PERSPECTIVES in genetic counseling

Volume 20 Number 4 Winter 1998/99

national society of genetic counselors, inc.

nsgc

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

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NSGC acknowledges Genzyme Genetics for a generous grant to support this newsletter.

genzyme GENETICS

Genzyme Genetics, committed to providing quality DNA-based, cytogenetic and prenatal biochemistry testing, service and education.

MEETING LOCATION DEBATE CONTINUES

Barbara Pettersen, MS, Chair, Education Committee and Cindy Soliday, MS, Chair, Annual Education Conference Subcommittee Is it time to spread our wings? Our needs as a Society are changing. Debate is ongoing. Is it time for NSGC to schedule meetings separate from ASHG?

BACKGROUND

An article appeared in PGC (20:2) and a membership opinion poll was taken from which 366 responses were returned. Should NSGC move to stand alone meetings? 52% responded yes, 35% responded no and 13% were undecided or offered other options. This information was reported to the membership in PGC (20:3).

The topic was again discussed during the Open Mike session in Denver. One member expressed concern that not enough of the membership responded to the poll, recommending a full membership vote. Another queried about our communications with ASHG regarding this issue.

Reasons presented for remaining with ASHG included: ...to p. 3

CANCER PREDISPOSITION TESTING FOR MENTALLY IMPAIRED PATIENTS

Jessica Mandell, MS

Recently published guidelines
On breast cancer testing by the
Stanford Program in Genomics,
Ethics and Society (PGES, June,
1998) states that while the value of
genetic testing depends on the
context of the disease for those
affected or threatened, and that
testing is an option for people at
high risk, testing for "particularly
vulnerable groups," including
children, fetuses — and the
mentally impaired — is
"inappropriate."

I consider these guidelines whenever I talk to a patient simultaneously balancing her own breast cancer diagnosis, a BRCA1 gene mutation, and the knowledge that she passed this mutation to her 25 year old mentally impaired daughter. The decision to test her daughter was made over several counseling sessions, with strong consideration paid to the daughter's carrier risk, the availability of surveillance should the daughter test positive and the mother's legal guardianship allowing her to provide consent. While the mother states that her daughter understands certain medical information, she does not plan to inform her of the testing.

Members of the Cancer SIG also recall unaffected family members seeking genetic testing for ...to p. 4

KNOWING THE PRIORITY ISSUES; WORKING TO ADDRESS THEM

Debra Lochner Doyle, MS, President

vision states that NSGC is "the leading voice, authority and advocate for the genetic counseling profession." We "own" that distinction because of a track record of knowledgeable, professional members serving our own and other organizations. The challenge before us is to maintain this level of respect and credibility. I believe this challenge is achievable as long as we continue to prioritize the issues that affect our members and successfully address them.

STRATEGIC PLAN

In 1998, with your input, our second strategic plan was created. Priority issues identified include:

- improving billing and reimbursement;
- increasing jobs and expanding roles;
- dispelling the perception that there are increasing training programs generating more graduates than there are jobs; and
- improving communication both

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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.

Submission deadline February 10

Next issue March 15
Submission deadline February 10

within and outside of the Society.

In addition, one issue that was carried forward from the previous strategic plan was that of increasing diversity within the profession.

DIALOGUE ON DIVERSITY

Earlier this year, I participated in a national dialogue on genetics in diverse populations. In this forum, I spoke with several

'A true sense of community...is a goal worth working toward.'

genetic counselors who are people of color. I asked if they feel comfortable participating in NSGC. Disappointingly, the response was, "No!" People said that they often felt that they stood out in the crowd and that it made them feel uncomfortable. This made me wonder if our male colleagues, our gay and lesbian colleagues and our colleagues with chronic illness or disability felt similarly.

I believe individuals and organizations can and do change. I hope that by raising awareness and sensitivity to the fact that not all of our colleagues feel embraced by their own professional society will cause all of us to become involved in reversing this sentiment. A true sense of community, where all people are valued and supported, is a goal worth working toward.

BILLING AND REIMBURSEMENT

Another priority area that I hope to address this year concerns improved billing and reimbursement. Health care purchasers continue to drive the changes that we're seeing in the health care delivery system. A report published this year by Watson Wyatt Worldwide and the Healthcare Financial Management Association

states that employers are not buying health care; they are "buying" healthy employees. This same report noted that 98% of employers recognize that health care benefits are "important or very important" for attracting and

retaining qualified employees.

Armed with this knowledge, how can we be sure that genetic services are

included in health benefits packages offered by employers? Over the past year, the managed care GeneAMP team has been developing an informational packet targeting health care purchasers. Interviews with corporate benefits managers revealed that they were interested in receiving educational materials. In the coming year, these packets will be distributed to corporate benefits managers of large companies across the country. I hope, with your help, to follow-up with these benefits managers to see if they'd be interested in meeting with a genetic counselor to discuss the materials. Contact me directly if there's a large employer in your area and if you would be willing to assist in this marketing project.

YOUR BOARD REPRESENTS YOU

Our success will be easily achieved if everyone participates. With this in mind, I encourage you to invest in the future of our Society. Even an hour a week can make a meaningful difference!

We are rapidly approaching our 20th Anniversary *and* a new millennium. I can't think of a better time to ensure our success as genetic counselors and as the Society that represents you. ❖

FUTURE OF CONFERENCE LOCATION, fr p. 1

Is it time to spread our

wings? NSGC wants to

be responsive to

member sentiments.

- The difficulty choosing between attending NSGC or ASHG.
- Our decreased presence at and contribution to ASHG conference and committee meetings.
- Some concern about the ability to meet CEU recertification. requirements.

Others voiced their support for stand alone meetings, stating:

- A separate meeting time would raise our professional stature.
- Stand alone meetings would enable us to choose convenient dates and less expensive meeting sites that truly meet our needs rather than conforming to ASHG's needs.
- The quality of our conference increases every year — meeting genetic counselors' educational needs better than ASHG.

LOGISTICAL CONCERNS

Some scheduling challenges we've encountered in recent years include:

- Finding hotel and meeting sites that meet our space needs and budget considerations.
- Working around ASHG meeting dates while avoiding Halloween and the Jewish High Holy Days. (The Board voted unanimously to hold a stand alone meeting in 2000 out of respect for our Jewish members.)
- Experiencing limited options for short course dates.

POTENTIAL SOLUTIONS

The Board has discussed the following options:

- 1. Move to a stand alone meeting ...in the Spring *or* Fall with our choice of conference sites.
- 2. Continue to meet with ASHG

and attempt to work with them to resolve some of the ongoing problems, understanding that this would not solve our dilemma about appropriate meeting sites,

hotel rooms and costs. We are currently researching 2001 and 2002 to determine if there are appropriate space options.

3. Meet with American College of Medical Genetics (ACMG) and

March of Dimes (MoD) in the Spring. ACMG and MoD have an arrangement to alternate between Los Angeles and Miami. However, a continuing education arrangement with Columbia University creates a layer of bureaucracy. In addition to significantly curtailing our site and space options, NSGC's conference is much larger and has needs that clearly may not be met by joining with a smaller conference.

 Invite ACMG and/or MoD to meet with us, with mutually agreed upon sites and dates.

CURRENT STATUS

The opinions voiced by the membership at Open Mike and from the written opinion poll were taken into serious consideration during the discussion at the Fall Board meeting.

The interim plan is to continue to meet with ASHG whenever possible. Sites, accommodations and dates will be evaluated on a year-by-year basis, with our planning projecting 24-36 months into the future. We are currently exploring our options for 2001 and 2002. The issue will be readdressed by the Board this Spring.

Regarding Continuing Education

Units, NSGC's Annual Education Conference will award *at least 2.0 CEUs* per year. Additional credits can be earned from NSGC short courses and regional meetings. Other national or regional genetics or medical meetings must have preapproval by the American Counseling Association to obtain credit for attendance. Since recertification is based on earning *an average of* 2.5 CEUs per year in a 10 year time period, meeting on our own should not present a recertification barrier.

