesirable role of gatekeeper and take on once again the role of educator and counselor. ❖

Addressing Priorities

Ed Kloza, MS

The existence of a screening test is not justification for offering it. Most patients referred for genetic counseling present for a specific reason: screen positive maternal serum screening test, maternal age, exposure to a suspected teratogen, etc. The principal focus of a genetic counseling session should be to address the issue prompting the referral. Beyond that, additional investigation is *opportunistic*, i.e., as long as the patient is there, why not apply a few additional appropriate screening inquiries?

If the reason for referral is Ashkenazi ancestry, the implication is that risk identification and management is the priority. However, the referring provider may not consider any risk beyond that for Tay-Sachs disease. Is it the duty, then, of the counselor to discuss other detectable disorders? Probably, but I would argue that except for well-established tests, the counselor is not obligated to detail each and every test that may be available unless the patient specifically requests or consents to such a discussion. Introducing unwanted, additional anxiety may not be to the patient's advantage. Unless there's some knowledge of the patient's interest in such discussion, the counselor runs the risk of engaging in an unappreciated dialogue, possibly diminishing the counselor's credibility.

Beginning the formal counseling session with a review of the goals of both the counselor and counselee, i.e., addressing priorities and advising that other testing opportunities may be available, could be a reasonable approach. This also addresses the distinction between *offering* a test and making a test *available*. By virtue of their Ashkenazi Jewish ancestry and the history of Tay-Sachs, CF and Canavan testing, these tests could be offered.Then the patient could be told about the availability of additional tests for (perhaps) rarer disorders. Offering some tests and making others available is not necesarily directive as long as there is a reasonable basis for doing so. Implying that all tests available to Ashkenazi Jewish patients are equally appropriate is less useful.

Large scale efforts to help determine the characteristics and appropriateness of genetic testing will clarify the role that each test should play among various populations. Both the Secretary's Advisory Committee on Genetic Testing (SACGT) and the CDC-sponsored ACCE Project (Analytic validity, Clinical validity, Clinical utility, and Ethical, legal and social implications), will be applying a set of standards to tests and the contexts in which they should be used. Until then, we need to be cautious about overwhelming patients who present to genetic counselors for help in clarifying their risk positions. ❖

Cancer Genetics Starter Pack Now Available

Susan Manley, MS & Jeff Shaw, MS

The Cancer Genetic Counseling Starter Packet noted in the last issue of *Perspectives* (V23:3, p9) is available by mail as well as online.

The packet includes materials and resources that have been gathered over many years from various centers with different foci and orientations. This packet is meant to serve as a general resource in developing a clinical cancer genetics service. It is neither intended to provide everything needed to create a clinical service nor to serve as an example of how things "should" be done. Rather, it is a resource of useful reference materials and issues to be considered in providing cancer genetics services.

Additional reading, investigation and work within one's own institution will be necessary to develop a cancer genetics program.

☞ www.nsgc.org, then access the Member's Corner, then <<Tools for your Practice>> ❖

How to Order a Starter Pack if you are not Online

Copies of the Cancer Genetics Starter Pack are available on a PC disk. Indicate your request for the "Cancer SIG Starter Packet" by phone: ✆610-872-7608, press #3 or fax: 610-447-8489 Attn: Lisa. ❖

'00 Professional Status Survey...

Anu Chittenden, MS, Kristen M. Shannon, MS, Jennifer Farmer, MS, & Jesse Chittams, MS

In response to numerous requests from the members of the Familial Cancer Risk Counseling Special Interest Group, a subset of the data from NSGC's 2000 Professional Status Survey was analyzed. The data set includes counselors who spend at least 50% of their time in cancer-related work. 138 out of 957 respondents (14%) fit this category.

Demographics

The demographics of this subset of genetic counselors are similar to that of the general NSGC membership: predominantly Caucasian females under the age of 40.

Gender	**N**	**%**
Female	123	89
Male	15	11
Age	**N**	**%**
21-30	60	44
31-40	55	40
41-50	15	11
51-60	6	4
>61	1	1
Ethnicity	**N**	**%**
Caucasian	127	92
Asian	9	7
African American	0	0
Hispanic	1	1
Other	1	1

Regional Distribution

Region distribution matched the general NSGC population. (See membership directory for breakdown of regions.)

Training/Certification

- 88% (121/138) of members hold an MS/MA in Genetic Counseling or Human/Medical Genetics.
- 3% hold nursing degrees (BSN/ RN; MSN). 3% hold a PhD.
- 2% have a MPH and no one has a MSW/MSSW.
- The following advanced degrees, MD, JD, and MBA, are only held among less than 1% of the members responding to the survey. None of the respondents report being currently enrolled in a degree program.
- Greater than 80% of members have Board Certification.
  - Of those certified, 66% (91/137) are ABGC Certified and of these respondents about two-thirds were certified in 1996 and 1999.
  - 13% (18) are ABMG Certified. 15% (21) plan to take the 2002 exam.
  - 5% (7) have no exam plans or are not eligible to take the certification exam.

Employment Experience

Roughly half of the respondents have worked less than five years as a genetic counselor and the vast majority has worked less than five years in their current position. This parallels the entire NSGC membership.

1. Yrs employed as a GC *n=137*

Yrs	%
0-5	52
5-10	23
10-15	12
15-20	8
>20	5

2. Yrs in current position *n=136*

Yrs	%
0-5	83
5-10	10
10-15	5
15-20	1
>20	1

Work Environment

Primary Work Setting

The majority (58%) work in a University Medical Center v. 44% of the general NSGC membership respondents.

...Comparing Cancer Genetic Counselors to Others

Billing

Almost half report that they bill patients under the doctor's name only, and an additional 15% report that they do not charge for counseling or operate under an HMO.

Patient Billing	N	%
My Name Only	3	2
Mine and MD	10	8
MD Only	55	45
Comp Fee	11	9
Pay Service	7	6
No Charge/HMO	19	15
Other	7	6
N/A	11	9

Patient Volume

The average number of new patients that the respondents counseled in a week was four and the number of return patients was two. The original study results showed an average number of nine new patients per week and two returns.

 # Patients Counseled in 1999

N	Mean	Median	Min	Max
116	144	107	0	648

 # New Patients Counseled over Past Seven Days

N	Mean	Median	Min	Max
113	4	3	0	15

 # Return Patients Counseled over Past Seven Day

N	Mean	Median	Min	Max
92	2	2	0	7

Salary

The salary data presented are based on respondents who are full members with Master's level degrees working full time in the US or Canada (N=107). Canadian salaries have been converted to US dollars. The following chart breaks down yearly gross salary in $5000 increments.

Yearly Gross Salary

Salary	N	Percent
≤30K	4	4%
30-35K	13	12%
35-40K	22	21%
40-45K	16	15%
45-50K	17	16%
50-55K	14	13%
55-60K	9	8%
>60K	12	11%

The following chart reports salary by years of experience.

