PERSPECTIVE S in genetic counseling

Volume 24 Number 1 Spring 2002

national society of genetic counselors, inc.



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

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NSGC acknowledges Women's Health Care Services of Wichita, Kansas, for a sponsor's grant to support this newsletter.



Women's Health Care Services, providers of late abortion care for fetal anomalies, George R. Tiller, MD, Medical Director. 800-882-0488.

New PR Firm Named

STAR GROUP TO REPRESENT NSGC

Bea Leopold, MA

The Board of Directors is pleased to announce a new public relations team, STAR/Rosen Public Relations with offices in Philadelphia, Pennsylvania and Cherry Hill, New Jersey. STAR/Rosen is an award winning public relations company. The firm is a division of The STAR Group, a full service, fully integrated marketing communications organization, which is ranked in the top 10 on the Philadelphia Business Journal's list of Top 100 fastest growing companies in the Greater Philadelphia region. The STAR Group's philosophy is to think strategically first.

FINDING THE RIGHT TEAM

Kathy Schneider, Liz Stierman, Vivian Weinblatt and I represented NSGC on the interviewing team after the group ranked at the top of a competitive bid process in February. Once chosen, this team was joined by Angela Trepanier, our Media Subcommittee Chair, for an intense half-day session in which the STAR team learned about us and our vision for this program.

STAR/Rosen has been charged with the following public relations objectives:

- position NSGC as a recognized leader in its field
- increase awareness and understanding of genetic counseling to consumers and the media
- educate and clarify the role of genetic counselors, and
- dispel myths and apprehensions about genetic counseling.

The plan includes: the development of a survey to learn about news-

...to page 3

LICENSURE UPDATE

Eric Rosenthal, MS

enetic counselors in various states are trying to mobilize efforts for licensure, but so far activity has been slow. The process is daunting, and some state governments have reportedly told counselors that the profession is either too small or that costs would be prohibitive. Many counselors remain confused about the pros and cons of licensure, leading to ambivalence or active opposition.

Perhaps the most problematic issue is the status of genetic counselors without ABGC certification. Licensure

provides legal authority for states to enforce standards of professional competence, and this typically involves passing an exam. Since we have an exam in place, it is reasonable that most states will require this as proof of competence. Unfortunately, it is only offered once every three years, raising the possibility that counselors could have to wait before being eligible for licenses. Possible solutions include administering the exam

PRESIDENT'S BEAT

Dear Colleagues,

It's been a busy few months since the last issue of *Perspectives*. Rather than list all of my activities, I am choosing to highlight a few key items: excerpts from two letters, a few deadline reminders and a reference to oral testimony to the Secretary's Advisory Council on Genetic Testing (SACGT).

EXCERPTED LETTERS

February 6

Along with Betsy Gettig, in her capacity as President of the Association of Genetic Counseling Program Directors, I cosigned a letter to Sydney S. Gellis, MD, Editor, *Pediatric Notes: The Weekly Pediatric Commentary.* I'd like to thank all of you who voiced your concerns about the editorial, prompting the following response.

"... We strongly disagree that the only genetic counselors deserving of the title are physicians. (Commentary in Pediatric Notes, Dec 27, 01)

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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 **June 15**Submission deadline **May 10**

Perspectives in Genetic Counseling 24:1 — Spring 2002

"The profession of genetic counseling has been with us for over 30 years. ... To imply that graduates of [genetic counseling] training programs are unqualified to be genetics specialists is frankly inaccurate.

"... The creation of the masters-level trained genetic counselor has enabled tens of thousands of people to access quality genetic services. As members of a health care team, we currently work in an array of medical specialties including prenatal, pediatric, neurology, oncology and public health. Although it is disheartening to read [your] dismissive comments about our profession, we are secure in knowing that most physicians and families appreciate our extensive knowledge of genetic syndromes and current technologies, our specialized training in counseling skills and our dedication to quality patient care."

March 4

The following letter was sent to the AMA's Dr. Grace Kotowicz, CPT Editorial and Information Services, to request a seat for a genetic counselor on the Health Care Professionals Advisory Committee. We were asked to justify that we would be appropriate to serve as the umbrella organization for genetic counselors, that we meet their criteria to serve and that we have understanding of and use CPT codes.

"Thank you for considering our request to appoint a genetic counselor representative to the Health Care Professionals Advisory
Committee. ... NSGC's [vision qualifies us to serve as a voice for the profession] and [meets] eligibility criteria for requesting representation on HCPAC based on your definitions. The NSGC: 1) is a national medical specialty society that does not qualify for representation in the AMA House of Delegates and 2) is a national organization of professionals that

provides services reported under the supervision of physicians. ... NSGC has members who are familiar with issues of coding who would be eager to assist the AMA in their endeavors to further refine codes suitable for non-medical doctors.

"... One expected outcome of the human genome project is a dramatic increase in genetic counseling and testing referrals. Thus, having genetic counselor representation on HCPAC is both important and timely. I look forward to hearing from you after the May 2002 ... meeting."

DEADLINES

Lastly, please note the following deadlines, as noted in my letter in the February Membership Mailing:

- Fri, Apr 5: Call for Board Nominations
- Wed, May 1: Jane Engelberg Grant Proposals
- Wed, May 15: Special Project Fund Grant Proposals
- Fri, June 7, 11:59pm, EST: Abstracts for 21st Annual Education Conference Contributed Papers

We've held this issue one week beyond scheduled presstime to provide you with highlights of our Board meeting, held Mar 22-24 in Philadelphia.

Wishing you all a happy, sunny and productive Spring!

— Katherine A. Schneider, MPH
President, 2001 - 2002

SACGT RESOURCES

Feb 14 Meeting Complete
Proceedings: www4.od.nih.gov/oba/sacgt.htm

NSGC President's Oral Testimony: www.nsgc.org/nr_test_feb142002.asp

PR TEAM NAMED from p. 1

worthy information for story development with the media; at least one media tour in New York City or Boston; visibility for research presented at our 2002 Annual Education Conference in Phoenix, Arizona; ongoing media relations counseling; and proactive editorial opportunity support for NSGC and its members.

HITTING THE GROUND RUNNING, STRATEGICALLY

In just the first month of activity, the agency helped leverage news of a recently published article in *JAMA*, "Preimplantation Diagnosis for Early-Onset Alzheimer Disease Caused by V717L Mutation," which NSGC member Christina Masciangelo of The Reproductive Genetics Institute, Chicago, was the co-author. As a result of their efforts, a *New York Times* interview and placement was generated, highlighting the world of genetic counselors.

AWARD WINNING PROFILE

Our STAR/Rosen Public Relations Team consists of Steve Rosen, President; John Wannenburg, Vice President; Dina Tau, Account Supervisor; and Linda Woody, Account Executive. Steve has worked with top national corporatations and healthcare organizations, and brings strong strategic quarterbacking to the team as well as relationships with top tier news media. John brings a global perspective to the table, as well as breadth and depth of experience in journalism and has excellent problem solving skills. Dina is a seasoned client relations manager and currently serves as President of the Philadelphia Chapter of the Public Relations Society of America. Linda is known as the team's "media relations maven," with excellent experience in positioning medical experts as media spokespeople in top-tier print and broadcast news media.

The STAR Group has more than 70 employees with six managing partners. The company has won numerous awards in 2001 including Best of Show and 11 first place Addys at the 2001 Philadelphia Ad Club Awards competition; Best of Show, Best of Print and Best of Broadcast at the 2001 Philly Gold Awards competition; the Bronze Clio in the 2001 Clio Awards; recognition in Ad Age's 100 Best Commercials of 2001; was one of 18 agencies recognized nationally at the American Association of Advertising Agencies O'Toole Awards for creative excellence; and over 20 Public Relations Society of America's Pepperpot Awards.

In addition to public relations, the firm has expertise in an array of positioning and marketing services as well as experience with not-for-profit professional health care associations and agencies.

We are well positioned for this launch, and we acknowledge the efforts of Peter Benkendorf and Russ Klettke who brought us to this point.

Learn more about our new PR Team www.storgroupl.com &

Do You Have News? Timing is Key

Are you working on a research study or professionally-related project that you believe is newsworthy? Would you like to raise the profile of genetic counselors by having your story told in the media? Timing is key. The sooner we alert our team to the opportunity, the more prepared they can be to position us in the lead. Advance notice, even if 'embargoed' (held in confidence) until publication or launch date, will be respected with upmost professional care.