NEW DIRECTIONS

Contemplating a change like this is difficult, and it takes time to sort out all of the available options. However, it is important and impressive to realize that our organization is continuing to grow in size, stature and visibility.

We will inevitably outgrow parts of our current structure and ways of operating. The time may not be right to make a permanent decision about future meetings. However, we suggest that the time is now to take a thoughtful and open look at new solutions to meet our future needs. ❖



WE INVITE YOU TO WRITE!

...Address Letters to the Editor/ Membership for *Perspectives c*/o Janice Berliner, Editor.

...Address letters to the Board for consideration at the March meeting to: Barbara Pettersen, Education Chair, Kaiser Permanente, 5755 Cottle Rd, Bldg 1 Genetics, San Jose CA 95123; Barbara.Pettersen@ncal.kaiperm.org

🖙 Deadlines: February 10.

THE BUZZ FROM DENVER

Jacqueline Krogh, MS & Liz Stierman, MS

Leticontent of our Annual Education Conference is not thought-provoking! Here's just a sampling of some of the discourse and information from our recent conference in Denver.

PSYCHOSOCIAL ISSUES IN THE GENETIC COUNSELING SESSION

Ethicist Dorothy Wertz's presentation triggered strong audience response. She surveyed patients and genetic counselors about topics covered in genetic counseling sessions, mostly in a pediatric setting. Wertz compared her results to a similar study conducted 10 years ago, questioning whether there would be more attention to "psychosocial issues" now that most respondents were master's level counselors rather than MDs. Results were essentially unchanged — few sessions included discussion of:

- cost of the disorder
- progression of the disease into adulthood
- stress on family and
- resources for services and support.

The audience reacted strongly with many pointing out that topics covered depended largely on individual circumstances.

INSIDE GENETIC TESTING

Many were moved to tears by a breakfast presentation sponsored by Myriad Genetics. Nancy Prouser chronicled her experiences learning that she carries a BRCA2 mutation and her decision to undergo prophylactic mastectomies.

Perspectives in Genetic Counseling 20:4 — Winter 1998/99

In painful detail, she described the strain her fears caused on her relationships and her difficulties in finding support for her feelings and decisions. She urged the development of support groups to help women in all stages of the testing process.

An interesting note: Although both of Nancy's parents died of breast cancer, it was her Sephardi father, not her Ashkenazi mother, who passed the gene on to her.

NEW SCIENCE INSIGHTS

Marga White, PhD, impressively clarified the intricate technique of the new and exciting DNA chip technology and explained how it is used for diagnostic purposes. She compared this new technology to more traditional techniques, such as DNA sequencing and immunohistochemistry.

SOCIOLINGUISTICS EXPLAINED

"Before this project, the last time I watched someone else do genetic counseling was in July 1980," recalled JEMF recipient, Judith Benkendorf. She, along with coinvestigator, Michele Prince, bravely played portions of their own taped genetic counseling sessions to illustrate the principles of sociolinguistics.

This emerging science studies how our language and conversational interactions reflect underlying values and styles. Judith and Michele demonstrated how their methods can be applied to all genetic counselors, providing an educational model for teaching genetic counseling communication skills. ❖

The JEMF Advisory Board is proud to have funded this innovative work.

Congratulations to Judith and

Michele! — Audrey Heimler

CANCER ...

mentally impaired relatives with cancer to determine an inherited risk. In this scenario, informed consent may be impacted by the experience of the mentally impaired women who already receives medical care and probably make some of their own decisions, and by the possibly biased views of the relatives seeking testing. Whether the impaired patient has been affected by cancer or is at risk, a review of our counseling practices seems to be in order to protect the interests of the impaired individual and the deciding party and to ensure ethical informed consent.

COMPETENCY

Since mental impairment covers a range of IQs and psychosocial abilities, it seems appropriate to try to involve impaired individuals in their own testing decisions.

This involvement might include a psychological assessment to determine the individual's competency. In many centers, such assessment is common for any patient before genetic testing. Legally, incompetence must also be proven before third parties can provide consent, further suggesting the need for assessment before assuming anything about a patient's decision-making ability.

GUARDIANSHIP

What of those patients who are legally incompetent and already have someone with power of attorney? In these instances, genetic counselors are advised to discuss all relevant medical information with guardians, as well as the guardian's personal motivations for requesting genetic testing. Reason presumes that guardians want to act in the patient's best interests. However, if

... Predisposition Testing, from Office to Ethics from p. 1

the guardian's reasons for testing are suspicious or might cause negative effects, other testing options could be suggested.

In a family without a known mutation, alternatives could include testing a competent affected family member first, offering research or commercial testing that the guardian may be eligible for or, in the case of an impaired patient with poor prognosis, DNA banking for use in the future.

In a family in which a mutation-positive guardian is seeking testing for an unaffected, impaired individual, the above considerations may vary. Cancer predisposition can be life-threatening and early detection can be life-saving, so testing the impaired person may be justified. However, testing may take an emotional toll on parents who feel responsible for contributing both mental impairment and cancer risk to their child.

ETHICS SUBCOMMITTEE COMMENTARY ON CANCER PREDISPOSITION TESTING FOR IMPAIRED INDIVIDUALS

Katherine Hunt, Chair

Jessica Mandell's thoughtful article describing the challenges of obtaining informed consent on a mentally impaired individual closely follows the genetic counseling Code of Ethics. She affirms the basic premise that all patients should have the opportunity to receive genetic counseling. She provides advice on how to counsel this population effectively while respecting their "autonomy, welfare, individuality and freedom," as stated in section II of the Code. The Code further supports Jessica's assertions, advocating for as much involvement as is possible of mentally impaired individuals in the genetic counseling process. This includes obtaining informed consent prior to genetic testing for hereditary cancer syndromes.

Part one of section II of the Code reinforces the fact that our clients include mentally impaired individuals as it states "equally serve all who seek services."

Part three of the Code states that genetic counselors should "enable their clients to make informed independent decisions free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences." This part is perhaps the most challenging portion of the genetic counseling process to accomplish successfully with a mentally impaired individual. Jessica provides us with some helpful suggestions such as concentrating on the psychosocial approach with the impaired individual by exploring the emotional response to the facts described during the session.

The conclusion of the article reminds us that informed consent and the counseling process for mentally impaired individuals is a team effort, again supported by our Code, which advises us to "refer clients to other competent professionals when they are unable to support the clients." *

GOALS OF CANCER RISK GENETIC COUNSELING

Traditional counseling techniques, like nondirectiveness, identifying past decisions and projecting future risks and plans, may not suit an impaired patient who has never experienced autonomy and who may focus on the present. In her guidebook, Working With Women Who Have Mental Retardation, Brenda Finucane recommends concentrating on a psychosocial approach with impaired individuals and achieving informed consent by discussing basic medical concepts and the individual's emotional responses to them.

Many issues still remain. How do we handle situations in which a mentally impaired cancer patient desires or already has children? What about options of risk-reducing surgeries or chemo-prevention? Or management of preventive lifestyle behaviors? What of follow-up for those who test negative but are still at increased cancer risk due to family history or age? How can confidentiality be maintained, especially for residents of an institution? These complexities cloud guidelines for cancer genetic testing of impaired individuals, just as they do for any individual.

In the least, we must rely on one constant of cancer genetic testing—that informed consent and counseling be approached by a team, including medical professionals, therapists and family or guardians, and that after testing, a similar team be available to provide continued medical care and emotional support. •

New Goals for Human Genome Project

Rosalie Goldberg, MS, Liaison to National Human Genome Research Institute (NHGRI) Council

The National Advisory
Council for Human
Genome Research convened at The
National Institutes of Health for its
24th meeting in September. Dr.
Francis Collins, NHGRI director,
introduced the day's agenda. The
first order of business was reviewing
and accepting the document draft,
The New Goals For The U.S.
Human Genome Project - 1998 2003. NHGRI is asking for not less
than \$270 million for FY1999 to
finance the new plan.