Salary by Years Experience

Yrs	N	Mean	Min	Max
0-4	59	$41,784	$23,575	$70,000
5-9	25	$49,714	$37,047	$80,300
>9	23	$55,476	$37,000	$77,000

Benefits

Conference Reimbursement

Of the entire NSGC membership, 92% of respondents are given some funding for meeting attendance. The same proportion (92%) of cancer counselors receive some type of reimbursement for these activities. Specifics include:

- Reimbursement for attendance by meeting:
  - 55% for NSGC Annual Education Conference
  - 25% NSGC Regional Meetings
  - 44% ASHG Meeting
  - 11% ACMG Meeting
  - 29% "Other" meetings
- 13% only if paper is presented
- 29% funding is budget dependent
- 28% were given a specific budget, ranging from $84-$2,500; the mean was $1,208.

Professional Activities

Ninety percent of respondents are involved in some professional activity. Some of the more common activities:

- 84% have spoken to lay groups
- 49% developed a conference for health professionals
- 41% served on a committee of NSGC, ASHG or ACMG
- 57% interviewed by the media
- 35% served on advisory board
- 25% served on state/local committee
- 31% developed genetics curriculum
- 30% developed conference
- 29% reviewed journal

Job Satisfaction

Cancer counselors experience similar levels of satisfaction in their present work environments and with the profession as compared with the NSGC membership. Participants were asked to rate their levels of satisfaction in their current positions and in the genetic counseling profession using a Likert scale (very satisfied, satisfied, dissatisfied/too many, dissatisfied/too few and not applicable). For reporting purposes the categories were combined into satisfied and dissatisfied and the not applicable responses were deleted from the analysis.

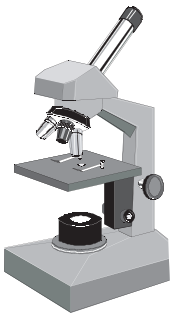
Eighty-six percent of respondents reported overall satisfaction with their current jobs. The highest levels of satisfaction are obtained from clinical and scientific activities while most of the dissatisfaction has been with salary and opportunities for advancement.

Similar levels of satisfaction and dissatisfaction are observed when respondents were asked about the genetic counseling profession.

Discussion

The data presented here are very similar to that of the entire NSGC membership. It is intended that this subset data will be used to serve not only the Cancer Risk counselors but all NSGC members. ❖

Research Network



Genetics of Recurrent Early-Onset Depression

The University of Pennsylvania is the coordinating site for this nationwide study funded by the National Institute of Mental Health. The study will create a DNA collection to permit qualified scientists to search for depression-related genes.

This is the largest psychiatric genetics study, attempting to gather more than 750 families. Volunteers will be interviewed about their psychiatric and family history, asked for a blood specimen and may be asked for help inviting family members to participate.

Eligibility: Families with two adult siblings, one of whom has had a recurrent major depression onset before age 30 and the other before age 40. Histories of bipolar I (manic-depressive) disorder in any sibling or parent will exclude the subject. Travel is not necessary; interviews can be conducted by telephone and blood specimens can be collected locally.

Compensation: Nominal reimbursement is provided.

☞ ✆877-407-9529
depressiongenetics.med.upenn.edu

☞ Kathleen Murphy-Eberenz, PhD, Study Coordinator: ✆215-746-5153, kme@mail.med.upenn.edu

☞ Douglas Levinson, MD, Principal Investigator: ✆215-746-5151, dfl@mail.med.upenn.edu ❖

On the Road

NSGC Represented at State Legislatures Conference

Judith Benkendorf, MS

On October 5-6 the National Conference of State Legislatures (NCSL) held a national policy forum entitled Genetics, Policy and the Law in Washington DC. Attended by state legislators, policymakers and a small number of genetics professionals, the conference marked the culmination of a three-year NIH-ELSI funded study of genetic technology and state public policy development, undertaken by the Georgetown University Law Center and NCSL. The conference featured 20 keynote and plenary sessions, all of the highest caliber. NSGC Social Issues Chair, Karen (Eanet) Wolff joined Paul Billings (GeneSage) and Elliott Hillback (Genzyme Corporation) on a panel discussing genetic testing and public policy.

Selected highlights from the conference include:

- Dr. James Hansen, Acting Chief of Clinical and Genetic Epidemiology at NCI, used cancer genetics research as a model for enacting a science policy agenda. Dr. Hansen also discussed the need for coordinated state policies for genetic healthcare services that span the life cycle to include chronic diseases.
- Dr. Sam Shekar, Associate Administrator of Health Professions at HRSA, spoke about health professional workforce development with regard to genetics. He discussed current HRSA initiatives and identified genetics, geriatrics and equity in access to services as goals for the 21st century, noting genetics crosscutting nature. Dr. Shekar challenged each state to recognize the need for genetics education amongst its public health workforce and to develop appropriate competencies, based on its unique demographics, which could then be integrated into state licensure.
- The ELSI-funded Communities of Color Genetics Policy Project, a collaboration among researchers at the University of Michigan, Michigan State University and Tuskegee University, along with 15 African American and Latino community-based organizations in Michigan and Alabama, reported key findings:

  · the public wants controlled access to genetic information

  · policy task forces should have fair and appropriate community representation

  · religious beliefs should not underpin legislation on genetic testing.

Overall, it was recognized that state laws are out-pacing federal laws in the area of genetic non-discrimination; but many believe that these issues are best dealt with at the state level. The NCSL Report for Policymakers: Genetics, Policy and the Law summarizes their findings and has multiple tables listing relevant genetics legislation state-by-state.

The state legislators were excited about having genetic counselors (and students) present at the conference and many would welcome including us in local their activities. Genetic counselors' abilities to communicate complex scientific concepts to diverse audiences in an understandable manner and to shape policy debates with stories involving real issues in the lives of the elected officials' constituents, uniquely position us to collaborate in state-based genetics education initiatives. In 2002, NCSL will begin holding meetings in various states, patterned after this national forum. ❖

Resources

☞ Full Report: NCSL website: www.ncsl.org ☞ Your State Legislator's Office

Position Statements Updated Another Newly Adopted

The Social Issues Committee completed three position statements this year, two updated position statements on confidentiality and genetic discrimination and an approval of ASHG/ACMG's statement on genetic testing in adoption. Please review these statements and comment by January 30.

☞ Karen Wolff, Greater Baltimore Medical Center, Harvey Institute of Human Genetics, 6701 N.Charles Street Unit 23, Ste 2315, Baltimore MD 21204; ✆410-828-3131; kwolff@gbmc.org.

NSGC Genetic Testing and Adoption

The National Society of Genetic Counselors supports the American Society of Human Genetics and the American College of Medical Genetics joint statement entitled, "Genetic Testing in Adoption," with the addition of the following comments:

1. The NSGC supports the routine collection of accurate family, genetic, and medical history information for children entering into the adoption process or foster care system (American Society of Human Genetics 1991). Medical professionals should utilize this information to determine the likelihood of specific genetic conditions and the appropriateness of genetic testing for the child. Genetic testing should not be undertaken unless family, genetic or medical histories indicate that the results have the potential to be of timely benefit to the child.

2. The NSGC opposes the disclosure of genetic information to prospective parents that is not immediately medically relevant. Genetic test results that reveal information that is not of timely medical relevance (e.g. carrier status, a common polymorphism, a balanced translocation) should not be released to prospective adoptive parents. Adoptive parents should be informed that further information may be available from the testing and once the adoption is finalized a plan for disclosure and education regarding the findings should be developed. ❖

Note: Changes to original text are striken; new text is underlined and bold faced.