Bea Leopold, €610-872-5959; fyi@nsgc.org ❖

Board Meeting Highlights

Cindy Soliday, MS

The NSGC Board of Directors met in Philadelphia, March 22 - 24. The agenda was packed with items key to our future.

The meeting began on Friday evening with dinner and a tour of the Executive Office, the first time the entire Board gathered at the office.

President Kathy Schneider called the meeting to order on Saturday with a packed, full-day agenda, starting with updates on our three task forces: Billing and Reimbursement, Licensure and Partnerships. (Members of these task forces are listed in your 2002 Who's Who Guide to Leadership and Committee Membership.)

An eye-opening three-hour session with our legal counsel, Paula Goedert, followed. Ms. Goedert is lawyer with 25 years experience in association law at the Jenner & Block law firm in Chicago. She presented a not-for-profit primer, beginning with definitions of the differences between the profit and not-for-profit missions as well as the legal and fiduciary responsibilities of a not-for-profit Board of Directors.

She covered three major topics:

- regulations for UBITs (unrelated business income tax), categories of funds collected that not-for profit corporations must pay taxes on. Also discussed were regulations for the creation of an FPS (for profit subsidiary) and/or a foundation.
- lobbying regulations for our category of not-for-profit, 501(c)6 (trade or professional membership), with comparisons with 501(c)3s (charitable). Our category, (c6) can lobby to support our mission, the promotion of the genetic counseling profession, ...to page 9

RETROSPECTIVE: GENETIC COUNSELING ...

"concepts like nucleotide repeat

expansions, anticipation and

predictive testing for late onset

diseases were science fiction."

This new series will feature genetic counselors who have been in the field more than 25 years and will highlight their experiences.

Lynn Godmilow, MSW

GETTING STARTED IN A NON-EXISTENT FIELD

In October 1972, I left the Department of Social Services at Mt. Sinai Hospital in New York to join the Department of Pediatrics, Division of Genetics at Mt. Sinai School of Medicine. Dr. Kurt Hirschhorn, division chief, recruited me to help coordinate the Clinical Genetic Center, which had just been generously funded by NIH. The term "genetic counselor" was not even used in our discussions. He believed my social work experience in the NICU and the Cystic Fibrosis and Cleft Palate Clinics could add value to the division.

Dr. Hirschhorn was one of the earliest and most skilled clinical genetic practitioners. He believed that explaining what was happening to the family and exploring options with them was a high priority. I must admit that I didn't really understand what the job would entail, and we designed the job as we went along.

I spent the first six months in genetics observing and learning, and I became skilled in obtaining pedigrees and medical histories. The faculty and I worked with four genetic fellows who performed most of the clinical services. An expectation of the fellowship was the publication of clinical cases and research papers. I became involved in those efforts.

LEARNING ABOUT GENETICS

To get a real picture of how things were done in those days, understand that there were no copy machines. They hadn't been invented yet. We spent a great deal of time in the library

Perspectives in Genetic Counseling 24:1 — Spring 2002 searching for literature relevant to our cases and taking copious notes. We attempted to call the first author to get more information or suggestions for

testing, counseling and/or management. There were basic textbooks that we carried with us when we saw a new patient in the hospital or in the

clinic. These were our bibles, and we were always anxiously awaiting the newest editions. Included in this group of revered texts were McKuskick's *Catalogue* (now OMIM), Smith's *Recognizable Patterns of Human Malformations* and Stanbury's *The Metabolic Basis of Inherited Disease*.

Molecular testing didn't exist; the genetic testing we had available to us was primarily cytogenetic karyotyping and biochemical analysis, usually enzyme measurement. While we understood (we thought) the Mendelian inheritance of many syndromes and diseases, concepts like nucleotide repeat expansions, anticipation and predictive testing for late onset diseases were science fiction.

We had very little to offer our patients and their families beyond explaining the diagnosis and prognosis, the recurrence risks for the parents and the presumed carrier rates for the relatives. We referred our patients for support services and assisted them as they struggled with very difficult decisions. We followed children with progressive diseases and helped parents secure the multiple medical services these children required.

Managing Office Logistics

When preparing a manuscript or slides for a talk we used a Correcting Selectric IBM typewriter, which could actually back up and correct a typo! We had a Polaroid camera and made

our own slides for talks and illustrations for papers. We used handwritten overheads a lot.

Answering machines and voice mail

didn't exist. A secretary answered the phones, and if she stepped away, the

phone would just ring. There was no fax machine. If we needed paperwork or records from elsewhere we mailed a release form and waited for the snail mail to arrive.

COLLECTING DATA

All data collection and analysis of data were done manually. When we collected our first 1000 amniocentesis cases and published the results, all the data was collected by hand on long paper spreadsheets which we designed, and then we hand counted all the categories over and over to make certain that we hadn't made any mathematical errors. There were no computers, no databases, no spreadsheet computer programs to crunch the numbers for us. When we wanted to collect multiple patients and families with the same disease or condition, we kept index cards on each patient or family, filed by disease or condition.

COLLECTING SAMPLES

As more and more patients came to the lab to deliver their amniotic fluids after having amniocentesis, and I met with them to get some demographic information, I realized that most of the them did not understand the pros and cons of the procedure they had just had, the reason for the procedure or what they could expect to hear from us later. Dr. Hirschhorn and I agreed that we would institute a new policy requiring all patients to be seen

... IN Practice Then and Now

by me or a fellow prior to having a procedure. Initially the referring OBs protested but when faced with Dr. Hirschhorn's reply that they should find another lab to do the karyotypes (there were none) if they didn't want their patients to have counseling before the procedure, they capitulated

Another Look Back

OUR OFFICE THEN AND NOW

Fifteen years ago, in 1987, NSGC hired me as its first staff person with the title of Executive Director. At that time, the office was in a small, 9x13 spare bedroom in my home, and NSGC shared space with other medical not-for-profit groups unable to afford a full-time Executive Director: a tristate chapter of the Committee to Combat Huntington's Disease (now HDSA) and a local American Medical Women's Association group.

One of my first key responsibilities was to centralize the database, which had been maintained in three locations: by the Secretary, *PGC* editor and Treasurer, who conducted their respective mailings livingroom-style. Database information included names, addresses, phones, faxes (if available) and membership status. EMail wasn't around then! Today, our database is relational, linked to payment history for dues and conferences since 1996. It includes:

- Name, Degree and Membership status
- Addresses, preferred and alternate, including fax and emails
- Region
- Board Certification status
- Year joined NSGC and year graduated, if from a GC program
- Gender (males are indicated in an "XY" field)
- Board of Directors (current and past)
- Current committee membership
- SIG membership history
- Annual Education Conference (≥1988) and Short Course (≥1993) history
- Connecting Links
- Undergraduate Year, Degree(s) and Major
- GC Training Program, if applicable
- Privacy Code
- Social Security #s, for CEU purposes only

Back in 1987, the office was equipped with a Mac Plus, a fax machine and a single-line telephone. I was the sole staff person, with the exception of a bevy of high school students who would prepare the mailings, literally licking stamps. Today, we have a virtual office staff of four, plus a web team, a marketing team, legal representation and accounting services.

In 1987, an NSGC budget did not exist. According to our tax return in 1990, our total revenue was just under \$160,000. This year, the Board passed a budget of \$1million.

Growth and change can be difficult adjustments. I look back over these 15 years with awe, humor, a lot of pride and a glance toward all that the future will bring. �

— Bea Leopold

and our prenatal genetic counseling services were established. The addition of this service enriched our counseling skills as we were dealing with our patients in a new frame of reference. We honed our counseling skills by trial and error.

BECOMING CERTIFIED

I took the American Board of Medical Genetics exam the very first time it was given in 1981, an experience I would not like to repeat. To say that anxiety was high is an understatement. After the exam was over, a new exam had to be written to accommodate that handful of esteemed geneticists who actually took on the task of writing the exam. After all, once the results were posted, they were in an elite group who weren't certified! Exam requirements were designed to allow "genetic counselors" in the field to take the exam.