Of the eight major goals reviewed in the report, the following items most impact our membership:

GOAL 1: THE HUMAN DNA SEQUENCE

- Provide a complete sequence by the end of 2003, two years ahead of the original plan.
- Achieve coverage of at least 90% of the genome by 2001. (As more than one-half the genes are predicted to lie in the gene-rich third of the genome, the finishing effort should focus on these regions.)
- Make available the sequence as broadly as possible, including a resolve to merge publicly funded data within the NIH and DOE with data from private initiatives.

GOAL 2: HUMAN GENOME SEQUENCE VARIATION

- Sort out the relationships among human sequence variation, phenotypic variation and complex disease.
- Create public resources of DNA samples and cell lines.

GOAL 3: TECHNOLOGY FOR FUNCTIONAL GENOMICS

- Develop a comprehensive understanding of gene expression.
- Study genome-wide mutagenesis by creating mutations that cause loss or alteration of function.

GOAL 4: COMPARATIVE GENOMICS

 Sequence the DNA of a number of other organisms, e.g., drosophila, C. elegans and the mouse, since all organisms are related through a common evolutionary tree.

GOAL 5: ETHICAL, LEGAL AND SOCIAL IMPLICATIONS (ELSI)

This section was heated with much discussion and disagreement and will be changed considerably to reach consensus of the Council.

• Focus on the interaction between genes, environment and free will.

- Explore the potential benefits and risks of genetic testing and research participation.
- Involve target populations in planning research studies.
- Research the safe integration of genetic information into clinical care — critical as genetic research produces extensive data on individual susceptibility or resistance to diseases, behaviors and other traits.
- Develop research approaches that are culturally sensitive.

GOAL 6: TRAINING

- Develop programs to train scientists for careers in genomics.
- Train scholars who are knowledgeable in both genomic and genetic science and in ethics, law or the social sciences.

Meeting Manager

March 6, 1999 • Houston TX

"Catering to Your Clients: What's on the Menu?" Region V Conference. .7 CEUs approved. Contact: Katie Leonard, MS: © 713-798-4363; Fax: 713-798-4187; kleonard@bcm.tmc.edu

March 12, 1999 • Auburn MA

"Genetic Screening: What's on the Horizon?" Region I Conference, .65 CEUs applied for. Contact: Dawn St. Amand, MS: © 860-679-1501; Fax: 860-679-1531; stamand@nso2.uchc.edu

March 19 - 21, 1999 • Miami FL

Annual Clinical Genetics Meeting sponsored in cooperation with March of Dimes Clinical Genetics Conference. 2.0 CEUs approved.

"Update on Effective Coding, Billing and Compliance for Clinical and Laboratory Genetic Services," Post Meeting Workshop, March 22, CEUs not offered. Contact: Melanie Gross Greenfield, Meeting Coordinator: ©301-571-1887; Fax: 301-571-1895; mgross@fuseb.org

April 22-23, 1999 • Chicago IL

"Genetic Knowledge and Disability: Opportunity and Peril?" Jointly sponsored by numerous prestigious Chicago institutions, including Northwestern University Schools of Law and Medicine, City of Chicago Mayor's Office for People with Disabilities, and others. .975 CEUs approved. Contact: Kelly Ormond, MS: © 312-926-6478;

Fax: 312-926-0806; kormond@nmh.org

18th Annual Education Conference

Dates & Location: October 16 - 19 • Marriott City Center,

OAKLAND, CALIFORNIA

Our first conference in a hotel/convention center. Our 20th year celebration! Be sure to save these dates!

TITLE: LIFE CYCLE GENETICS - FROM PRECONCEPTION

TO ADULTHOOD

Enormous advances have occurred in the area of preconceptual diagnosis, assistive reproductive techniques and adult genetics. The implications are far-reaching for all genetics professionals, whether specialists or generalists. Education will occur in didactic and experiential forums and innovative minicourses ...intensive study in specific areas.

ABSTRACTS: New this year! Submit your abstracts online. Look for

more information in your mailbox in early February ...or check our website later this winter for

submission instructions. The deadline is May 14, so start considering now what you might want to submit

as a presented paper or poster.

WORKSHOPS: Eleven workshops include some new learning —

Disability Issues in Genetic Counseling; Empathetic Listening in Genetic Counseling; Tools of the Trade: The Process of Cancer Risk Assessment and some old favorites, too — Difficult Dilemmas, Men as Clients, Student Issues ...all these and intensive, four-hour sessions on popular topics requested by you!

SHORT COURSES: OCTOBER 15-16

• QUALITATIVE RESEARCH IN GENETIC COUNSELING *Chairs:* Barbara Lerner, Robert Resta & Vickie Venne — Geared for genetic counselors ready to take their first steps toward conducting a qualitative research project. Registration will be limited to 50.

• LEGAL ISSUES IN GENETIC COUNSELING PRACTICE Chair: Susan Schmerler

— Focus on legal and malpractice issues relevant to genetic counselors. Faculty will include prosecuting and defense attorneys and genetic counselors who have been involved with lawsuits. Social and ethical implications of genetic policies will also be explored.

PLANNING COMMITTEE:

CO-CHAIRS: Linda Robinson & Laura Thomson

PROGRAM: Kathryn Murray

WORKSHOPS: Kelly Ormond & Lyn Smith Hammond

PBS: Dawn Allain & Heather Hampel

ABSTRACTS: Leah Hoechstetter & Karen Wcislo

COMMUNICATIONS: Denise Tilley RESOURCES: Michael Banke LOGISTICS: Kimberly Barr

GeneAMP Awards

The objective of GeneAMP (Applied Marketing Project) is to establish genetic counselors as integral, valued participants in every health care system. GeneAMP provides funding for marketing projects targeted at five groups:

- Primary Care Providers
- Managed Care Organizations
- Medical Professional Organizations
- Consumers and Employers and
- Law and Policy-makers.

Projects are reviewed on the basis of their merit and strength as well as applicability to the GeneAMP objective. Projects funded in 1999:

- NSGC Materials & Exhibits, 1999 Oncology Meetings. Project Leader: S Cummings. Team Members: J Peters, E Knell, M Smith.
- Marketing to the Media: Genetic Awareness Campaign. Project Leader: J Berliner. Team Members: H Hixon, S O'Neill, E Knell.
- NSGC Banner Sponsor on Breast Cancer Network (BCN) Website and Newsletter. Project Leader: J Peters. Team Members: M Banke and members of Cancer SIG Steering Committee.
- Marketing NSGC and Genetic Counseling Profession to Legislative Assistants for Health in the U.S. Senate and House of Representatives. Project Leader: A Boldt. Team Members: M Aulik, T Brady, S Cohen, P Devers, S Endres.

GeneAMP Co-Chairs are Ed Kloza and Barbara Lerner. Thanks to Beth Balkite who stepped down after serving as co-chair for three years. Thanks, Beth for your efforts and expertise! •

Study Resources for the Boards

Aimee Tucker, MS

enetic counselors everywhere
are gearing up to take the
board exams by forming study
groups and dusting off old text books
...or shelling out money for new
ones! One of the best methods to
study is with a local study group. If
you don't have access to other active
candidate status genetic counselors,
or groups aren't your best learning
style, read on! Kate Dietrich has
summarized responses to an email
request for information on how
genetic counselors are studying.
Here's what she learned...

WEBSITES & LISTSERV

- American Board of Genetic
 Counseling http://www.faseb.org/
 genetics/abgc/abgcmenu.htm
 A great source of logistical
 information, including a list of
 topics covered on the exam.
- Clinical Genetics Courses and Lectures — http://www.kumc.edu/gec/ prof/genecour.html
 A link created on Debra Collins's website provides access to medical school syllabi and question banks. Other links include chromosome maps and disease specific websites.
- A listserv for active candidate status counselors is now available. Subscribe by sending an email to Majordomo@ohsu.edu with the command "subscribe gcboards" (do not use quotation marks) in the body of the email message, not in the subject line.

TEXTBOOK TEACHINGS

 Thompson & Thompson's Genetics in Medicine remains the perennial favorite. Unfortunately, the updated version is not slated for release until March 1999.