Non-discrimination

The NSGC opposes discrimination against an individual with regard to eligibility for or maintenance of employment, insurance coverage or medical benefits on the basis of ~~the results of genetic testing~~ **genetic information**.**Genetic information includes the results of genetic testing, other tests which reveal genetic information and information gathered upon review of the family history.** Consideration of testing information is appropriate only when used to protect the individual's best interests. (adopted 1991; updated 2001) ❖

Confidentiality and Privacy of Test Results:

The NSGC supports an individual**'s right to privacy and** confidentiality regarding genetic **information, including the results of genetic testing, other tests which reveal genetic information, and information gathered upon review of family history.** It is the right and responsibility of the individual to determine who shall have access to **his/her own** medical information, ~~particularly results of testing for genetic conditions.~~ **including genetic information.** (adopted 1991; updated 2001) ❖

'02 Conference

Location: Phoenix AZ

Short Course: November 8-9
Advanced Topics in Cancer Genetic Counseling

This high level short course is aimed specifically at experienced counselors who specialize in cancer genetics and will focus on advanced proficiency in general cancer issues, pathology and treatment. Current data on the risk assessment, clinical care and diagnostics of newly-emerging cancer predisposing genes for hereditary cancer syndromes, such as melanoma and prostate cancer, as well as recent gene findings and the incorporation of this information into expanding risk assessment services will be addressed. ❖

21st Annual Education Conference: November 10-13
Genetic Counseling: Coming of Age in the Technology Era

Advancements in technology, prenatal diagnosis and molecular testing have expanded genetic services to include many different disciplines. With this progress, and the anticipation of further advancements, genetic counselors have the opportunity to expand their roles in the health care setting. This conference will examine this trend, with emphasis placed on strategies to help genetic counselors become involved in new areas of health care. The course will also explore how genetic counselors can integrate new technologic information into their practices, while continuing to address the psychological needs of their clients. ❖

☞ Information will be mailed and posted on our website in March.

RESOURCE

The Iron Disorders Institute Guide to Hemochromatosis: A Genetic Disorder of Iron Metabolism

Editor: ***Cheryl Garrison with scientific advisors, Wylie Burke, P. D. Phatak, and E.D. Weinberg***

Publisher: **Henry Holt and Co**

Cost: **$15.95**

Reviewer: Kathleen Fergus, MS

It is a strange paradox that the most common genetic diseases seem to have the least written support material.

Case in point: hemochromatosis. I saw my first hemochromatosis patient about three years ago, shortly after the advent of DNA testing. As luck would have it, this patient was a healthcare practitioner who faxed me a page-long list of questions to be addressed at our session. It took many hours of searching through a variety of reference sources to find the answers to his questions. *The Iron Disorders Guide to Hemochromatosis* is designed to be a comprehensive patient resource and is a welcome addition to the patient literature.

This 360-page guide is divided into seven sections with a total of 31 chapters. These seven sections cover Iron Metabolism, Detection and Diagnosis of Hemochromatosis, Symptoms of Iron Overload, Other Iron Loading Disorders, Battles with Hemochromatosis (personal stories), Taking Care of Yourself and Support Across the US and World. The chapters within each section are short, which makes for easy reading, and there is an excellent index. In addition, it contains a seven-page section of commonly asked questions and a 15-page listing of international support groups organized by symptoms. It is a very comprehensive resource of information about hereditary hemochromatosis. I saved my patient's list of questions and, using this book, I found the answer to every question in under an hour!

Although very well organized, the reading level is a little high for the average person, but all terms are defined in the text and there is a comprehensive 40-page glossary. It has a very conversational style and does an excellent job of explaining technical jargon.

Interspersed throughout the book are patient anecdotes and numerous charts and diagrams used to illustrate main points and highlight important information. While the patient anecdotes are a very effective teaching mechanism, as a healthcare professional, I found them to be a little dramatic.

Another area of concern is that this book does not give enough information about the possibility of asymptomatic patients. It is clearly designed to be a guide to the symptomatic patient, and the information is presented with a bias toward symptoms. It would be very easy to pick up this book and convince yourself that you have hemochromatosis.

In addition, as a genetic counselor I wanted more of an explanation of the inheritance patterns, but this may be an occupational bias rather than a true deficiency.

❖ I would not hesitate to recommend this book to a patient with hemochromatosis and only wish that it had been in existence three years ago! ❖

RESOURCE

☞ www.irondisorders.com

WHAT'S ON THE WEB

Finding Clinical Trials on the Internet

Kathleen Fergus, MS

There are a number of sites that now allow you to search for clinical trials. I have not listed cancer-specific clinical trials; the Cancer SIG has compiled a great list of trials that might be of interest to genetics patients and the number of Internet sites devoted to cancer clinical trials is overwhelming.

In general, the government, non-profit organizations or pharmaceutical companies own clinical trial search sites. Each site has its own organization system — some are organized by disease category (i.e. dermatology) and others are organized by disease or keyword. Because of these different strategies, search the site a number of different ways. For example, on one site there were only five disorders listed under genetic conditions but a search for xeroderma pigmentosa found clinical trials listed under dermatologic conditions. Some allow you to receive email notifications of new clinical trials related to a particular disorder.

- www.clinicaltrials.gov was developed by the National Institute of Health and the National Library of Medicine and contains all clinical trials sponsored by the NIH.
- www.acurian.com contains listings from global pharmaceutical and biotechnology industries regarding clinical trials and new drug therapies.
- www.centerwatch.com
- www.clincaltrials.com
- www.veritasmedicine.com
- www.healthyexchange.org

In addition to the above, active support groups often keep a listing of ongoing research projects.❖

How the Abstract Committee Reviews Abstracts

Last year, the Abstract Committee was given the charge to "raise the bar" on the quality of abstracts accepted for contributed papers and posters at our Annual Education Conference. Susan Estabrooks and Liz Melvin are to be commended for instituting a review process that achieved its charge. And for members wanting to submit an abstract, here's a peek at how to enhance your chances of having your work accepted.

Cheryl Dickerson, MS, Cathy Wicklund, MS, Susan Estabrooks, MS & Elizabeth Melvin, MS

Our goal is to select high quality abstracts based on quality research for oral and poster presentations. Quality research can enhance patient care, justify the time and expense that genetic counselors put into attending our conference and enhance the professional reputation of genetic counselors.

These guidelines can be applied to quantitative and qualitative research as well as case reports. Quantitative research is hypothesis testing whereas qualitative is hypothesis generating.

Guidelines for Acceptance

Does the abstract comply with basic guidelines?

- It should have a clear message of original work and include only one or two major points. If there are more, write an additional abstract.
- The work should not have been previously published as a manuscript.
- It should not be based on anticipated data. Abstracts stating "results will be presented" or some variation of this will be rejected.

Are the major components included?