How Far We've Come

As I was writing this article, I thought back over the 30 years I have been in this field, and I realized how far we have come. How fortunate we are to be able to conduct GeneTests, MEDLINE or OMIM searches on line, print an article from an online journal or pose a question on the listserv and get an answer from a colleague in minutes. Training programs recognize and stress the importance of interpersonal counseling skills so important in preparing today's counselors for the challenges of our patients and families.

To prepare for future challenges, I believe it's important to take advantage of any and all technical training that is offered in your institution to stay on the cutting edge. With as far as we've come, I believe, the most exciting times remain ahead. �

Get Involved!

CALL FOR APPLICATIONS

ABSTRACT COMMITTEE ACCEPTING NEW REVIEWERS

The Annual Education Conference Abstract Committee has four positions available for 2003. Experience in research, publication and/or editing is strongly preferred. In addition, applicants must be Full or Associate NSGC members and have access to email.

Successful candidates will serve a three-year term and will be required to attend a mandatory training program at the 2002 Annual Education Conference in Phoenix, November 9 - 13. We encourage people with all levels of experience to apply! It's a great way to get involved in NSGC.

Applications and CVs will be accepted through May 3. Candidates will be notified of their acceptance status by May 17, 2002.

Information or application:
Noelle Agan €314-569-6884;
agannr@stlo.smhs.com ❖

SHORT COURSE PROPOSALS

Applications for our Short Course to be held in conjunction with the 2003 Annual Education Conference in Charlotte are being accepted through April 19. Members who have an innovative and high quality idea for a short course topic are encouraged to apply.

Recent Short Course topics have included: metabolic disorders, legal issues, research and assisted reproductive technologies.

Guidelines and applications:
Dawn Allain, €414-266-3047;
dollain@chw.org ❖

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PHOENIX...MORE THAN SUN AND SENIORS

Susan Estabrooks, MS

Originally, Phoenix was home to the Hohokam people from 300 B.C. to 1450 A.D. when they disappeared mysteriously. Later, small bands of Pima and Maricopa Native Americans traveled throughout the area. It was not until the mid 1860s when the US Army built Fort McDowell, northeast of Phoenix, that a permanent settlement began. A British settler suggested that the town had arisen from the ashes of the Hohokam, hence the name Phoenix was christened.

Phoenix quickly became an agricultural and transportation mecca. Eventually it became the territorial capital in 1889, at which time it had approximately 3000 inhabitants. As water was a limited resource, it was not until the completion of the Roosevelt Dam, and other dams throughout the Southwest, that Phoenix began to grow. These improvements, coupled with the presence of military training establishments during WW II, the advent of air conditioning shortly thereafter, and the diversion of Colorado River water in the late 1960s, created the modern version of Phoenix. Phoenix, now the capital of Arizona, is the 6th largest city in the US.

Phoenix is now home to one million people within the city limits. However, the surrounding cities of Scottsdale, Tempe, Mesa and others create a sprawling metropolis of close to three million. It is served by Sky Harbor Airport, a major international airport, which is only a ten minute ride from downtown where the Hyatt Regency Phoenix at Civic Center is located. Shuttle service is reasonably priced.

The Hyatt is located within walking distance to all kinds of attractions:

- SHOPPING: Arizona Center and Heritage Square with shops, restaurants and movie theaters
- MUSIC: Symphony Hall
- THEATER: Herberger Theater
- MUSEUMS: Phoenix History Museum
- Arizona Science Center
- SPORTS: Bank One Ballpark, home to the Arizona Diamondbacks World Champions, and America West Arena, home to the Phoenix Suns Basketball and Phoenix Coyote Ice Hockey teams
- RESTAURANTS: All kinds and price ranges to choose from within walking distance.

Other nearby points of interest include the Heard Museum, home to Native American history and art, Phoenix Art Museum, the Phoenix Zoo and the Botanical Gardens. For those with more time and adventurous spirits, Sedona with its beautiful red rocks is about three hours north of Phoenix. Hiking Camelback Mountain or Squaw Peak Mountain are popular destinations, all within a short drive from downtown.

To top off a great meeting, you will be greeted by great weather, typically in the 80s and sunny in November. You can enjoy relaxing by the pool, which includes a pool bar, working out in the health club or enjoying golf, tennis or hiking at many surrounding facilities.

🖙 Be on the lookout for our conference information brochure in early April! 💠



'02 CONFERENCE UPDATE

November 8 - 9:

Advanced Topics in Cancer Genetic Counseling November 9 - 13:

Strategies in Genetic Counseling: Beyond the Basics

Breakout Sessions

Four-hour, in depth Mini Course sessions cover a variety of topics:

- A. Ethnic-based Carrier Screening
- B. The Genetic Counselor as Educator
- C. Management Skills 101
- D. Family Therapy-based Techniques and Interventions
- E. Deafness Genetics
- F. Genetic Polymorphisms Associated with Cancer Risk
- G. Licensure

Two-hour Practice-based Symposia sessions:

- A. Counseling for Infertility and ART
- B. Connective Tissue Disorders
- C. Practical Tips to Influence Policy
- D. How to Write and Use Practice Guidelines
- E. ABCs of Genetics Professional Organizations
- F. Children/Adolescents with Genetic Conditions
- G. Spanish for Genetic Counselors
- H. Spirituality in Genetic Counseling Practice
- I. Adult Learning Strategies in Clinical Supervision

ABSTRACTS

Submit abstracts electronically by Friday, June 7 at 11:59 EST. Notification of acceptance will be sent by July 15. Visit www.nsgc.org/abstract/abstract_quidelines.asp

- Cathy Wicklund, MS, ©713-500-6464; Catherine.A.Wicklund@uth.tmc.edu or
- Cheryl Dickerson, MS, ©704-355-7916; Cheryl.dickerson@carolinashealthcare.org

SHORT COURSE

Statement of Purpose: This high level course targets genetic counselors and health care providers who specialize in cancer genetics. As more cancer-predisposing genes are discovered, professionals will have the opportunity to provide risk assessment for a wider variety of cancers, such as melanoma and prostate cancer. Also, as multidisciplinary cancer treatment clinics incorporate more genetic medicine into their practices, cancer genetic professionals will be expected to become proficient in general cancer issues, such as pathology, alternative treatment modalities and pharmacology. This course will cover current data on the clinical care and diagnostics of hereditary cancer syndromes, focus on recent gene findings, incorporate this new information into practice and address expanding roles in clinical trials. �

BOARD REVIEW COURSE UPDATE

Cramming for the exam or wanting to brush up on basic genetics? It's not too late to sign up for the Board Review Courses sponsored by NSGC and the University of Pittsburgh. Identical courses will be given:

- May 31 June 2 in Baltimore
- June 21 23 in San Francisco

This intensive 21/2 day course will cover the range of topics: biochemical genetics, cytogenetics, quantitative genetics, molecular genetics, clinical genetics, genetic counseling. A total of 2.36 CEUs will be awarded to participants, and all meals are included in the registration fee.

In addition to a program book set in a PowerPoint format, each registrant will receive a copy of *Quick Look Genetics* by Patricia Hoffee. This popular study guide is included in the registration fee.

www.nsgc.org/board_review_course.asp or nsgc@aol.com �

'03 AND '04 CONFERENCE DATES AND LOCATIONS

- Our 2003 Annual Education Conference will be held in Charlotte, North Carolina, September 13 - 16. A Short Course will precede the conference, September 11 - 12. Stephanie Cohen and Ellen Schlenker have been named as co-chairs.
- Our 2004 Annual Education Conference will be held in Washington, DC, October 7 - 11. A Short Course will precede the conference, October 6 - 7.

Information will be posted on our website as it becomes available. �

Angela Geist, MS & Roxanne Ruzicka, MS

Archives of Internal Medicine, 11/12/01 — "Accuracy and Ambiguity in Counseling Patients About Genetic Risk" asked the question, "Are the imperfect accuracy and ambiguity of testing likely to do more harm than good?", using the example of hemochromatosis and BRCA mutations. The article stated that "most physicians do not have the knowledge, tools or time to adequately counsel these patients" and mentioned that "genetic counseling is a multistep process that should include pretest counseling to identify the patient's genetic risks and completion of at least a 3-generation pedigree." The article additionally stated that "genetic testing should be obtained only after the patient has given informed consent and is given an opportunity to discuss therapeutic options." The insufficient number of trained genetics counselors to meet the demands of patients was also mentioned.