- Smith's Recognizable Patterns of Human Malformation (Jones) is useful for making flashcards to study dysmorphology and syndrome identification.
- Gardner and Sutherland's Chromosome Abnormalities and Genetic Counseling reviews genetic counseling and risk assessment for chromosome abnormalities.
- Bridge's The Calculation of Genetic Risk provides Bayes practice and pedigree analysis and Scriver's The Metabolic Basis of Inherited Disease, has great summaries at the beginning of each chapter.
- The newly published A Guide to Genetic Counseling may also prove to be a good resource in studying for the genetic counseling section of the exam. (See review, page 10.)

STUDY GUIDES

- Berliner's *Medical Genetics: Overview and Study Guide*, 3rd ed, covers all the basics of medical genetics, teratology, prenatal screening and assisted reproductive technologies. Each chapter has study questions and answers. For information, ©908-771-5582 or visit: http://members.ool.com/jlberliner/
- If you simply can't get your hands on enough practice questions, visit http://www.umuzon.com or your local bookstore. Look for a number of genetics reviews and self test books aimed at those taking the United States Medical License Exam. Try Wilson's *Genetics: Self-Assessment and Review* (Pretest, Basic Science Series), 3rd ed and *Genetics*, 2nd ed, published by the National Medical Series for Independent Study.

REVIEW COURSES

• NSGC and the University of

- Pittsburgh School of Medicine are co-sponsoring identical courses on April 30 May 2 in Pittsburgh PA, and May 14 16 in Oakland CA. Contact NSGC for information: 610-872-7608#6; Fax: 610-565-6220 or nsgcossist@ool.com.
- ACMG's Genetics Review Course (formerly "the Baylor course") is being offered April 23-25 in Schaumburg IL. Fax your name, address and email to Melanie Gross Greenfield: 301-571-1895; mgross@genetics.fuseb.org.

However you choose to study, best wishes and happy reviewing!

This article was intended to provide and overview of resources. It is not exhaustive and is not intended to advertise or serve as an endorsement by NSGC of any of the resources. The author of Medical Genetics: Overview and Study Guide, 3rd ed, is the editor of Perspectives. One of the authors of A Guide to Genetic Counseling is President-elect. *

BASIC FACTS FOR THE EXAM

- EXAM DATE & LOCATIONS: June 23 in Philadelphia, Chicago, Atlanta, Los Angeles and Washington DC.
- Deadline For Application:
 December 31. Late Submissions:
 \$250 penalty assessment must accompany applications submitted through January 31; applications postmarked on or after February 1 will be returned without review. No exceptions!
- EXAM INFORMATION:
 Contact ABGC: srobinson@faseb.org
 Fax: 301-571-1895. ❖

ABGC Update DECISIONS ON RECERTIFICATION, ELECTIONS ANNOUNCED

Virginia Corson, MS, ABGC President

herecertification program will be based on the accumulation of CEUs with an average of 25 hours/year (2.5 CEUs) required. Diplomates certified in 1996 will need to obtain a total of 200 hours over the next eight years as we are already two years into their recertification cycle. Credits accumulated during the last two years are eligible toward this total. In addition to national conferences which have begun to offer CEUs for counselors, relevant conferences following CME/CEU guidelines will be eligible for approval. A letter detailing the process will be sent to diplomates in early 1999. Voluntary recertification for diplomates certified prior to 1996 is encouraged. Thanks to Recertification Committee members Nancy Callanan, Nancy Steinberg Warren, Lisa Hillman and Elinor Langfelder for their research and reports to the Board.

New officers and committee chairs for next year:

Pat Ward President Judith Benkendorf . . Vice-President and Credentials Chair

Michael Begleiter..... Treasurer Bonnie LeRoy.... Secretary Janice Edwards Accreditation Chair

Thanks to the 1998 Nominating Committee: Diane Baker, Deborah Eunpu, Shari Baldinger, Susie Ball and Pat Ward, for their review of candidates nominated for the Board and selection of the ballot. Nominations for next year's ballot are requested by January 30. Fax to Sharon Robinson, ABGC Administrative Office, ©301-571-1895. ❖

ENGELBERG FELLOWSHIP SUPPORT DOUBLES

Through the generous support of the Engelberg Foundation, the annual amount for the Jane Engelberg Memorial Fellowship (JEMF) has increased to \$50,000.

This award is open to genetic counselors who are full members in good standing of National Society of Genetic Counselors (NSGC) and who are certified in genetic counseling by ABGC or ABMG or who have been granted active candidate status by the American Board of Genetic Counseling.

The award will be granted to one or more genetic counselors for study, research, writing or exploration of new interests that strive to enhance current skills or develop new skills, con-tribute to the body of knowledge in the field or expand professional roles. Applicants must demonstrate that the work supported by the Fellowship will produce results that

- will be of sufficiently broad interest to warrant professional publication and/or presentation, and
- will enrich the base of knowledge in the professional community concerned with genetic counseling.

Applicants may elect to pursue Fellowship work on a full- or parttime basis for a maximum of one year.

A Program Application and Guideline prospectus will be mailed to Full members in January for projects to be funded in 1999-2000. Applications are due May 3. The 7th Fellowship award will be presented at the NSGC's 18th Annual Education Conference in Oakland.

JEMF Advisory Board members are: Audrey Heimler, Chair; Bonnie Baty, Robin Bennett, Katherine A. Schneider and Joan Scott.

For information, contact Audrey Heimler, Advisory Board Chair, Fax 860-567-1340; AHeimler@ool.com. *No phone calls, please.* •

RESEARCH NETWORK

FOCAL SEGMENTAL GLOMERULOSCLEROSIS (FSGS) RESEARCH

The Renal Division
of the Brigham
and Women's Hospital
of Boston MA is
conducting research into
genetic factors under-lying
the development of inherited forms
of FSGS and causes of kidney
failure and abnormal urine protein
excretions.

Researchers at this Center have identified a gene locus for FSGS on chromosome 19. Continuing studies are being conducted in families with two or more individuals with FSGS or unexplained proteinuria.

The Center is conducting other research for known or suspected inherited renal disease, i.e., polycystic kidney disease, Alport syndrome, thin basement membrane disease, inherited kidney stones, persistent hematuria, Bartter syndrome, familial hypocalciuric hypercalcemia and other inherited electrolyte disturbances.

► Dr. Martin Pollak, Laboratory Director, ©617-525-5840 or Lori Ann Correia, ©617-525-5846; lcorreia@rics.bwh.harvard.edu. ❖

Book Review

FINALLY...A TEXT BOOK FOR GENETIC COUNSELING

edited by: Baker, D, Schuette, J and Uhlmann, W pubished by: John Wiley & Sons, Inc., 605 Third Ave, New York NY 10158-0012; ©212-850-6000 cost:\$49.95 pb; \$79.95 hb reviewed by: Karen Eanet, MS

After reading A Guide to Genetic Counseling, my first reaction was, "It's about time." The number of training programs granting master's degrees in genetic counseling is expanding, the number of available counseling jobs is on the rise and genetic counseling, as a profession, is becoming more visible. There may not be a better moment to publish a book by genetic counselors for genetic counselors. Carpe Diem!

This textbook fits its bill as an overview of the fundamentals of genetic counseling. It is an invaluable tool for directors of genetic counseling programs in designing curriculum, compiling reference materials and improving student rotations. Each topic is covered clearly and concisely, with a complete list of cited references. Many chapters have an appendix that strengthens the text and demonstrates the practical application of the principles covered. Throughout the book, case examples are used to illustrate specific points. This technique makes it easier to read and digest even difficult subject matter, such as the educational models and the psychological theories that influence our work.

Genetic counseling students will find this book an essential addition

to their libraries. There is an excellent historical review of the establishment and development of the current model of genetic counseling, which provides a foundation for the profession. Discussion of professional development and the expansion of

genetic counseling services into nontraditional areas will inspire students and those

'This book has a great potential for increasing the visibility of genetic counseling...and defining the contributions that genetic counselors make to medical practice.'

new to the field. Practical approaches to student supervision, medical documentation, the details of case management and the essential components of a medical genetics evaluation are clearly and usefully described. Examples of patient letters, risk interpretations and consent forms are also provided.