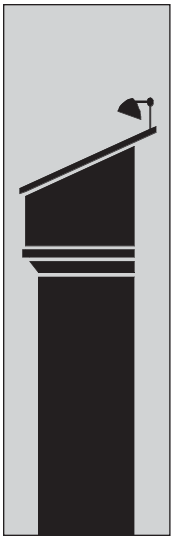
An abstract generally has six parts: title, introduction/statement of the question, hypothesis/purpose, definition of the model and methods, results and conclusions. Case reports deviate from this scheme, but should include a title, purpose of reporting the case, the case itself and conclusions drawn from the case that have wider applicability or purpose.

- Title: Does the title summarize the abstract and grab the reader's interest?
- Introduction/Statement of the Question: States the importance of the research and includes two key components: what is already known (previously reported information) and what is unknown (the question being investigated).
- Hypothesis/Purpose: Usually only one sentence, the hypothesis describes something that can be generated (qualitative research) or tested (quantitative research). It should be clear what the objectives of the study were. For case reports, the author(s) should clearly state why reporting the case is important.
- Definition of the Model and Methods: Usually this is one half to one third of the abstract. Not every research study has a theoretical framework, but if one was used either to frame the research or to interpret results, then this should be stated. Is the study population (and control group) defined along with how it was identified and selected? Did the author(s)…
  - Define what was measured?
  - Describe the tools used to measure the variable(s)?
  - Use tools that measure the variables appropriately?
  - Briefly describe the development of the tool, if it is a new tool?
  - Define or assess the accuracy of the tool?
  - Use the appropriate method of analysis for the intent of the study?
- Does the method of analysis…
  - Fit the methodological approach?
  - Describe how the data was tested?
- Results: Do the results/findings address the hypothesis or purpose of the study?
  - Are the data presented in a clear, concise and consistent manner?
  - Is the order in which the author(s) describe(s) items retained throughout the document?
- Conclusions: The conclusion should relate back to the purpose or hypothesis and be stated in simple terms.
  - Is there clear and sufficient data to support the conclusions?
  - For case reports, the contribution of the case should be clearly stated. It is not sufficient to simply describe the case. State how the case adds to what is already known about the subject matter.

References

Clark E. Writing a Quality Abstract for a Scientific Meeting, *AJDC* 142:422-424.

Taboulet P. Advice on writing an abstract for a scientific meeting and on the evaluation of abstracts by selection committees. (2000) *Eur J Emerg Med* 7:67-72.



We would like to acknowledge the contributions of Bob Resta and Allyn McConkie-Rosell to the material in this article. ❖

Media Watch

Angela Geist, MS and Roxanne Ruzicka, MS

Wall Street Journal (8/31) — "Testing for Cancer Genes Allows for Earlier Detection" was an informative article that discussed genetic testing for breast, ovarian and colon cancer. Katherine Schneider and Jill Stopfer were quoted discussing the complexities of determining cancer risks and the differences in medical management once an individual has been found to carry a cancer gene. NSGC and its website were also mentioned as resources.

"ER" (10/4) — This TV show portrayed a patient with Marfan syndrome who had an aortic dissection. Dr. Carter mentioned that the patient was tall and had a pectus and he said those traits were associated with Marfan syndrome. Also, the October 18th episode presented a six year-old with trisomy 18 who came in with a bowel obstruction. The fact that trisomy 18 is usually fatal was mentioned as well as the severe MR and common bowel obstructions.

BBC News (10/11) — This news channel reported that research described in *New Scientist* magazine has found that early stage embryonic cells obtained through amniocentesis can be grown into connective tissue to create grafts that can be used to correct body wall defects, such as gastroschisis. This technology has already been tried in animals with some success, and the article projects future application to humans.

Southwest Airlines' *Spirit Magazine* (Oct) — This monthly magazine featured an article, "Body of Knowledge," which explains "how a new crop of genetic counselors can predict and improve the future health of you and your family." The facts presented are fairly accurate and the article features the roles of genetic counselors in health care. Quotes from Vivian Weinblatt and Bea Leopold speak to how genetic counseling helps to demystify the complex field of genetics and hereditary diseases. The article recommends who should seek genetic counseling and where to find genetic counselors. NSGC and our website are mentioned.

Seattle Times (10/28) — Vivian Weinblatt and Karen Heller were quoted in "Genetic Advisers Help Predict Future." The article speaks about the role of genetic counselors, the number of training programs and the average salaries. It also mentions that while the Human Genome Project has made large strides in understanding genetics, genetic technology is not yet able to predict who will develop diabetes and other health conditions. ❖

Meeting Manager

Apr 4-7	Region VI Conference, "Celebrating the 10th Asilomar," Asilomar Conference Center, Asilomar CA. ☞ Kim Hart, HartK@peds.ucsf.edu, ✆415-476-5048 or Jason Coryell, coryelj@sutterhealth.org, ✆415-750-6127.
Apr 12-13	Region IV Conference, Northwestern Medical School, Chicago IL ☞ Dawn Allain, dallain@chw.org
Apr 19	Region I Conference, "Taking Care of Business While Taking Care of Yourself: A Professional Issues Potpourri," Auburn MA ☞ Lisa Tuttle, lisa46xx@yahoo.com or Valerie Loik, vloik@yahoo.com
Apr 19-20	Region III Conference, "The Growth of our Profession into the 21st Century," Columbia SC ☞ Kristine Chamberlain, MS, kchamberlain@carolinas.org or Claire Singletary, MS, cnsingle@richmed.medpark.sc.edu Region Rep: Karen Potter, MS, potterk@med.unc.edu
Jun 7-8	Third International Meeting on chromosome 22q11.2 deletion, Pontificia Universita Urbaniana, Rome, Italy ☞ Bruno Marino, MD or Maria Teresa Caldaretti, Organizing Secretariat, ✆011-0039/06/68.59.22.90; Fax: 011-0039/06/68.59.24.43; congressi@opbg.net
Board Review Course - 2 locations	NSGC / University of Pittsburgh Board Review Courses for ABGC and ABMG Exams. Great as Board Review or Basic Genetics Brush Up. 2.37 CEUs. Rates: $500 members; $600 non-members. Brochure available in January.
May 31 - Jun 2	BWI Airport location, Baltimore MD
Jun 21-23	SFO Airport location, San Francisco CA

SIG Activities

Thinking about joining a Special Interest Group? Check it out by noting the activities listed for the coming year or by contacting one of the chairs. Members can join SIGs any time by paying an additional $20 per SIG with dues or any time during the year. Of your $20, $12 is applied to SIG-directed activities; $8 is administrative support to NSGC. You can start a SIG by recruiting at least seven members sharing your area of interest. Applications are available by contacting the Executive Office.