Times Health, 11/26/01 — "A First for Genetic Testing" was an informative article that discussed the implications of the recommendation by the American College of Obstetricians and Gynecologists and the American College of Medical Genetics that CF testing should be made available to all expectant parents. The complexities of the counseling and testing as well as the difficult ethical issues that could be raised were addressed.

British Journal of Obstetrics and Gynecology, 11/01 — "Amnio Miscarriage Risk Greater in Older Women" is an article many newspapers

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reported. According to the study, women 40 and older have a 5.1% chance to miscarry after an amnio. The risks for women 20-34 and 35-39 were 2.5% and 3.4% respectively. Study participants included women with and without miscarriage risk factors.

PMA (a journal for medical assistants) Nov/Dec01 — "A Guide to Genetic Testing and Counseling" detailed why family history is important, what to ask for and how to make referrals. Bonnie LeRoy, Betsy Gettig and Liz Stierman were quoted.

"60 Minutes II," 11/28/01 — "Holy Grail" suggested that "stem cells are thought of as the Holy Grail of medicine." This article featured a boy with sickle cell disease who was cured by a stem cell treatment using umbilical cord blood. The article suggested that using cord blood cells rather than stem cells from human embryos in such treatments causes no political debates or controversy.

The Indianapolis Star, 1/09/02 — "Demand for Genetic Counselors is on the Rise" accurately described the profession of genetic counseling and how the availability of new genetic tests has increased the need for genetic counseling services. Vivian Weinblatt and Karen Heller were quoted.

Smart Computing, 3/02 — "Newborn Screening Gets Shot in the Arm," an article in the Technology News and Notes section, discussed the availability of tandem mass spectrometry for newborn screening. CBR Systems' NewScreen test was highlighted and the article stated that more than 50 genetic disorders can be detected through expanded newborn

screening, making early detection and therefore management possible. No mention was made of genetic counseling for those found to have positive newborn screening results.

Washington Post, 2/26 — "New Breed: Medical Family Trees Get Smarter" discussed the importance of compiling an accurate pedigree for determining susceptibility to genetic disorders. It also explained that there is a genetic component to many common health problems, such as heart disease, epilepsy, psychiatric disorders and some forms of cancer. The article described websites of different organizations that assist in constructing a pedigree and, in some cases, anonymously use the information for research purposes. Three NSGC members, Donna Russo, Robin Bennett and Cara Schmidt, were quoted.

New York Times, 3/3/02 — "Genes, Embryos and Ethics" discussed the ethical issues raised by a case described in the Journal of the American Medical Association in which pre-implantation diagnosis was used for an early-onset form of Alzheimer's disease. Genetic counselor Christina Masciangelo was quoted supporting the patient's decision to have a child despite the ethical considerations.

New York Times, 3/5/02 — The article," Tests for Breast Cancer Gene Raise Hard Choices," discussed the physical and emotional issues involved in BRCA1 and BRCA2 testing. A Sloan Kettering study, which was recently published in the Journal of Clinical Oncology, was described. Lauren Scheuer, genetic counselor, is the first author. She was quoted describing the emotional impact of BRCA1/BRCA2 testing. ❖

BOARD MEETING PACKED WITH STRATEGIC ISSUES AND CONSIDERATIONS, fr p. 1

with tax requirements and registration with federal and/or state entities.

• partnerships, with a focus on IRS rulings on funds received.

Robin Bennett, President-elect, said, "This is the clearest presentation I've ever heard on these issues," a comment shared by the entire Board. Of greatest tribute was the sentiment expressed by all that the three hours flew by and that we could have listened and

learned for another three!

A lively discussion was led by Teresa Brady, Treasurer, including a report from our first-ever audit (we passed!) and considerations for future outsourcing for a bookkeeper. The report was followed by a discussion of suggested fund raising endeavors, led by President-elect Robin Bennett and Past President II, Wendy Uhlmann. Creating corporate sponsorship via a

Corporate Sponsorship Advisory Council, a Foundation, a "bookstore" through Amazon.com, additional short courses as well as increasing marketing of our pamphlets were all discussed. Some ideas were assigned for further exploration.

Bea Leopold prepared a report with Liz Stierman, Communications Chair, on creating a new logo and "corporate (uniform) look" for printed materials as well as the transition to a new domain, nsgc.org. During the transition, our aol.com address will continue to function.

The Board participated in an eyeopening, fast paced competitive team building leadership Olympics, led by President Kathy Schneider.

Kelly Ormond, Education Chair, and Dawn Allain, Region IV Representative and Annual Education Conference Subcommittee Chair, led a lively discussion about the timing of our conference, including plans for a satisfaction survey about our standalone meeting. Preliminary reports are that our stand-alone meetings are successful and we anticipate that member satisfaction will be high. Kathy Schneider, President, informed the Board that we have received a formal invitation to join the American College of Medical Genetics at their meeting in the Spring. No action will be considered before our survey results are analyzed.

On Sunday, we enjoyed a presentation by our new PR team, the STAR Group (see page 1). We then discussed a draft succession plan, created by the Executive Office committee, which will present a final report this fall. The last item on the agenda was an exploration of how funding could be achieved to hire a public affairs staff person. We hope to seek proposals later this year from lobbying firms. �

Perspectives in Genetic Counseling 24:1 — Spring 2002

NSGC Attends Pre-Show Taping on Genetic Issues

Barbara Biesecker, MS

On February 23-24, Fred Friendly Seminars filmed a series of provocative shows in Washington DC. The series, co-sponsored by the Robert Wood Johnson Foundation, NIH, NSF, Alfred P. Sloan Foundation and the Dept of Energy, is slated to be aired early next year on Public Broadcasting System.

Our Genes/Our Choices includes three shows, one addressing genetics and privacy, another on genetics and reproduction and one on the genetics of complex disease. Each show was filmed for nearly three hours in front of a live and informed audience. The room was filled with geneticists, science educators, science journalists and project consultants. Katherine Schneider, President, Kelly Ormond, Education Committee Chair, and Bea Leopold, Executive Director, were invited to represent NSGC.

Fred Friendly Seminars has a 20-year legacy of seminars and programs exploring complex and vital issues. A panel of experts responds to a moderator following a Socratic dialogue format to "bring complex political and ethical issues down to a palpable, human level." Role-plays allow the public to hear a range of responses and the dialogue among informed panel members models the deliberative process around difficult issues.

To intensify the scenarios, the panelists were not informed of the program's script prior to taping. In the first taping, a scenario involved a man who learned he had HNPCC, his/his family's right to privacy and his decision making process about getting tested. The second taping involved prenatal testing and the dilemmas of reproductive decision-making. The last explored a community involved in a privately-funded research project on alcoholism.

For several years, I have served as an advisor to bring this project to fruition. I was asked to participate in the genetics and reproduction show, moderated by John Hockenberry. In my opinion, it was very contrived and limited in conveying important issues. Since each taping will be edited down to 50 minutes, the success of each show will depend upon the editing. The series will air on National Public Television in January 2003 coincidental with the anniversary celebration of the discovery of the DNA helix by Watson and Crick. A large public education effort will be an important extension of the series.

The completed program will consist of a series of three broadcasts. Information about viewing and other opportunities will follow.

POST PRODUCTION NOTE: NSGC has been asked to be a resource partner for the series. In the coming months, we will work with the producers to link this important national viewing audience to the genetic counseling community.



New NSGC Resources

Through a special promotion, NSGC is now offering John Wiley & Sons books penned by genetic counselors at a special discounted rate. For a limited time only, we are offering a 10% discount which includes fees for postage, handling and tax.

Counseling about Cancer: Strategies for Genetic Counselors, by Katherine Schneider. 352pp. 2001. The definitive guide for genetic counselors and health care professionals to help patients navigate through the facts and emotions of hereditary cancers.

List Price \$39.95

You SAVE (less) <u>4.00</u>

Your Price \$35.95 inclusive

Psyche and Helix: Psychological Aspects of Genetic Counseling, essays by Seymour Kessler, Edited by Robert G. Resta. 192 pp. 2001. A collection of classical and original essays on psychological aspects of genetic counseling. Topics cover a range of critical psychosocial and emotional issues facing genetic counselors.