Experienced counselors will also find this book useful for reviewing basic theory and practice guidelines. The chapter on taking a family history is instructive regarding the use of standard pedigree symbols, while the chapters on psychosocial counseling, interviewing techniques and multiculturalism remind us of the high standards of care toward which our profession is constantly striving.

An indirect outcome of this book is the validation of genetic counseling as a multifaceted process that should be carried out by qualified, well-trained professionals. Each chapter emphasizes the complexity of the issues surrounding these topics, constantly reinforcing the idea that genetic counseling goes beyond the seemingly

straightforward presentation of recurrence risks and patterns of inheritance. While this is not a foreign concept to genetic counselors, it may be a novel one to many physicians and managed care organizations.

Although this is an outstanding book overall, some areas could have been covered in more depth. Information regarding the organization and

critical reading of research papers as well as guidelines for conducting subjective and objective research studies would be welcome.

Finally, there are very few practical hints for defining genetic concepts to clients. Communication of genetic principles is a constant challenge to those in our profession. Novel approaches for communicating these ideas are always appreciated by experienced counselors and are very helpful for novices developing their own styles.

The market for this textbook is obviously the genetic counseling profession and other health care providers involved in medical genetics, and the benefits of this text to those individuals is clear.

This book has a great potential for increasing the visibility of genetic counseling, stressing the importance of utilizing appropriately trained genetic counselors and defining the contributions that genetic counselors make to medical practice. •

EXECUTIVE OFFICE GROWTH: GETTING THE HELP YOU NEED

Whitney Neufeld-Kaiser, MS

Lused to be that when members had a question about NSGC, the response was, "Call Bea."

As our society has grown and flourished — now surpassing 1700 members! — our Executive Office has grown as well and now has staff members. This has increased the

efficiency of the Executive Office, but has added some confusion for members. Who *do* you call to get a copy of the mailing labels?conference registration?career information for prospective genetic counseling students? Directly contacting the appropriate staff person will help the Executive

Office address your needs in the most timely fashion.

You received a set of three rolodex cards in your September NSGC Membership mailing summarizing frequently used numbers so they will be right at your fingertips. If you did not receive these rolodex cards, or if you would like an extra set, contact Lisa.

EXECUTIVE OFFICE CONTACTS

VoiceMail (VM): ©610-872-7608 or use these Emails and faxes to quickly retrieve the information you need!

CONTACT LISA nsgclistQ@aol.com or fax 610-872-1192

- NSGC listserv (how to join, how to suspend service, questions or problems)
- Career packets, including list of current training programs: VM#1
- Publication orders: VM#3
- Guidelines for how to apply for CEUs

CONTACT AUDREY nsgcassist@aol.com or fax 610-565-6220

- JobConnection (to obtain current job listings, post a position, get an invoice or learn deadlines) or call VM#2
- Dues and conference payments, including receipts, VM #6
- NSGC mailing labels
- Membership (renew, rejoin, verify current membership status)
- Special Interest Group (SIG) information (except budgets)
- Consumer Referrals. *Where can I find a genetic counselor in my area?* VM#7 or visit ResourceLink on our Website, www.nsgc.org
- Database information changes
 Fax last page of NSGC directory to 610-565-6220
- Information about short courses and Board review course VM#6

CONTACT BEA VM#8; Members Only Line ©610-872-5959; Fax 610-872-1192 or nsgc@ool.com with questions concerning:

- Member and society concerns
- Strategic plan
- Annual Education Conference: planning, forms, logistics, who gets reimbursed, etc. (*Do not call the hotel*)
- Regional conference planning
- Requests to include information in regularly-scheduled mailings

WHERE TO TURN

- Examinations. Any and all questions: ©301-571-1825; Fax: 301-571-1895; srobinson@abgc.faseb.org; or visit www.faseb.org/genetics/abgc/abgcmenu.htm
- For *any and all* questions about professional liability insurance, contact ACA Insurance Trust ©800-347-6647x284;
 Fax: 703-823-5267;
 ACAIT@worldnet.ott.net
- "NSGC's web site www.nsgc.org is also a place to check for updates and information. The website contains all this and more!
 - Dates, locations and information about NSGC educational programs
 - Information and deadlines for Jane Engelberg Memorial Fellowship, Special Projects Fund and GeneAMP proposals
 - ResourceLink
 - Position statements and resolutions and Code of Ethics ...and much more.

Keep these contact options handy, and bookmark our webpage in your browser. Then visit us every so often to learn what's new. *

WHAT'S ON THE WEB?

Shelly Cummings, MS

- BREAST CANCER SUPPORT GROUPS IN U.S. & CANADA The University of California at Davis has a website listing cancer support groups from around the United States and Canada. cancer.ucdmc.ucdavis.edu/brstsupp.html
- NATIONAL LIBRARY OF MEDICINE
 If you are curious about genetic
 topics from Marfan Syndrome to
 male pattern baldness, surf over to
 Genes and Disease. The site
 briefly describes the role of genes
 in about 60 diseases and offers
 links to other databases, e.g.,
 OMIM and PubMed.
 www.ncbi.nlm.nih.gov/disease
- GLOBIN GENE SERVER

 This site provides information
 about human hemoglobin
 mutations and the regulation of
 the beta-like globin gene clusters.
 It contains a very helpful database
 called, "The Syllabus of Human
 Hemoglobin Variants," useful for
 understanding the hematology of
 these variants. In addition, this
 site provides extensive
 information about lab data with
 references. globin.cse.psu.edu ❖

COME VISIT OUR NEW SITE!

NSGC's homepage has recently been redesigned and contains many useful hotlinks. Stop by and surf around!

http://www.nsgc.org

Perspectives in Genetic Counseling 20:4 — Winter 1998/99

ListServings

Info on: AUTISM; CONSENT; PREIMPLANTATION

Lyn Smith Hammond, MS

For those of you without access to our general listserv, some valuable resources were recently shared among members on this important news-breaking topic.

Possible Breakthrough in Treatment of Autism

The possible connection between autism and secretin was the subject of several recent postings to the listserv and has been the focus of a recent *Dateline NBC* segment. Secretin is a hormone that stimulates the exocrine function of the pancreas and is used in the diagnosis of gastrointestinal problems. *Caution:* Only one study has been published: Horvath K *et al.* (1998). Improved social and language skills after secretin administration in patients with autistic spectrum disorders. *J Assoc Acad Minor Phys*, 9(1):9-15.

Another helpful reference:

Chudley AE, et al. (1998). Outcomes of genetic evaluation in children with pervasive developmental disorder. *J Dev Behav Pediatr*; 19(5):321-5.

WEBSITES

DECLINE? PLEASE SIGN

The MSAFP consent form at St. Agnes Hospital in Baltimore requires the patient's signature if she declines the test. Their genetic counseling screening form has a concluding statement for persons who decline invasive tests stating that the patient received genetic counseling, understands what the fetus is at risk for and has decided not to have CVS/amniocentesis.

If you want copies, call Deborah @410-368-2621; dkass@stagnes.org.

PRE-IMPLANTATION: A STEP AHEAD

A group at the Dutch Speaking Free University in Brussels, Belgium (Dr. Inge Liebaers, Department Medical Genetics, ©2-477-6071; fax: 2-477-5800), is attempting preimplantation diagnosis for myotonic dystrophy and Huntington's Disease.