■ **ART/Infertility**
Lauri Black . . . . . BlackLD@sutterhealth.org
Jill Fischer . . . . . JillF@sbivf.com
• Listserv • 2002 Practice-based symposium • ASRM professional group for genetic counselors • Lecture series for GC training programs • Fact sheets for NSGC web site • Theme issue for *JGC*

■ **Clinical Supervisors**
Sue Demsey . . . . . sue.a.demsey@kp.org
Liz Stierman . . . . . nsgccomm@earthlink.net

■ **Connective Tissue**
Michelle Moore
. . . . . Michelle.Moore@memhospcs.org
• 2002 Practice-based symposium
• Information on NSGC website

■ **Diversity**
Barbara Harrison . . . bfwillis@howard.edu
Kathryn Spitzer Kim . kkim@Brandeis.edu
• Minority student outreach at Annual Education Conference • Information on website • Spanish resource list • Minority Mentorship Project • Speakers' Bureau with supportive PowerPoint slides • Student scholarships for Annual Education Conference

■ **Familial Cancer Risk**
Susan Manley . . . . . .smanley@myriad.com
Jeff Shaw . . . . . .JeffShaw@Centura.Org
• Listserv • Directory • Quarterly literature reviews • Updated comprehensive information packet for members developing cancer risk clinics and research project database (available online) • Practice guidelines for cancer risk counseling

■ **Industry**
Heather Brown ..... hbrown@cordblood.com
Kathleen Fergus.....kfergus@dhs.ca.gov

■ **Laboratory**
Melissa Bennett .....Bennem@labcorp.com
Eric Schmitt .....eschmitt@bcm.tmc.edu
• Listserv • Educate genetics and medical communities about genetic testing issues • 2002 Practice-based symposium

■ **Legal**
Sandra Factor . . . . . engravitas@aol.com
Tracy Field . . . . . tracy.field@agg.com

■ **Neurogenetics**
Suellen Hopfer . SHopfer@mednet.ucla.edu
Jennifer Williamson
. . . . . william@sergievsky.cpmc.columbia.edu
• Information on NSGC website • Submit abstracts to the American Academy of Neurology (AAN) and possibly sponsor booth at AAN meetings • Neurogenetics packet for training programs • Listserv

■ **Pediatrics**
Helga Toriello . helga.toriello@spectrum-health.org

■ **Prenatal**
Renee Chard. . . . . chardr@poa.mmc.org
Molly Carpenter . . . carpem@poa.mmc.org
• Guidelines for ethnicity-based prenatal screening • Establishing committees

■ **Private Practice**
Barb Pettersen . . . BarbPett@bendcable.com
• Information on NSGC website • E-mail lists; seeking volunteer to manage a listserv

■ **Psychiatric Disorders**
Holly Peay.....hlpeay@nchpeg.org
• Bibliography of psychiatric genetics references • Involved in Natl Alliance for Autism Research website • SIG member co-authored autism genetics review article, in press, *Nature Genetics Reviews* • • Members from National Coalition for Health Professional Education in Genetics (NCHPEG) producing CD-ROM on psychiatric genetics. SIG members involved in multiple phases of development

■ **Psychotherapy & Expanded Skills**
Vivian Ota Wang . . . . otawang@asu.edu

■ **Public Health**
Sylvia Au . . . . . sau@hgea.org

■ **Research**
Robin Grubs . . RGrubs@helix.hgen.pitt.edu
Emily Hanson. . . ehanson@meriter.com
• Survey to ascertain members' research activities • Directory on website • Listserv

■ **Support Groups**
Lois Lander. . . . llander@geneticalliance.org
Gail Stapleton . . . . . gstapleton@ghs.org
• Brochure to help genetic professionals and support group members better relate to one another • Listserv

■ **Telegenetics**
Robin Bennett . . robinb@u.washington.edu
Becky Butler . . . . butlerbeckyb@uams.edu

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■ **LOS ANGELES CA:** Opening for FP Coordinator. RN w/ BA/BS or higher and OB/MCH/PH exp or BC/BE Genetic Counselor req. Exp req; tchg, public spkg a plus. Coord State of CA Expanded Alpha Fetoprotein (XAFP) Scrng Prog cases for assigned catchment area. Work under provisions of contract between Cedars-Sinai & State Dept of Health Svcs Genetic Disease Branch: handle and report case results, authorize foll/up svcs, obtain preg outcomes and report to GDB. Serve as educ resource. Salary: $44,346 - $62,700.
☞ Susan Williams, ✆310/423-5455; Fax: 310/423-0381; williamss@cshs.org. EOE/AA

■ **MADERA CA:** Immediate opening for Genetic Counselor. Join team providing clin genetic & metab dx & trtmt svcs for Central Valley at one of largest metab clins nationwide.
☞ Dr. Susan Winter or Dr. Berkley, Medical Genetics/Metabolism, Powell Valley Children's Hospital, 9300 Valley Childrens Place, Madera CA 93638 ; ✆559-353-6400. EOE/AA

■ **ORANGE CA:** Immediate openings for two BC/BE Genetic Counselors. Computer skills pref. Join c'hensive PNDx Ctr: amnio, CVS, AFP, genetic/ ped, craniofacial, cancer clins, molec & other subspec activ.
☞ Robert C. Meyer, MBA, V.P., Genetics Center, 211 S. Main St, Ste E, Orange CA 92868; ✆714-288-8520; Fax: 714-288-8525; nzadeh@aol.com; www.geneticscenter.com. EOE/AA

■ **PASADENA & WALNUT CREEK CA:** Immediate openings for 2 BC/BE Genetic Counselors. GC & computer exp pref. Knowledge of Human Genetics, principles of crisis i'vention, i'viewing, business-level English, independent workstyle req. Pasadena position prefers fluency in Vietnamese. Add'l consideration given for Span as 2nd lang. Walnut Creek position does not req add'l lang skills. Work w/ perinatalogist in busy priv practice to provide GC: usual referrals: AMA, MSM scrng, fam hx, terat & U/S abnorm. Relocation expense allowance avail.
☞ CV, brief cover ltr & 2 ltrs rec: Human Resources, Alfigen The Genetics Institute, 43 W. Del Mar Blvd, Pasadena CA 91105; Fax: 626-568-9643; HR@alfigen.com. EOE/AA

■ **RIVERSIDE CA:** Immediate opening for BC/BE Genetic Counselor. Exp & knowl of crisis i'vention & i'viewing, devel educ progs in human & med genetics req. Knowl of fed, state & local regs req. Abil to clearly explain complex med info verbally & in writing. Fluency in Span highly pref. Computer exp pref. Extraordinary customer relations & quality svc critical. Abil to demonstrate these skills & dedication to providing highest quality svc to health plan members req. Provide GC & referral svcs: preconcep, PN, multiple miscarriage, terat, abnorm expanded AFP/multiple marker scrng, NB consult & cancer GC. Act as consult to health care providers re: highly specialized genetic info pertinent to pt mgmt.
☞ Debbi Cruzan, RN, MSN, CDE, OB/GYN Clinic, Kaiser Riverside, Riverside CA; ✆909-353-3569. EOE/AA

■ **SAN FRANCISCO CA:** Immediate opening for BC/BE Genetic Counselor/Program Coordinator. Motivated, self-starter req. Join active infertility grp in acad med setting. Primarily male factor infertility GC w/ PGD & prostate cancer risk prog coord, ovum donor GC. Oppty for prof growth, publishing, rsrch, pt contact in GC & tstg, admin respon in prog devel as well as prof devel & commun svc through focus groups, peer & pt talks, hosting GC interns & grant, course & paper writing.
☞ Paul Turek MD, Dept Urology, University of California San Francisco, 2330 Post St-6th Floor, San Francisco CA 94115-1695; ✆415-353-7352; Fax: 415-353-7252; Mrvas@itsa.ucsf.edu. EOE/AA