List Price \$79.95
You SAVE (less) <u>8.00</u>
Your Price \$71.95 inclusive

The Practical Guide to the Genetic Family History, by Robin Bennett. 251pp. 1999.

Easy-to-use resource describes how to take and record a patient's genetic family medical history and provides a basic foundation in human genetics.

List Price \$52.50
You SAVE (less) _5.25
Your Price \$47.25 inclusive

Perspectives in Genetic Counseling 24:1 — Spring 2002

RESOURCE

A Guide to Genetic Counseling, edited by D. Baker, J. Schuette, W. Uhlmann. 443 pp. 1998. Describes how to provide genetic counseling with examples from the genetic counseling, medical and legal fields.

List Price \$62.50
You SAVE (less) 6.25
Your Price \$56.25 inclusive

Testing for Huntington's Disease: Making an Informed Choice, by Robin Bennett Comprehensive guide to decision-making for individuals and families atrisk for HD. Definition, testing, and information, impact, issues of family planning and more. 16pp. 2002.

<u>Unit</u>	<u>Price</u>	<u>#</u>	<u>P&H</u>
1	\$3.25 ea.		\$ 1.25
2-9	\$2.75 ea.		\$ 5.25
≥10	\$2.25 ea.		\$ 9.00

Pre-Board Special! An Ethics Casebook for Genetic Counselors.

Take 10% off the price of both casebooks if purchased as a pair before Aug 1, 02! This dissertation dissects NSGC's Code of Ethics, offering practical examples of its application. Learn, think, apply! 66 pp.

<u>Unit</u>	<u>Price</u>	<u>#_</u>	<u>P&H</u>
1	\$9.75 ea.		\$ 3.50
2-10	\$8.50 ea.		\$ 10.00

Genetic Counseling Casebook

A collection of 22 cases covering a myriad of topics. A great teaching or study guide.22 pp.

1	\$7.00	 \$ 2.25
2-10	\$8.50 ea.	 \$ 7.50

<u>Disclaimer</u>

This list is not intended to serve as an endorsement by NSGC of any of the resources. Some authors are members of NSGC's Board of Directors: *Counseling about Cancer...*President, Kathy Schneider; *The Practical Guide...* and *Testing for HD...*, President-elect, Robin Bennett; *A Guide to Genetic Counseling*, Past President II, Wendy Uhlmann.

ORDER INFORMATION

Send check with a copy of this page as your order form, use the Publication Order Form included in your Winter membership mailing or download the form from our website: www.nsgc.org/publications.asp



OTHER RESOURCES

REPRINTS

 RL Bennett, K Hart, E O'Rourke, J A Barranger, J Johnson, K D MacDermot, G M Pastores, R D Steiner, R Thadhani. Fabry disease in genetic counseling practice: Recommendations of the National Society of Genetic Counselors. *JGC* 11:121-146.

TKT has generously agreed to distribute these reprints to NSGC members at no cost.

- Catherine Auger, ©617-349-0327; couger@tktx.com
- RL Bennett, AG Motulsky, A Bittles, L Hudgins, S Uhrich, D Lochner Doyle K Silvey, CR Scott, E Cheng, B McGillivray, RD Steiner, D Olson. Genetic counseling and screening of consanguineous couples and their offspring: Recommendations of the National Society of Genetic Counselors. JGC 11:97-119.

The March of Dimes has generously donated these reprints.

Robin Bennett, robinb@u.washington.edu �

CHARGE SYNDROME

- CHARGE SYNDROME: NEW PARENT PACKET. Includes a welcome letter, Syndrome Facts, Frequently Asked Questions, newsletter and resources. No charge for new parents; a nominal fee for others.
- CHARGE SYNDROME MANAGE-MENT MANUAL FOR PARENTS, v. 2.0 (2001). Updated manual is 270 pages and includes medical, developmental and educational information for parents and professionals. \$20. Spanish update coming in late 2002. ❖
- 800-442-7604; www.chargesyndrome.org

PEDIATRIC NEUROGTRANSMITTER DISEASE ASSOCIATION

₩ www.pndassoc.org/ ❖

LICENSURE LEGISLATION from p. 1

more often, developing exams on a state-by-state basis, or demonstrating that genetic counselors can be competent without passing an exam.

Utah Status

In Utah, a Genetic Counseling Licensing Board of four genetic counselors and an appointed public representative convinced the Department of Professional Licensure (DOPL) to issue temporary licenses to counselors who have ABGC active candidate status. These licenses are good for 42 months, and the holder must take the next available ABGC exam. Candidates who do not pass can renew the license once. Temporary license holders must be supervised by a licensed genetic counselor or an ACMG certified medical geneticist. This supervision must include "at least twice monthly face-to-face meetings with chart review and weekly case review." This arrangement is unique for professions licensed in Utah.

Following a public hearing in on March 21, where all objections to the proposed regulations will be heard, genetic counselors will have one month to apply for a license. After April 21, genetic counselors without a license cannot practice in that state.

www.dopl.utah.gov

California Status

In California, licensing will be designed and administered by the Genetic Disease Branch (GDB) of the California Department of Health and Human Services. There is no licensing board with mandated representation by genetic counselors or the public. It appears that the GDB will propose that uncertified genetic counselors be issued provisional licenses, which will be good for three years and can be renewed. An individual seeking a

provisional license will also have to pass an exam to be developed by the GDB. There will be no supervision requirement. The timeline in

California remains uncertain. �

FLORIDA LICENSURE LEGISLATION PROGRESSES Dan Riconda, MS

Senate bill 2026, the Genetic Counseling Practice Act, was voted on favorably in the Health, Aging and Long term care Senate Subcommittee of Florida. The bill requires licensure to practice genetic counseling; creates a Board of Genetic Counselors; provides for biennial renewal of licensure; accounts for continuing education; provides penalties for lapses in maintaining licensure; provides grounds for disciplinary action; and provides for denial of licensure or imposition of other disciplinary actions as authorized by the law.

There was no opposition. The bill needs to be reviewed by at least two committees in the Senate before it goes to the Senate floor for a full vote.

Amendments in the bill are continue to be made. One issue is temporary licensure for genetic counselors with active candidate status. We may have to limit such a license to two years. This would present a problem for new graduates, unless a mechanism similar to Utah's is created.

Although we are optimistic about next year, the Bill is not expected to be brought to the Senate floor this year because the House bill (H1831) was not submitted to Committee on time.

Dan Riconda, driconda@orhs.org;

www.leg.state.fl.us/cgibin/view_page.pl?File=sb2026.html&Directory=session/2002/Senate/bills/billtext/html&Tab=session&Submenu=1

NSGC'S BI-ANNUAL SURVEY GOES ONLINE

Kristen Mahoney Shannon, MS.

This year, the Professional Status Survey (PSS), our bi-annual report of the profession, will take on a different look. While the content of the instrument will remain consistent, it will be moving from paper to an online, computer-based system.

Although this "start-up" year will be fairly costly, NSGC has secured outside funding to cover these initial expenses. The movement away from the paper system will dramatically cut down on data entry and mailing costs so that in future years the survey will be carried out at a fraction of the expense it has incurred in the past. In addition, an online system results in rapid turn around of data in weeks, not months.

The online PSS will be designed so member do not need to complete the entire instrument in one sitting and can come back to complete it. Each member will need to use his or her NSGC Unique ID number (same ID needed to access "Members' Only Corner" of NSGC webpage) to access the survey.

Because we are concerned about confidentiality of responses, the PSS will be hosted at a private company's secure server, and NSGC will never have in its possession a dataset linked to ID numbers.

For those who do not have internet access or need to complete the survey on paper, a request can be made for a hard copy by contacting NSGC's Executive Office.

™ Kristen Mahoney Shannon, MS, keshannon@partners.org ❖



BULLETIN BOARD



NSGC Funding Opportunities for Members

Information about both grants can be obtained by entering the Members' Corner of our website: www.nsgc.org, click on Funding Opportunities.

SPECIAL PROJECTS FUND

The Special Projects Fund provides a \$5000 award annually for projects that focus on the future of the genetic counseling profession and/or improving the provision of genetic services. The fund is an opportunity to enhance professional development.