According to Sermon K, et al. (1997), Prenatal Diagnosis, 10:925, 932, the success rate is poor, perhaps related to difficulty in keeping embryos viable vs. the ability of the woman to achieve pregnancy. Success rate in the repeat expansion disorders seems lower than the usual low yield for other conditions. •

At Your Fingertips

1999 SIG CHAIRS

ART/INFERTILITY Jill Fischer ©616-391-3068

Jill.Fischer@spectrum-health.org

CANCER RISK Stephanie Kieffer ©403-492-4810; skieffer@gpu.srv.uolberta.ca and Shelly Cummings ©773-702-4749

sacummin@smtp.mcis.uchicago.edu

CLINICAL S'VISORS Liz Stierman @323-732-1023; LStierman@aol.com

CONNECTIVE TISSUE Melanie Pepin ©206-543-5464; mpepin@u.washington.edu

DIVERSITY Ilana Mittman @410-602-8662; imitman@howard.edu

DNA DIAGNOSTIC TESTING & LABS Barbara Pettersen @408-972-3311

> Barbara.Pettersen@ncal.kaiperm.org and Cathi Rubin Franklin ©800-877-2520 x6157 CathiFranklin@sb.com

GC Training Prog Directors Judith Tsipis ©781-736-3165 Tsipis@binah.cc.brandeis.edu

LEGAL ISSUES Susan Schmerler @973-754-2727; schmerler@sjhmc.org

NEUROGENETICS. Deborah DeLeon ©212-844-8719; ddeleon@bethisroelny.org and Karen Krajewski

©313-577-8317; ac5339@wayne.edu

Prenatal Melissa Kershner ©610-954-3900; kershnm@slhn.org and Renee Laux ©757-481-8900; RAL46XX@ool.com

PEDIATRICS Julie Rutberg ©410-955-3071

jrutberg@welchlink.welch.jhu.edu

PRIVATE PRACTICE Susan Donlon ©808-739-9445; donlon@lava.net

PSYCHIATRIC DISORDERS Beth Rosen beth.rosen@mci2000.com

PSYCHOTHERAPY Luba Djurdjinovic ©607-724-4308; luba@spectra.net

PUBLIC HEALTH Sylvia Au ©808-733-9055; squ@hgeq.org

RESEARCH Kim Wentzlaff ©507-266-0292; wentzlaff.kimberly@mayo.edu

PEDIATRIC SIG

Julie Rutberg, Chair

- Sponsored the practice-based symposium, "Communicating with the Child in Pediatric Genetic Counseling" at this year's Annual Education Conference.
- Compiling a list of literature about genetic disorders written for children, and a bibliography of publications helpful for families whose children have special needs.

DIVERSITY SIG

Ilana Mittman, Chair

- Sponsored a workshop at the Annual Education Conference focusing on counseling clients with multicultural backgrounds.
- Sponsored a breakfast to spearhead a Mentorship program. The event was attended by 30 individuals.
- Awarded \$150.00 in scholarships to two genetic counseling students, Claudia Carriles (AZ'99) and Samita Kabadkar (CO'99), to help offset the cost of attending the conference. Both students presented essays about the contribution of counselors of diverse backgrounds to the genetic counseling profession.
- Developed a brochure describing the SIG's purpose, goals and mission.

Future Direction:

- Expand focus beyond ethnic and racial diversity to include males, individuals with disabilities, recent immigrants and any other unique backgrounds.
- Work with NSGC to develop career packets and posters targeting multicultural populations.
- Compile a directory of students of

diverse backgrounds for distribution among students.

NEUROGENETICS SIG

Deborah DeLeon & Karen Krajewski, Co-Chairs

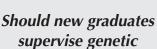
 Developing a brochure, "New Frontiers in Genetics: Genetic Counseling for Neurogenetic Disorders." This brochure will be distributed to Neurogenetics SIG members. Single copies are available at no charge by contacting the Executive Office.

CLINICAL SUPERVISION SIG

Liz Stierman, Chair

- Creating a listsery to discuss dilemmas, share tips and experiences of supervising students, given the lack of formal supervision training.
- Gathering evaluation forms used at various sites for future distribution.
- Discussing the viability of a Short Course.
- ■Unless otherwise noted, contact SIG chair directly for more information about any of the activities noted. ❖





supervise genetic counseling students?
Fax or EMail your thoughts,

comments and opinions to:

Faye Shapiro
Fax: 609-338-9211;
ggrfand@ool.com�



BULLETIN BOARD



CALL FOR PROPOSALS

Applications for a short course in 2000 are being accepted through March 31.

Short courses offer intensive study in specific areas of genetics. The working title of our Annual Education Conference in 2000 is,

IN MEMORY OF

MARGARET KOLODIEJ

It is with great sadness that we share with the NSGC community the loss of one of our colleagues, Margaret "Peggy" Kolodziej, age 33, of Omaha, Nebraska. Peggy was killed in a tragic car accident on October 7 as she was returning home from an outreach clinic.

She was a 1997 graduate of the University of Cincinnati Genetic Counseling Program and was employed by Boys Town Institute and the University of Nebraska Medical Center.

Peggy found great joy in genetic counseling and truly advocated for her patients. She related to patients, colleagues and friends with a remarkable level of sensitivity and a quiet, unassuming manner.

Peggy will be greatly missed but never forgotten by her family, friends, colleagues and patients. Those who knew her were blessed to have been touched by her gentle spirit. * "Exploring the Counseling Role in Genetic Counseling." We therefore encourage short course proposals with a scientific or clinical focus to provide balance to the conference's counseling/pyschosocial emphasis.

Guidelines and applications are available from Cindy Soliday, Chair, Annual Education Conference Subcommittee; ©408-972-3332; Cindy.E.Soliday@ncal.kaiperm.org

CALL FOR PRESENTATIONS

Healthy Mothers, Healthy Babies Coalition is accepting presentation, poster and workshop submissions for their conference in Seattle, August 2-4. Submissions are being accepted through Jan 15.

The program committee will consider proposals that fall into one of three broad tracks: Reducing Disparities, Improving Access and Ensuring Quality. Presentations may focus on Clinical Research, Cultural Competency, Technology, Economics, Ethics and Maternal and Child Health Issues as they impact the three broader tracks listed above.

For a presentation submission prospectus, ©703-836-6110 or visit: www.hmhb.org.

NATIONAL AND REGIONAL AWARDS RECOGNIZE MEMBERS

The Natalie Weisberger Paul Award is granted to a member who has exemplified extraordinary national achievements. This year's recipient was Audrey Heimler. 1998 Region Awards went to: Region I, Janet Rosenfield; Region II, Ann C.M. Smith; Region III: Nancy Adams; Region IV: Nancy Steinberg Warren; Region V: Joy Redman and Region VI: Kerry Silvey. Congratulations all!

WEB SITE EXPANDED

Have you visited our new web site yet? Have a great idea to enhance the information we are providing for our members and the community "out there?" To submit your idea, contact Beth Billings, eabillin@iupui.edu, Chair, Computer Users Group, a subcommittee of the Education Committee.

BIOETHICS FELLOWSHIP

The Center for Bioethics at University of Minnesota will have a one-year post-doctoral fellowship available July 1999. The goal of the fellowship is to foster scholarship and career advancement in the field of biomedical ethics. The award will be \$27,000 plus health benefits.

Requirements include: completion of a PhD, MD, JD or other relevant terminal degree; evidence of academic excellence and scholarly promise; history of work in bioethics and topics focused on the study priorities at the Center.

Applications, which may be obtained contacting the Center for Bioethics: 612-624-9440; fax: 612-624-9108; vange001@tc.umn.edu are due February 15. *



COMING THIS SPRING TO YOUR MAILBOX

1999 Membership Directory *February 15*

Deadline for new or revised information

Early April

• New directories to be mailed to membership

Conference Information

Mid March

EMPLOYMENT OPPORTUNITIES

- LITTLE ROCK AR: Immediate opening for BC/BE Cancer Genetic Counselor. Ability to work independently. Broad range of cancer genetic cases w/ concentration in breast & colon cancer in this newly created position in rapidly growing, comprehensive reg'l cancer ctr. Satellite, interactive video clinics. Tchg/rsrch opptys.
- Becky Butler, University of Arkansas for Medical Sciences, 4301 W. Markham, Repro Genetics, Slot 506, Little Rock AR 72205; ©800-358-7229; Fax 501-269-1701; ButlerBeckyB@exchange.uoms.edu. EOE/AA
- LITTLE ROCK AR: Immediate opening for BC/BE Genetic Counselor. New grads welcome to apply. Join clin genetics team for outpt peds & adult clinics & inpt peds consults. Oppty to partic in prof educ, develop innovative ideas in pt care & personal advancement.