■ **NEW HAVEN CT:** Immediate opening for BC/BE Genetic Counselor.. Exp pref. High motiv, excellent org & i'personal skills, team player req. Join busy general clin genetics prog in academic univ setting: genrl clin genetics, biochem genetics, specialty clins.
☞ CV & 3 ltrs ref: Elizabeth M. Cherniske, MS, Dept of Genetics, Yale Univ School of Medicine, PO Box 208005, New Haven CT 06520-8005; ✆203-785-5794; Fax: 203-785-3404; elizabeth.cherniske@yale.edu. EOE/AA

■ **WILMINGTON DE:** Immediate opening for BC/BE Genetic Counselor. Join The Helen F. Graham Cancer Center, Christiana Care Health System, a new state-of-the-art regl cancer ctr .
☞ Christiana Care Resume Service, Attn: PGCP/ PR99, PO Box 549251, Suite 200, Waltham MA 02454-9251; christianacare@hiresystems.com. EOE

■ **GAINESVILLE FL:** Immediate opening for BC/BE Genetic Counselor. Excellent org & i'personal skills req. Join busy, univ-based regional genetics prog working w/ pediatric/adult populations. Opptys for tchg & rsrch. Coord onsite & sattelite clins.
☞ Heather Stalker, MSc, University of Florida, Box 100296, Div Pediatric Genetics, Gainesville FL 32610; ✆352-392-4104; Fax: 352-392-3051; stalkhj@peds.ufl.edu. EOE/AA

■ **JACKSONVILLE FL:** Immediate opening for BC/BE Genetic Counselor.. Join team w/ focus on pediatric genetics. Acad appt at Mayo Medical School avail.
☞ Pamela Arn, MD, Chief, Div Genetics, Nemours Children's Clinic - Jacksonville, 807 Children's Way, Jacksonville FL 32207; ✆904-390-3586; Fax: 904-390-3720; parn@nemours.org; www.nemours.org. EOE/AA

■ **DECATUR GA:** Immediate opening for BE/BC Genetic Counselor. Interest or exp w/ PN GC & lab operations req. Org, flex & abil to multitask req. C'hensive pt follow-up & back-up for team of 10 GCs in acad setting: PN GC in Atlanta & reg'l outrch at Emory affiliates & priv perinat grps.
☞ Cathy Tesla, MS, Emory Genetics Laboratory, 2711 Irvin Way, Suite 111, Decatur GA 30030; ✆404-297-1521; Fax: 404-297-1512; clt@rw.ped.emory.edu. EOE/AA

■ **HONOLULU HI:** Immediate opening for BC/BE Genetic Counselor. Creativity pref; abil to work autonomously req. Oppty to use GC skills to implement activ in State Genetics Plan: educ, data integration, legislation, social mktg & possible clin work. Oppty for contin educ.
☞ Sylvia M. Au, MS, State Genetics Coordinator, Hawaii Dept of Health, 741 Sunset Ave, Honolulu HI 96816; ✆808-733-9063; sau@hgea.org. EOE/AA

■ **CHICAGO IL:** Immediate opening for BC/BE Genetic Counselor . PN & Peds GC, coord partic in rsrch protocols &/or wrkg with directors and staff of clin DNA & cyto labs. Oppty to partic in trng med & GC students & clin genetics fellows. Independent, motiv w/ rsrch & lab exp pref.
☞ Contact: Patti L. Mills, MS, Dept Human Genetics, The University of Chicago, 5841 S. Maryland Ave., Rm. L-039, MC 0077, Chicago IL 60637; ✆773-834-0555; Fax: 773-834-0556; pmills@genetics.uchicago.edu. EOE/AA.

■ **INDIANAPOLIS IN:** Immediate opening for BC/BE PT Genetic Counselor w/ poss for FT. Fluency in Span pref, not req. Busy PNDx clin in univ hosp setting several satellite clins. Trng & tchg GC students, med students & residents.
☞ Send CV + 3 ltrs rec: Kristyne Stone, MS, Prenatal Diagnosis Clinic, Indiana Univ Medical Center, 550 North Univ Blvd, Room 2405, Indianapolis IN 46202; ✆317-274-7022; Fax: 317-278-0104; krstone@iupui.edu. EOE/AA

■ **SHREVEPORT LA:** Immediate opening for BC/BE Hereditary Cancer Genetic Counselor. Handle assmt of pts at risk for hered cancers, pedigree analysis, assmt for gene testing, GC on outcomes of tstg & public educ.
☞ Resume & prof ref: Moira MacIver, Human Resources Dept, Louisiana State Univ Health Sciences Ctr, 1501 Kings Hwy, Shreveport LA 71130-3932; ✆318-675-5254. EOE/AA

■ **BOSTON MA:** Immediate opening for 80% PT Genetics Counselor. Exp pref. Work independently. Join 2 GCs & 1 MD geneticist in busy acad high risk PN genetics prog; opptys for tchg, cancer GC, rsrch.
☞ Diane Ahern, MS, Beth Israel Deaconess Medical Center, 330 Brookline Ave, BostonMA 02215; ✆617-667-3356; Fax: 617-667-1551. EOE/AA

■ **BOSTON MA:** Immediate opening for BC/BE Genetic Studies Project Manager. Min 3 yrs rsrch exp req. Oversee genetic rsrch collab incl wkg w/ PIs on study start up, collection & transfer of samples & data. Work w/ hosp study coord pool s'visors to assign coord to rsrch projs & track progress.
☞ Gretchen Schneider, MS, Harvard-Partners Center for Genetics & Genomics, 77 Avenue Louis Pasteur, HIM Suite 640, Boston MA 02115; ✆617-525-5752; gschneider@partners.org. EOE/AA

■ **BOSTON MA:** Immediate opening for BC/BE Genetics Counselor/Research Coordinator. Exp pref. Strong org skills & abil to work independently req. Familiarity w/ computer databases pref. Work on rsrch team in Molec Neurogenetics Unit: fam ascertainment, informed consent, IRB approval, pt enrollment, specimen collection, data storage.
☞ Susan A. Slaugenhaupt, PhD, Asst Professor Neurology, Harvard Medical School, Harvard Institute of Human Genetics, HIM Bldg Rm 422, 77 Avenue Louis Pasteur, Boston MA 02115; ✆617-432-7025; /7026 (lab); Fax: 617-432-3698; slaugenhaupt@helix.mgh.harvard.edu. EOE/AA

■ **FRAMINGHAM MA:** Immediate opening for BC/BE Genetic Counselor. Excellent verbal/written commun skills, flexibility & abil to multi-task req. Daily interactions w/ GCs, health prof w/ variable knowl of genetics & lab staff: coord tstg, commun DNA results to clients, review & report results.