Project proposals must be submitted by May 15 by an NSGC member in good standing. Student thesis projects cannot be funded. Awards are based on the proposal's strength and feasibility. The winners will be announced at the Annual Education Conference in Phoenix. The call for proposals was mailed with the Winter membership mailing in February.

Committee members are: Amy Bazyk, Renée Chard, Jeanne Homer, Lisa Kessler and *(ex officio)* Teresa Brady and Nathalie McIntosh.

Peter Levonian, Committee Chair, ©608-775-3995; plevonia@gundluth.org. ❖

RECENT RECIPIENTS OF SPECIAL PROJECTS FUND AWARDS

2000: R. Bennett. Recommendations for Genetic Counseling and Screening of Consanguineous Couples and Their Offspring

2001: B. Lerner. Current Issues in Genetic Counseling: Interactive Internet Based Continuing Education Program for Genetic Counselors

2002: B. Billings, S. Goldman, V. Venne. Genetic Counselor Licensure: Experiences and Opportunities

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JANE ENGELBERG FELLOWSHIP

The 11th Jane Engelberg Memorial Fellowship (JEMF), an annual \$50,000 grant of the Engelberg Foundation to NSGC, will be awarded for 2003 to one or more genetic counselor(s) for study, research, writing or exploration of new interests to enhance present skills, develop new skills, contribute to the body of knowledge in the field of genetic counseling or expand professional roles.

JEMF invites proposals from genetic counselors who are full, Board-certified NSGC members. Individuals who have been granted active candidate status by the American Board of Genetic Counseling also are eligible to apply. Applicants may elect to pursue fellowship work on a part-time or full-time basis for a maximum of one year. The award will be presented at NSGC's 2002 Annual Education Conference in Phoenix. Applications are due May 1. A Program Application and Guideline Booklet was mailed to all full members in January.

- Application and list of prior funded projects: www.nsgc.org/MembersCorner.osp
- Andy Faucett, aif3@cdc.gov
- ™ Wendy Uhlmann, wuhlmann@umich.edu ❖

READ JOURNAL ARTICLES FOR CEU CREDIT ...ARE YOU INTERESTED? Heather Brown, MS & Barbara Lerner

Now is your chance to decide on an important membership benefit. NSGC's Continuing Education Subcommittee is investigating ways to expand continuing education opportunities for genetic counselors.

Results from a previous survey of the membership identified online courses and *Journal of Genetic Counseling* article readings as preferred alternatives for obtaining CEUs. We now need more input from you to make a journal-based CEU program become a reality.

Please take a few moments to complete the online CEU survey.

Link from our website Members' Only page; or www.zoomerang.com/survey.zgi?6AEQ87AP10 BWJBHBK3W73YJX; or, for a hard copy, ©781-736-3149. ❖

FREE ONLINE ACCESS TO JOURNAL

Medical Genetics, guest edited by Bonnie Jeanne Baty and Diane Baker. The link will be posted on the listserv when available. Seminars in Medical Genetics is a thematic section of the American Journal of Medical Genetics.

FIRST DOCTORAL DEGREE IN GENETIC COUNSELING

The Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Program is now offering a second track, preparing students for a master's of science degree (Sc.M.) with an option for continued study toward a doctoral degree in the Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, after completion of the Sc.M. degree. The doctoral degree requires additional coursework and a doctoral dissertation. The master's thesis may provide pilot data for the doctoral dissertation. It is expected that students enrolled in the second track will require at least five years to complete the Program. ❖

COMMITTEE, STUDENT & SIG ACTIVITIES

STUDENTS DIALOGUE WITH GREAT MENTOR

Seymour Kessler participated in a conference for genetic counseling students from the California State University Northridge and University of California Irvine programs in late November. Dr. Kessler discussed difficult issues in genetic counseling sessions and role-played scenarios with critique and commentary.

Dr. Kessler began by noting that our job as genetic counselors is to move people a miniscule step down the road that they are on and to have them leave us a bit better than when they came. He characterized genetic counseling as a "human interaction" and not a "communication process" which may be a more accurate and useful definition of our work.

A lengthy question and answer session allowed attendees to ask specific questions about the difficulties they encounter with patients. In the afternoon session, the students role-played scenarios that illustrated some other difficult issues in genetic counseling sessions, such as when one member of the partnership monopolizes the conversation.

The conference ended with Dr.

Kessler's recognition of the difficulties we face with this type of short-term counseling. He emphasized the need to refine our counseling skills to become more effective. He also comforted us with a reminder that it is not always possible to make a connection with every client.

Those of us privileged to attend this conference will never forget our interaction with this wonderful mentor. �

CF POSITION STATEMENT REVISION ASSISTANCE REQUESTED

The Genetic Services Committee is looking for members to serve on a subcommittee to revise NSGC's current position statement on CF screening. If this is your area of expertise or interest, here is your chance to become involved in NSGC and make a difference. Please reply by March 31.

™ Heather Ferguson, MS, ©617-525-5769; hferguson1@partners.org ❖

ETHICS SUBCOMMITTEE AVAILABLE FOR CONSULTATION

Have you ever felt the need of input regarding ethical dilemmas and issues of moral distress in your practice? The Ethics Subcommittee is available for both formal and informal confidential consultations.

Perspectives in Genetic Counseling 24:1 — Spring 2002

GENETIC COUNSELORS DAY DEBATED WITHIN MEMBERSHIP

Kristen Mahoney Shannon, MS, Chair, Professional Issues Committee

The idea of a National Genetic Counselors Day has been raised on numerous occasions. Days of celebration exist for other professionals — why not genetic counselors? Instituting a national day of recognition, however, requires much effort and diligence. Before undertaking this effort, the Professional Issues Committee (PIC) polled the membership to determine whether or not genetic counselors were interested.

On November 29, a message was posted on NSGC's listserv soliciting opinions on the subject. Seventy three responses were received. Of these, 41 (56%) indicated that a National GC Day was *not* something worth pursuing. Twenty three (31%) indicated that they supported a National GC Day. The remaining nine members indicated that a National GC Day was a good idea but didn't think it would be worth the work. The chart below expands these opinions:

ON THE PRO SIDE

- Media attention
- More professional recognition
- Morale builder
- Public awareness

ON THE CON SIDE

- Too much effort
- Negative connotations
- Waste of time and money
- No real purpose for the day
- Embarrassing/demeaning to the profession (crying for attention)

Although the majority of respondents were against a National Genetic Counselors Day, members of the PIC believe that 73 responses are too few to solidify this issue. The PIC has decided to assign a task force led by Kate Crow and Christine Barth to investigate this issue further. Anyone interested in participating in this effort — or vocalizing your opinion further — is encouraged to contact Kate or Christine.

- Kate Crow crowkos@pop.mts.kpnw.org or
- Christine Barth ckborth@hotmail.com �

CLASSIFIED

- Los Angeles CA: Immediate opening for highenergy, BC/BE PN Genetic Counselor. Exp & Spanish fluency pref. Join active academic PN svc providing full range of PNDx procedures & svcs.

 Bill Herbert, MS, Coordinator, Genetic Services, Cedars-Sinai Medical Center, 444 S. San Vicente Blvd. Ste 1001, Los Angeles CA 90048; ©310-423-9935; Fax: 310-423-9939; bill.herbert@cshs.org. EOE/AA
- Los Angeles CA: Immediate opening for BC/BE Genetic Counselor. Adult Genetics/Cancer Risk GC exp pref. Join active, expanding adult genetics clinic w/ emphasis on cancer & cardiovascular disease risk assessment: GC, educ, partic in rsrch & s'vision of med & GC students, residents & fellows.

 ** Mark Pinto, MS, GenRISK Program, Cedars-Sinai Medical Center, 444 S. San Vicente Blvd, Suite 604, Los Angeles CA 90048; ©310-423-9911;
 Fax: 310-423-9946. EOE/AA
- MODESTO CA: Immediate openings for BC/BE Genetic Counselors. Oppty to work in a diverse perinat prac. Work i'pendently & from home, but w/ support from colleagues & med geneticists throughout Calif. Some trav may be req.