 Ser Send CV, cover ltr & 3 refs to: Mary A. Curtis, MD, University of Arkansas for Medical Sciences, 4301 West Markham, Slot 512-22, Little Rock AR 72205;

 501-320-2966; Fax 501-320-1564; curtismary@exchange.uums.edu. EOE/AA
- SAN FRANCISCO CA: Immediate opening for BC/BE Genetic Counselor in neurogenetics clinic, primarily Frontotemporal dementia/ Alzheimers. Strong rsrch component in addition to clinical work. Expanding multidisc team: dx, GC, intervention & rsrch.

 ** Andrea Zanko, MS, Div Medical Genetics, UCSF, Box 0706, San Francisco CA 94143; Fax 415-476-9305. EOE/AA
- San Juan Capistrano CA: Immediate opening for BC/BE Genetic Counselor/ Genetics Associate w/ 3-5 yrs clin exp, pref in strong academic setting where utilization of state of the art laboratory svcs are a priority. Strong verbal & written commun skills req. Working knowledge of PC operations & familiarity w/ genetics software desired. Provide clients w/ high qual consult svcs to ensure optimal use of molecular, biochemical & cyto genetic tstg. Assist labs w/ case mgmt & develop educ & promotional materials for prof, pts & staff. Guide ethical & regulatory compliance in genetic tstg.
- Send CV & salary hx to Human Resources L30, Quest Diagnostics, 33608 Ortega Hwy, San Juan Capistrano CA 92690-6130; ©949-728-4080; Fax 949-728-4985; EOE/AA
- New Haven CT: Temp oppty for 2 Genetic Counselors from March - June '99 in busy PNDx svc in tertiary care facility. Varied caseload; educ oppty; competitive salary. ™ Miriam S. DiMaio, MSW, Yale University School of Medicine, Dept Genetics, Prenatal Diagnosis Unit 330 WWW, 333 Cedar St, New Haven CT 06510; ©203-785-2661; Fax 203-785-7673; miriom.dimoio@yale.edu. EOE/AA
- WILMINGTON DE: Immediate opening for Part-time (20 hrs/wk) Master's level Genetic Counselor w/ interest in PNDx, abil to interpret AFP results, respond appropriately & effectively to pt crises & situations, knowledge of genetics & the impact on maternal/fetal medicine. Excellent interpersonal & commun skills req. Provide GC to PN & preconceptual women/families; represent Christiana Care in state & reg'l activities re: genetic svcs.

- S J. Daly, Human Resources, Christiana Care Health System, PO Box 1668, Wilmington DE 19899; ©800-999-9169 x5768; Fax 302-428-5770; jddly@christianacore.org; www.christianacore.org. EOE/AA
- CHICAGO IL: Immediate opening for BC/BE Genetic Counselor. Bilingual Span/ Eng desired. Join Dept OB/GYN to coun OB pts & parents of infants affected by genetic disorders. Pt & commun educ; partic in clinoriented rsrch studies & perinatal loss prog.

 Fran Jaeger, DrPH, University Illinois at Chicago, Perinatal Center, 820 S Wood Street M/C 808, Chicago IL 60612-7313;

 ©312-996-0818; Fax: 312-413-0263; fjoeger@uic.edu. EOE/AA
- SPRINGFIELD IL: Immediate opening for BC/BE Genetic Counselor. Genr'l peds, GC & spec clinics, instruct medical students.

 □ Dr. Virginia Kimonis, SIU School of Medicine, PO Box 19658, Springfield IL 62794-9658; vkimonis@wpsmtp.siumed.edu. EOE/AA
- DANVERS MA: Immediate opening for P/T Genetic Counselor. Work in MFM Prog at the Women's Health Ctr. Work closely w/ perinatologists, MFM nurses, radiology team & admin to provide state of the art, sensitive PN care to women in high risk pregnancies. Women's Health Center of the North Shore, One Hutchinson Dr, Danvers MA 01923; ©978-777-1070 x226; Fax 978-774-9635. EOE/AA
- DETROIT MI: Immediate opening for independent BC/BE Genetic Counselor. Min 3 yrs PN exp req. Potential to expand Tay Sachs Screening Prog into Jewish Genetic Disease Screening Prog. Expanded opptys for cancer GC. Great work environment.

 Karen Mackenzie, Administrative Secty, DMC/Sinai Hospital, Dept ObGyn, 6767

 West Outer Dr, Detroit MI 48235; ©313-493-6060; Fax 313-493-7503. EOE/AA
- DETROIT MI: Immediate opening for BC/BE Prenatal Genetic Counselor. High motivation, PN exp req. Excellent oppty for partic in rsrch, tchg & special projects. Join active Reproductive Genetics Ctr w/ diverse referral indications & cultural/socioeconomic backgrounds: maternal age, PN scrng, U/S abnormalities, family hx & teratogens. Amnio, CVS, 1st trimester scrng, fetal dx & therapy.

 Eric Krivchenia, MS, Div Repro Genetics, Dept OB, Hutzel Hospital, 4707 St. Antoine Blvd, Detroit MI 48201; ②313-745-7067; Fax 313-993-0153. EOE/AA
- EAST LANSING MI: Immediate opening for BC/BE Genetic Counselor. Genrl genetics, PN & satellite clinics w/ multidisc team: PN scrng, DNA dx & cytogenetic labs. May incl CF educ & use of DNA tstg results. Oppty for BrCa & HD clinic involvement

 ** Michael L. Netzloff, MD, Dept Pediatrics/
 Human Development, Michigan State Univ, College of Human Medicine, B-240 Life Sciences Bldg, East Lansing MI 48824-1317; 517-353-2030; Fax 517-353-8464/ EOE/AA
- MINNEAPOLIS MN: Immediate opening for BC/BE Genetic Counselor. MS from ABGC-

- approved program req; min 2-4 yrs exp in clin genetics pref.
 Enthusiastic, motivated, independent w/ good commun & org skills req. Partic in all aspects of GC & case mgmt; develop clin proc & educ progs; train/ s'vise GC & residents; conduct rsrch. Focus on peds, HD, ALS, cancer. See complete job description @ www.hcmc.org/geneticcounselor.html.

 **Pavid Eggen, Human Resources Dept, Hennepin County Medical Center, 701 Park Ave, Minneapolis MN 55415; @612-347-2287; Fax 612-904-4285. EOE/AA
- ST LOUIS MO: Immediate opening for BC/BE Genetic Counselor. Min 1 yr exp pref. Join busy multidisc team on busy PN U/S and genetics service in univ setting. Work w/3 GCs, 2 medical geneticists 1 perinatologist. Send CV, ltr of interest & 3 refs to: Heidi Beaver, MPH, Barnes-Jewish Hospital -North, 216 S Kingshighway, St Louis MO 63110; ©314-454-8168; Fax 314-454-7358 EOE/AA
- NEWARK NJ: Immediate opening for BC/BE Genetic Counselor. Spanish req. Function independently in PN, peds & adult settings in outreach clin & univ-based inner city med ctr. Opptys for rsrch and tchg. Team incl: 3 clinical & 4 PhD geneticists, 5 GCs.

 SET Lorraine Suslak, MS, Ctr Human & Molecular Genetics, UMDNJ/NJ Medical School, 90 Bergen St, Ste 5400, Newark NJ 07103; ©973-972-3311; Fax 973-972-3310; susloklo@umdnj.edu. EOE/AA
- ALBUQUERQUE NM: Immediate opening for P/T BC/BE PN Genetic Counselor. Oppty for a wide variety of PN & preconceptual cases & prog development & outreach clins.

 Katherine Hunt, Dept OB/GYN-4ACC, University of New Mexico Hospital, 2211 Lomas NE, Albuquerque NM 87131-5286;
 ②505-272-6315; Fax 505-272-6385. EOE/AA
- Albuquerque NM: Immediate opening for BC/BE Genetic Counselor. Join office/ hosp-based perinatal practice to work closely w/ BC MFM physicians & BC clin geneticist spec in PNDx, GC & fetal therapies.