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☞ Amy Foster, Corporate Recruiter, Genzyme Corporation, 15 Pleasant St Connector, PO Box 9322, Framingham MA 01701; ✆800-357-5744 x23728; amy.foster@genzme.com. EOE/AA

■ **BALTIMORE MD:** Immediate opening for Genetic Counselor or Nurse Geneticist/Clinical Research Supervisor. Clin rsrch & s'vision exp req. Help lead new 3-yr natl rsrch proj on genetic svcs models & health workforce. HRSA & NHGRI/ ELSI funded. Salary range: $40-54K.
☞ Position #769-0000-DS-RS. J Cooksey, MD, MPH, Dept Epidemiology/Preventive Medicine, 660 W Redwood St Rm 109, Baltimore MD 21201; jcookseyumuic@aol.com; www.umaryland.edu/hs/personic/. EOE/AA

■ **ANN ARBOR MI:** Immediate opening for BC Genetic Counselor Coordinator. Min 3-yrs exp pref. Join expanding Cancer Genetics prog. Coord clin & provide c'hensive GC svcs to diverse cancer genetics prac. Opptys for tchg, rsrch & writing.
☞ Send CV & 2 ltrs rec: Stephen Gruber, MD, PhD, MPH, Univ of Michigan, 4301 MSRB III, Box 0638, Div Medical Genetics, Ann Arbor MI 48109-0638; ✆734-615-9712; Fax: 734-763-7672. EOE/AA

■ **COLUMBIA MO:** Immediate opening for BC/BE Genetic Counselor. Join 3 GCs, 2 nurses & 3 MD geneticists in busy, full svc, acad ctr. Primary respon PNDx coord & GC, plus ped/adult genetics. Opptys for spec clins, prof growth, rsrch & prog devel.
☞ Judith Miles, MD, PhD, Div of Medical Genetics, Dept of Child Health, Univ of Missouri Health Care, Columbia MO 65212; ✆573-882-6991; MilesJH@missouri.edu. EOE/AA

■ **RENO NV:** Immediate opening for PT BC/BE Genetic Counselor. BC/BE. Bilingual (Eng/Span) a plus. Provide perinatal svcs nationwide; wide range of PNDX issues in busy, expanding perinatal prac.
☞ Send salary req attn: HR Dept, Pediatrix/ Obstetrix Medical Group, 2119 W. Orangewood Ave, Orange CA 92868; Fax: 714-634-1762; anita_downs@pediatrix.com. EOE M/F/D/V

■ **LEBANON NH:** Immediate opening for BC/BE Genetic Counselor. Excellent org, clin & commun skills w/ abil to work independently and on PNDx team w/ 2 GCs & 4 MFM physicians.
☞ Dorothy Williams, Human Resources, Dartmouth Hitchcock Medical Ctr, One Medical Center Dr, Lebanon NH 03756; Fax: 603-650-8919; dorothy.williams@hitchcock.org. EOE/AA

■ **HACKENSACK NJ:** Immediate opening for BC/BE Genetic Counselor. Strong interest &/or cancer exp a plus. Self-motiv, abil to work independently, excellent verbal, written commun & org skills req. Join 6 GCs & MD geneticist in busy, c'hensive, high vol PN & peds genetics dept. Ex-panding cancer risk assmt. Rsrch & tchg opptys.
☞ Sivya Twersky, MS, Manager, Genetics Service, IMUS Pediatric Center, 30 Prospect Ave, Room 258, Hackensack NJ 07601; ✆201-996-5264; Fax: 201-996-0827. EOE/AA

■ **CHARLOTTE, NC:** February opening for BC/BE temp (6 mo) Genetic Counselor. Option for FT permanent exists. Join busy PN prac w/ 5 perinatologist and 3 GCs. Independent & team work style req. GC student and resident trng.
☞ Cheryl Dickerson, MS, Carolinas Medical Center, Women's Institute, PO Box 32861, Charlotte NC 28232; ✆704-355-3149. EOE/AA

■ **COLUMBUS OH:** Immediate opening for BC/BE Genetic Counselor. Min 2 - 3 yrs exp & computer skills pref. Respon for genetic consult in conjunction w/ fetal/maternal dx procedures & preconcep GC. Opptys for resident tchg, prog develop & rsrch. Interact & collab w/ local multidisc genetics network.
☞ Order number D39883_1, Joel Pierce, Ohio Health, 550 Thomas La, Columbus OH 43214; Fax: 614-566-6953; jpierce@ohiohealth.com. EOE/AA

■ **DAYTON OH:** Immediate opening for BC/BE Genetic Counselor. GC families in genetics & spec clins & priv consults. Opptys for cancer GC & prof educ. S'visory & grant writing respons.
☞ Ann Good, Human Resources, The Children's Medical Center, One Children's Plaza, Dayton OH 45404; ✆937-641-5417. EOE/AA

■ **NASHVILLE TN:** Immediate opening for BC/BE Genetic Counselor. Partic in growing genetic rsrch in common complex diseases (e.g. cardio, Alzheimer disease, epilepsy, pharmacogenetics, pilot studies). Coord pt ascertainment, enrollment, specimens, fam hx & clin data collect for collab efforts. Travel.
☞ Amy Crunk, MS, Human Genetics, Vanderbilt Univ Medical Center, 519 Light Hall, Nashville TN 37232-0700; 615-343-8582; Fax: 615-343-8619; amy@phg.mc.vanderbilt.edu. EOE/AA

■ **PHILADELPHIA PA:** Immediate opening for temp FT BC/BE Genetic Counselor from 12/01-3/02. Perm employment a possibility. Trav to different sites req. Join busy team of 14 GCs serving Greater Phila area. All PN & preconcept GC. Opptys for professional growth in clin rsrch, public'tns, commun educ, business, mgmt & mktg.
☞ Amy Foster, Corporate Recruiter, Genzyme Corporation; ✆800-357-5744 x23728; amy.foster@genzyme.com. EOE/AA

■ **CORPUS CHRISTI TX:** Immediate opening for BC/BE GC. Travel to satellite locations. Join busy expanding full svc genetics center svg entire S. TX area. Main office site includes state-of-the-art cyto, U/S & triple screen dx labs. Referrals: peds, AMA, triple screen, u/s abnorm, terat, ethnic scrng & abnorm fam hx.
☞ Sara MacKay, MS, Center for Genetic Services, 7121 S.P.I.D., Ste 202, Corpus Christi TX 78412, 361-985-6600; Fax: 361-985-6603; sarabmackay@hotmail.com. EOE.

■ **HOUSTON TX:** Immediate opening for BC/BE Genetic Counselor. Span req. Primarily PND w/ some peds in acad grp wkg in co. hosp & outrch clins. Abil to work independently req.
☞ Katie Plunkett, MS, Baylor College of Medicine, 6621 Fannin MC 3-337, HoustonTX 77030; ✆832-824-4295; Fax: 832-825-4294; plunkett@bcm.tmc.edu. EOE/AA

■ **HOUSTON TX:** Immediate opening for BC/BE Genetic Counselor. Risk assmt & GC for adult-onset, gyn diseases req; for malignancies & pts w/ HNPCC pref. Implement & provide GC svcs for all assigned pts & at-risk individuals. Coord grant submissions, assist in clin studies, develop educ materials.
☞ Ref code NSGC1101: Didi Menard, Human Resources, UT M.D. Anderson Cancer Center, 1515 Holcombe Blvd, Box 205, Houston TX 77030; ✆713-745-0062; Fax: 713-794-5951; dmenard@mdanderson.org. EOE/AA

■ **HOUSTON TX:** Immediate opening for FT or PT BC/BE Genetic Counselor. Independent work style desired. GC for individuals, eval fam med hx, GC & med educ, ID & recruit fam for genetic rsrch, work closely with physicians and fam to *...next page*