 ** Apply online at www.genzyme.com. Ref: Job Code #946 c/o Amy Foster, Corporate Recruiter, Genzyme Corporation, 15 Pleasant Street Connector, PO Box 9322, Framingham MA 01701; ②800-357-5744x 23728; omy.foster@genzme.com. EOE/AA
- OAKLAND CA: Immediate opening for BC/BE Genetic Counselor/Craniofacial Clinic Coordinator.Min 2 yrs clin exp (internships accepted) req. Admin, org & computer skills important. Spanish or Cantonese lang a plus. Supportive, large, multifaceted HMO genetics dept: peds, adult & PN genetics incl follow up for triple scrn and abnl U/S. Coord regl craniofacial multispec clin w case mngmt.

 Ellen Bloch, Kaiser Permanente Medical Center, Genetics Dept, 280 W. MacArthur Blvd, Oakland CA 94611; ©510-752-7541; fax: 510-752-6754;
 Ellen.Bloch@kp.org. EOE/AA
- ORANGE CA: Immediate opening for BC/BE Genetic Counselor. Spanish speaking pref. Provide PN GC svcs in Orange & LA counties. Other duties as assigned. Some travel req.
- ** Apply online at www.genzyme.com. Ref: Job Code #1411 c/o Amy Foster, Corporate Recruiter, Genzyme Corporation, 15 Pleasant Street Connector, PO Box 9322, Framingham MA 01701; ©800-357-5744x 23728; gmy.foster@genzme.com. EOE/AA
- SACRAMENTO CA: Immediate opening for .5PT BC Genetic Counselor. Exp in metab disease a plus. Join active, expndg metabolic team: GC, educ, case mngmt, partic in rsrch & prog promotion. May expand to CF & Sickle Cell Clins.

 ** Cherie D. Hiner, Manager, Sutter Medical Center.
- **Cherie D. Hiner, Manager, Sutter Medical Center Sacramento, 5271 F St, Bldg C, Children's Outpatient Services, Sacramento CA 95819; ©916-733-1992; Fax: 916-733-7001; hinerc@sutterhealth.org; www.sutterhealth.org. EOE/AA

- SAN DIEGO CA: Immediate opening for BC/BE Genetic Counselor. Spanish speaking & exp pref. Respon: tailored to the selected applicant's exp & capabilities but incl partic in PNDx svcs & ped subspec clins.
- La J. T. Mascarello, PhD, Children's Hospital, 3020 Children's Way, Genetic Services, MC5031, San Diego CA 92123; ©858-966-5809; jmoscorello@chsd.org. EOE/AA
- SAN FRANCISCO CA: Immediate opening for 2 BC/BE Cancer Genetic Counselors. Strong initiative, excellent writing, oral and people skills. Multilingual pref. UCSF Cancer Ctr & San Fran General (multiethnic, low-literacy patients)
- ^{ESS} Beth Crawford, MS or Robin Lee, MS, UCSF 1600 Divisadero St. Box 1714, San Francisco CA; 94143; ©415-885-7779; Fax 415-885-3787. EOE/AA
- SAN FRANCISCO CA: Immediate opening for BC/BE Genetic Counselor in NeuroMetabolic Genetics Program. Join multidisc team to provide GC, dx and mngmt to pts/families with metabolic disorders. Team of Clinical Geneticist, Gen fellows, neurologist, gc and metabolic nutritionist.
- © CV & ref: Cindy Morgan, 533 Parnassus U585, San Francoisco, CA 94143-0978; ©415-476-9997, fax: 415-476-9976. EOE/AA
- San Jose CA: Immediate opening for BC/BE Genetic Counselor. Exp. pref. Join active team in estab c'hensive genetics prog in HMO setting. Provide broad range of genetic services: PN, CA, ped & adult. Oppty for partic in spec clins.

 © Cindy Soliday, MS, Kaiser Permanente, 5755

 Cottle Rd Bldg. 1-Genetics Dept, San Jose CA 95123; ©408-972-3332; Fax: 408-972-3298; Cindy.E.Soliday@kp.org. EOE/AA
- DENVER CO: Immediate opening for BC/BE Genetic Counselor. Eng/Span speaking a plus. Join reg'l & ped hosp-based prog serving CO & WY: clin coord, case mngmt, direct GC & follow-up. Air & ground trav involved. Work as team member w/ 3 clin geneticists & 5 GCs providing genrl & ped genetic services.
- Connie R. Janzer, The Children's Hospital UCHSC, 1056 E. 19th Ave B300, Clinical Genetics & Metabolism, Denver CO 80218; jonzer.connie@thden.org. EOE/AA
- CHICAGO IL: Immediate opening for 2 Genetic Counselors in newly created clin cancer genetics prog. Exp in cancer GC req.
- Boris Pasche, MD, PhD, Assistant Professor of Medicine, Northwestern University Medical School, Dept Medicine, Div Hematology/Oncology, 710 N. Fairbanks Ct, Olson 8410, Chicago IL 60611; ©312-908-5284 (office), 312-503-2845 (lab); Fax: 312-503-2513; bposche@northwestern.edu. EOE/AA
- IOWA CITY IA: Immediate opening for Genetic Counselor w/ Master's degree in nursing, public health, human genetics, GC or related field or equiv comb of educ & exp. Bachelors in nursing & license to practice in Iowa or Master's in GC w/ BC/BE pref. Provide genetic eval & GC svcs in Reg'l Genetic Consultation Svc; conduct clin, educ, admin, liaison & rsrch activ.
- Rattn. #64 c/o Janine McBride-Rahn, University of Iowa, Dept Pediatrics, 200 Hawkins Dr, Iowa City IA 52242-1083. EOE/AA

- SCARBOROUGH ME: Immediate opening for Genetic Counselor. Skills in lit rsrch, writing, commun w/ genetics & primary care prof, project coord a plus. Interest in primary care genetics education pref. Coord updating of primary care PN genetic risk assmt materials (ProgramME). Trav in NH & ME. Oppty for expansion to FT w/ clin, mktg, & applied rsrch respon.
- Research, PO Box 190, Scarborough ME 04070-0190; www.fbt.org. EOE/AA
- BALTIMORE MD: Immediate opening for BC/BE Genetic Counselor. PN exp pref. Oppty for enthusiastic, energetic & innovative GC to join multi-disc team in i'natl-noted fetal med & PNDx prog. Oppty for faculty appt, tchg, student s'vision & clin rsrch.
- Far: June Dennen, University of Maryland Medical Center, Dept OB/GYN, 22 South Greene St, Rm. N6E09, Baltimore MD 21201; ©410-328-3338; Fax: 410-328-1981. EOE/AA
- ROCKVILLE MD: Immediate opening for BC/BE PN & Cancer Genetic Counselor. Join private PN genetics prac. pre- & post-amnio GC, terat, fam hx, recurrent miscarriage, abnorm MSAFP scrng & abnorm U/S finding GC. Some cancer GC. Independent position w/ prof & commun educ. Travel to satellite clin req.
- Rockville MD; ©301-770-5300 (AA); ©410-581-8300 (DW); Fax: 301-770-2005 (AA). EOE/AA
- FRAMINGHAM MA: Immediate opening for BC/BE Genetic Coordinator. Excellent verbal/written commun skills, flex & abil to multi-task req. Join molec testing lab: daily interactions w/ GCs, health prof w/ variable knowledge of genetics & lab staff. Coord tstg, commun DNA results to clients, asst w/ review & results reporting.
- **Fapply online at www.genzyme.com. Ref: Job Code #976 c/o Amy Foster, Corporate Recruiter, Genzyme Corporation, 15 Pleasant Street Connector, PO Box 9322, Framingham MA 01701; ©800-357-5744x 23728; mmy.foster@genzme.com. EOE/AA
- Springfield MA: Immediate opening for BC/BE Genetic Counselor. Spanish & 1-3 yrs exp pref.
 Perform variety of duties pertaining to dx & mgmt of genetic diseases in reg'l ctr: PN, peds, adult & cancer.

 WAY Faughnan, Recruiter, Baystate Health System, Dept Clinical & Reproductive Genetics, 280 Chestnut St, Springfield MA 01199; Fax: 413-794-3325; www.boystoteheolth.com. EOE/AA
- DETROIT MI: Immediate opening for 2 BC/BE Genetic Counselors. 1) Provide clin GC & risk assmt for variety of cancer syndromes, act as liaison to referring MDs & provide educ to local medical & lay commun. Main focus: cancer genetics w/ some partic in ped, PN & adult genetics on multidisc team of 3 GCs, 3 MD Geneticists & 2 PhDs. 2) Conduct cancer genetics rsrch & educ into psychosocial issues re: cancer genetic testing & GC. Some clin respon in Cancer Genetics Clin. Funded by endowment, not a grant. Educ, rsrch & pub opptys for both positions.