 **Send CV & 3 ltrs of rec: Kent Argubright, MD, Perinatal Associates of New Mexico, Ltd., 201 Cedar SE, #405, Albuquerque NM 87106; ©505-764-9535; Fax 505-845-9646; kfomd@ool.com. EOE/AA
- EAST MEADOW NY: Immediate opening for P/T BC/BE Genetic Counselor. Spanish a plus. Join state funded outreach prog: provide PN, cancer & hemoglobinopathy GC to clins in Nassau & Suffolk Counties in addition to in-house respon; involved w/ educ progs to health prof throughout Long Island & assist in the establishment of a Teratogen Info Svc for area physicians.
- Program Coordinator, Nassau Co. Medical Center, 2201 Hempstead Turnpike, Bldg B Rm 224, East Meadow NY 11554; ©516-572-5717; Fax 516-572-6413. EOE/AA See next page

national society of genetic counselors, inc.



233 CANTERBURY DRIVE WALLINGFORD PA 19086-6617



EMPLOYMENT OPPORTUNITIES

... from previous page

- NEW YORK NY: Immediate opening for Genetic Counselor/Staff Associate in Dept. Neurology. MS in GC & 1-2 yrs related exp req. Some travel. Act as Study Coordinator for funded clin genetics projects & GC for Ctr for Parkinson's Disease & other Movement Disorders: Enroll families in studies, obtain family hx, i'view pts & families, org data for grants & manuscripts, collect blood for DNA analysis, adult GC. Send CV & 3 refs: Stanley Fahn, MD, Dept Neurology, Div Movement Disorders, Columbia University, 710 West 168th St, New York NY 10032. ©212-305-1540; Fax: 212-305-5450. EOE/AA
- ROCHESTER NY: Immediate opening for BC/BE temp F/T Genetic Counselor. Exp desired, not req. Join multidisc team to provide maternity leave coverage in repro genetics svc: broad range PN/ preconceptual GC in univ-based academic med ctr. Work w/3-4 GCs, 7 perinatologists & 2 ped geneticists.

 □ Devereux N. Saller, Jr., MD, University of Rochester Medical Center, Div Maternal Fetal Medicine, Section Repro Genetics, 601
 Elmwood Ave-Box 668, Rochester NY 14642;
 □ 716-275-3297; Fax 716-256-1416. EOE/AA
- DURHAM NC: Immediate opening for BC/BE Genetic Counselor. Exp w/ cancer syndromes pref, but not req. Join ongoing rsrch efforts in hereditary breast/ovarian syndromes, expanding rsrch to other sites in developing hereditary cancer clin & rsrch prog. P. Kelly Marcom, MD, Duke University Medical Center, Box 3147, Durham NC 27710; ©919-684-3877; Fax 919-684-4221; morco001@mc.duke.edu. EOE/AA
- GREENSBORO NC: 8/1/99 opening for BC Genetic Counselor to serve as Director, Graduate Program in GC. Admin & supervisory exp in GC pref. Guide accreditation process for new prog to begin Fall 2000. Instructional respon for core courses & clin exp (rotations) in variety of hosp settings.

 Ser Send CV, letter & 3 refs: Dr. Brad Bartel, Graduate Dean, UNC Greensboro, 241

 Mossman, Greensboro NC 27402-6176;

 ©336-334-5375; Fax 336-334-4424;

 b_bortel@office.uncg.edu. Application deadline: 1/18/99. EOE/AA

- CLEVELAND OH: Immediate opening for BC/BE Genetic Counselor. Exp pref; interest in colorectal cancer a plus. Work in PN, peds, adult & cancer settings w/ 3 geneticists & 1 GC. Meagan Krasner, MS, Dept Medical Genetics-T-10, Cleveland Clinic Foundation, 9500 Euclid Ave, Cleveland OH 44195; ©800-998-4785; Fax 216-445-6935; horism@cc.cd.org. EOE/AA
- PHILADELPHIA PA: Immediate opening for temp P/T Genetic Counselor. Self motivated & computer exp pref. Join growing adult genetics prog w/ genrl & spec progs (NF, Connective Tissue & Hemochromatosis).

 *** Jennifer Farmer, MS, Div Medical Genetics, Hospital of the University of Pennsylvania, 1 Maloney Bldg, 36th & Spruce St, Philadelphia PA 19104; ©215-614-0937; Fax 215-614 0298. EOE/AA
- GREENWOOD SC: Immediate opening for BC/BE Genetic Counselor/Clinical Coordinator to join large, multidisc team. Some travel to instate clinics. Assist MD clin geneticists in genrl & specialty clinics (Down syndrome, skeletal), PN GC, some pt & commun educ.

 □ Richard Schroer, MD, Greenwood Genetic Center, 1 Gregor Mendel Cr, Greenwood SC 29646; ②864-941-8100; Fax 864-941-8114; ksweet@gg.org. EOE/AA
- MEMPHIS TN: Immediate opening for BC/BE Genetic Counselor w/ exp in cancer. Excellent speaking skills & abil to work independently req. Continue developing cancer-genetic prog in community hosp, all aspects of GC svcs.

 Greg Fecteau, Oncology Administrator, Baptist Memorial Hospital, 899 Madison Ave, Memphis TN 38146; ②901-227-0039;

Fax 901-227-0035. EOE/AA

- HOUSTON TX: Immediate opening for BC/BE Genetic Counselor in large, acad lab. Good working knowledge of molec tstg & strong ability to multi-task req; exp a plus. Primary role: answer inquiries re: molec tstg & review/report results. Secondary: rsrch & educ. Secondary: srch & educ. Secondary: nostic Laboratory, One Baylor DNA Diagnostic Laboratory, One Baylor Plaza, #T536, Houston TX 77030; ©713-798-6536; Fax 713-798-6584; curolynr@bcm.tmc.edu. EOE/AA
- HOUSTON TX: Immediate opening for BC/BE Genetic Counselor. Independent,

- computer friendly, self-starter req, Span pref. Join pre-conceptional team to coord developing commun-based pre-conceptional GC & educ prog. Oppty for tchg & rsrch.

 Tousty Fleming, MS, Dept OB/GYN, LBJ General Hospital, 5656 Kelley St, Houston TX 77026; ©713-636-4546; Fax 713-636-4521; dfleming@obg.med.uth.tmc.edu or Aimee Tucker, MS, Dept Pediatrics, University of Texas Medical School, 6431 Fannin, MSB 3.144, Houston, TX 77225; ©713-500-5766; Fax 713-500-5689; dtucker@pedl.med.uth.tmc.edu. EOE/AA
- SALT LAKE CITY UT: The University of Utah Dept of Pediatrics is seeking a BC or active candidate status Genetic Counselor. Must demonstrate good commun skills, abil to work independently & partic on a team. Commitment to excellence req. Provide comprehensive genetic svcs for l'natl Genetics Consult Prog: direct client GC, public educ & prog devel. Aid investig to plan, implement, interpret & present clin genetics rsrch.

 Bridget Kramer, RN, Dept Human Genetics, University of Utah, 15 N. 2030 E, Rm 2100, Salt Lake City UT 84112-5330; ®801-585-9495; Fax 801-585-9148; bkrumer@genetics.utah.edu. EOE/AA

International Opportunities

- TORONTO ONT, CANADA: Immediate opening for BC/BE Genetic Counselor. Provide genetic assessment & GC for ind/families in Metabolic Genetics. Identify rsrch opptys & implement or partic in rsrch projects. Disseminate new knowledge through presentations, publications & tchg opptys. ¹⁸⁸ Kris Moore, Human Resources, The Hospital for Sick Children, 555 University Ave, Toronto, ON CANADA M5G 1X8; ©416-813-8222; Fax 416-813-5671; kris.moore@sickkids.on.ca. EOE/AA
- OSLO, NORWAY: Immediate opening for cancer genetic counselor. BC/BE pref; working knowledge of a Scandinavian lang req. Join multidisc team at largest cancer hosp in No. Europe. Partic in all aspects of cancer counseling svcs. Clin rsrch oppty.

 **Pal Moller, MD, PhD pmoller@ulrik.uio.no;

 *Fax: 011 47-2293 5219; ©011 47 2293 4786.

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 Norway or Trine Levin, MS, trinele@lobmed.uio.no