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from previous page

obtain clin records and samples, assess & GC for pts w/ adult genetic disorders in clin & hosp setting. Salary Min $32,076, Mid $40,092.
☞ Dr. Dianna M. Milewicz or Norma L. Adams, Division of Medical Genetics, The University of Texas Medical School in Houston, 6431 Fannin St, Rm 1.614, Houston TX 77030; 713-500-6727; Fax: 713-500-6556; Norma.L.Adams@uth.tmc.edu; Dianna.M.Milewicz@uth.tmc.edu. EOE/AA

■ **Salt Lake City UT:** Immediate opening for BC/BE Genetic Counselor/Manager of Medical Support. Clin exp in hereditary cancer risk assmt req. S'vise prof Support Specialists, work w/ Customer Relations, Sales & Mktg to develop & maintain educ materials for health care profs & pts; support dx svcs.
☞ Tom Frank, MD, Vice President of Medical Services, Myriad Genetic Laboratories, 320 Wakara Way, Salt Lake City UT 84108; Fax: 801-883-3333; tfrank@myriad.com; www.myriad.com. EOE/AA

■ **Salt Lake City UT:** Immediate opening for (3) Regional Medical Trainers (Southeast, Central-Southern Midwest and Northern Midwest) BC/BE Genetic Counselors. Hered cancer risk assmt exp & excellent public spkg skills req. Travel w/in defined regions to educ & train health care providers to assess pts for hered cancer risk & interpret test results.
☞ Tom Frank, MD, Vice President of Medical Services, Myriad Genetic Laboratories, 320 Wakara Way, Salt Lake City UT 84108; Fax: 801-883-3333; tfrank@myriad.com; www.myriad.com. EOE/AA

■ **Salt Lake City UT:** Immediate opening for BC/BE Genetic Counselor/Professional Support Specialist.Exp in hered cancer risk assmt req. Assist in reporting & explanation of dx genetic tstg results to health care providers (incl i'natl clients), provide add'l supt for health care providers via 800 helpline & email, provide educ supt for Sales & Mktg dept.
☞ Tom Frank, MD, Vice President of Medical Services, Myriad Genetic Laboratories, 320 Wakara Way, Salt Lake City UT 84108 ; Fax: 801-883-3333; tfrank@myriad.com; www.myriad.com. EOE/AA

■ **Salt Lake City UT:** Immediate opening for BC/BE Genetic Counselor. Clear speech, occasional light lifting, abil to work overtime. Min 1 yr exp pref. Provide GC svcs to clients, ref physicians & pts re: genetic tests in molec & biochem genetic labs. Monitor activ of genetic tstg & devel publications about ARUP genetic tstg svcs. Resource to units/depts, prof educ re genetic diseases.
☞ Posting #101-649: Linda Ivie, Recruiter, ARUP, 500 Chipeta Way, Salt Lake City UT 84108; ✆801-583-2787 x2123; Fax: 801-584-5218; iviel@aruplab.com. EOE/AA

■ **Falls Church VA:** Immediate opening for BC/BE Genetic Counselor. Cancer exp pref. Knowl of GC practices; med documentation, ref mechanisms & avail of supt svcs. Excellent i'personal skills to i'act w/ physicians, students, faculty, pts.
☞ Attn: SBS-NSGC-GC-11/19, HR Dept, Inova Fairfax Hospital, Inova Cancer Ctr, 3300 Gallows Rd, Falls Church VA 22042; Fax: 703-698-2268; susan.bennett -smith@inova.com; www.inova.org. EOE

■ **Lynchburg VA:** Immediate opening for Genetic Counselor. PN exp pref. Written & verbal skills w/ abil to work independently req. Work w/ MFM physicians in priv PN prac.
☞ Deborah Alfers, Business Administrator, Women for Women, 2215 Langhorne Rd, Ste 101, Lynchburg VA 24501; ✆804-528-5290; Fax: 804-528-3952. EOE/AA

■ **Richmond VA:** Immediate opening for BC/BE Genetic Counselor. Exp req. Join team of 6 GCs, 5 MD geneticists in univ setting w/ strong focus on excellence in clin svcs, tchg & rsrch. Lifespan range of pt & fam issues, active role in s'vision & tchg of students in GC prog, opptys for i'disciplinary coord.
☞ CV & 3 ref: Lauren Vanner MS or Joann Bodurtha MD, MPH, Dept. of Human Genetics, Virginia Commonwealth Univ, Box 980033, Richmond VA 23298; ✆804-828-9632; Fax: 804-828-3760; lvanner@hsc.vcu.edu; Bodurtha@hsc.vcu.edu. EOE/AA

■ **Richmond VA:** Immediate opening for BC/BE Genetic Counselor/ Research Assistant. Tchg, org skills, GC exp pref. Case mngmt, tchg respon w/ grad, med, dental and nursing students. Trav to referring hosp & satellite clins.

☞ CV & 3 ref by 2/28: Joann Bodurtha MD, MPH, Dept. of Human Genetics, Virginia Commonwealth Univ, Box 980033, Richmond VA 23298;
Fax: 804-828-3760; Bodurtha@hsc.vcu.edu. EOE/AA

■ **Milwaukee WI:** Immediate openings for 2 BC/BE Genetic Counselors. Exp pref, not req. Enthus, org & abil to work independently req. Join Women's Health and Cancer Services teams at Aurora Health Care: provide c'hensive PN & cancer GC svcs. Opptys for educ students, prof & commun.
☞ Bill Laffey, Director of Cancer Services, St. Luke's Medical Center, 2900 W. Oklahoma Ave, Milwaukee WI 53215; ✆414-649-6225. EOE/AA

In Canada

■ **St. John's, NF**: Opening for Genetic Counsellor III. Masters in GC pref. Partic pn team approach with Clin Geneticist and other health care prof to provide general GC, clin coord & educ svcs. $5,000 Sign on Bonus.
☞ Lisa Phelan, Health Care Corporation of St. John's, Waterford Bridge Road, St. John's, NF A1E 4J8; Fax: 709-777-1303; hcc.phel@hccsj.nf.ca.

■ **Toronto, ON:** Immediate opening for ABGC/CAGC-BC/BE Genetic Counselor. Min 2 yrs exp desired. Join active Univ Hosp Prog in Cancer Genetics: multidisc approach involv Onc & Genetics & GC for ped pts & fam. All aspects of GC (indep & team-based), prof educ & rsrch. 1 yr contract w/ possible option to renew.
☞ CVs by 11/30: Cheryl Shuman, Div Clinical & Metabolic Genetics, The Hospital for Sick Children, 555 University Ave, Toronto, ON M5G 1X8; ✆416-813-6386.

■ **Winnipeg, MB:** Immediate opening for Genetic Counselor w/ MS in GC or equiv.
Provide all aspects of GC in major genetics ref svc w/ pop base of 1.2 million.
☞ CV & 3 ltrs ref: Dr. Ab Chudley, Section of Genetics & Metabolism, FE229 - Community Services Bldg, Health Sciences Centre, 820 Sherbrook St, Winnipeg, MB R3A 1R9; ✆204-787-4743; Fax: 204-787-1419; achudley@exchange.hsc.mb.ca.