 CV & 3 Itrs rec: Amy Decker, MS, Henry Ford Hospital, Dept. Medical Genetics, 2799 W. Grand Blvd. CFP-4, Detroit MI 48202; ②313-916-1303; Fax: 313-916-1730; udekerl@hfb.org. EOE/AA

CLASSIFIED

- EAST LANSING MI: Immediate opening for BC/BE Genetic Counselor. Join univ-based genetics team to provide c'hensive genetic svcs: clin, rsrch, lab & educ opptys. GCs staff PN, ped/adult genetics, cancer & HD clins, involved w/ DNA & PN scrng labs & work w/ students/residents.

 *** Rebecca Zoller, MS, Michigan State Unversity, B-240 Life Sciences, East Lansing MI 48824;

 **©517-355-1297; zollerre@msu.edu. EOE/AA
- FRIDLEY MN: Immediate opening for BC/BE Genetic Counselor in new GC setting. Cancer risk exp pref. Genetic Counselor. Support mission, goals and objectives of hospital, program and this department. Assess fam hx and risk, coord care, collab w/ health care providers, pt/fam educ & GC.. Provide leadership in development of new svc.

 □ Human Resources Department, Mercy & Unity Hospitals, Allina Hospitals and Clinics, 7590 Lyric Lane NE, Fridley MN 55432; ②763-236-JOBS; Fax: 763-236-3630. EOE/AA
- ROCHESTER MN: Immediate opening for BC/BE Genetic Counselors. Join 6 lab-based GCs providing pre/post test consult, tech support & GC expertise. Primary assignment in molec genetics lab. Potential for educ, rsrch & clin assignments.

 ** Submit cover ltr, CV & references Attn: Ref #: 02-412.NSGC c/o Chad Musolf, Staffing Specialist, Mayo Clinic, 200 First Street SW OE 4, Rochester MN 55905; ②800-562-7984; Fax: 507-266-3167; coreers@moyo.edu; www.moyoclinic.org. EOE/AA
- BILLINGS MT: Immediate opening for BC/BE Genetic Counselor. Seeking candidate valued for excellent commun skills, compassion & independant scientific process in progressive perinatal prac svg

- Central MT tertiary care. Oppty for rsrch in telegenetics & 3D PNDx & imaging. Partic in resident & physician assistant educ progs.

 Pavid N. Jackson, MD, Fetal Diagnostic Center, 2900 12th Ave North Suite 130 W, Billings MT 59101; ©406-237-5888; Fax: 406-237-5899; doc@montanapregnancy.com; www.montanapregnancy.com. EOE/AA
- Las Vegas NV: April opening for BC/BE Genetic Counselor (temp 4/02-6/02). Either 1 FT position or 2 PT positions (2-3 days/wk) avail. Work w/ 3 perinatologists in busy prac to provide GC for AMA, TMS, fam hx, terat & U/S abnorm.

 Elyse Mitchell, MS, Center for Maternal Fetal Medicine, 400 Shadow Lane Ste 206, Las Vegas NV 89106; ©702-382-3200; Fax: 702-382-3575; emitchell@mfmcenter.com. EOE/AA
- BUFFALO NY: Immediate opening for BC/BE Genetic Counselor or similarly qualified Advanced Practice Nurse. Exp in cancer & genetics areas pref. Partic in & provide clin, educ & rsrch activ & svcs at Comprehensive Cancer Ctr. Join nurse practitioner/GC & GC working with multidisc teams.

 © Carolyn D. Farrell, MS, CNP, Director, Clinical Genetics Service, Roswell Park Cancer Institute, Elm & Carlton Sts, Buffalo NY 14263; ©716-845-8400; Fax: 716-845-5720. EOE/AA
- Las VEGAS NV: Immediate opening for BC/BE Genetic Counselor. Oppty to work independently in private perinatology prac. Supported by colleagues in CA region w/ BC MD geneticist. Opptys for prof growth in clin rsrch, publications, community educ, business, mgmt & marketing.

Apply online at www.genzyme.com or Amy Foster, Corporate Recruiter, Genzyme Corporation, 15

Pleasant Street Connector, PO Box 9322, Framingham MA 01701; @800-357-5744x 23728; omy.foster@genzme.com. EOE/AA

■ New York NY: Immediate opening for BC/BE Genetic Counselor. Spanish speaking & exp pref. Join busy medical center providing peds and PN GC. Oppty includes tchg, conference partic & coord of spec clins. Send CV & 2 lts of rec: Carrie Koval, MS, Div Clinical Genetics, New York Presbyterian Hospital, 3959 Broadway, BHN 601A, New York NY 10032; cak9003@nyp.org. EOE/AA

■ New York NY: Immediate opening for Genetic Counselor w/ Masters degree; min 1 yr GC exp pref. Provide GC to pts & fam: risks & limitations of dx tech, risk of occurrence & recurrence, etc; interview pts & fam to obtain relevant genetic, med & psych info; determine plan, dx or trtmt; refer pts to physicians or other counseling or trtmt.

© Donna DiMichele, MD, New York Presbyterian Hospital, Hemophilia Treatment Ctr, 525 East 68th St, P695, New York NY 10021; Fax: 212-746-8986. EOE/AA

- WEST ISLIP NY: Immediate opening for BC Genetic Counseling. Provide GC and educ to families with adult & ped genetic disorders, incl hereditary cancer syndromes, development of educ literature, assisting in data collection and reports.

 Attn: Professional Recruiter GM. Good Samaritan Hospital Medical Center, 1000 Montauk Highway, West Islip NY 11795; humanresourcesgs@chsli.org. EOE. Member of Catholic Health Svcs of Long Island
- YONKERS NY: Immediate opening for Manager.

 Manage Genetic Counselors, provide 1-2 days/week of direct pt care, complete performance reviews, interact with salesforce & physician clients.

 Papely online at www.genzyme.com. Ref: Job Code #1327 c/o Amy Foster, Corporate Recruiter, Genzyme Corporation, 15 Pleasant Street Connector, PO Box 9322, Framingham MA 01701; ©800-357-5744x 23728; gmy/foster@genzme.com. EOE/AA
- AKRON OH: Immediate opening for BC/BE
 Genetic Counselor. Cancer exp pref. Join 5 GCs & 2
 MDs in a dynamic reg'l ctr. Primary focus: cancer
 GC & cancer prog development; provide back-up
 for PN, peds, adult and educ programs.

 Submit application online: www.dkronchildrens.org or
 Human Resources, Children's Hospital Medical
 Center of Akron, One Perkins Square, Akron OH
 44308, fax: 330-543-3176; hresources@chmco.org. EOE/AA
- COLUMBUS OH: Immediate opening for BC/BE Genetic Counselor. Exp pref, not req. Join busy, univbased perinatal prac: PNDx clin, weekly conf w/opptys for tchg & prog development. Interact & collab w/ multidisc genetics network.

 Betsy Schmalz, MS, The Ohio State University, 546 Means Hall, 1654 Upham Dr, Columbus OH 43210; ©614-293-4716; Fax: 614-293-8993. EOE/AA
- PHILADELPHIA PA: May 2002 opening for 2-yr, paid fellowship in Cancer Genetic Counseling starting end of May. Exp in cancer not req. Position offers training & mentorship in cancer GC, functioning in cancer risk assmt progs for breast, ovarian, GI, skin & prostate cancers on multidisc team. Fellow will partic in & conduct genetic rsrch studies.

 Sam Anne Naumer, MS or Josephine Wagner Costalas, MS, Family Risk Assessment Program, Fox Chase Cancer Center, 7701 Burholme Ave, Philadelphia PA 19111; ©800-325-4145; Fax: 215-728-4061; __costalos@fccc.edu; oc_noumer@fccc.edu. EOE/AA

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

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- PHILADELPHIA PA: Immediate opening for BC/BE Genetic Counselor. Provide GC to PN & preconcept pts in city & rural settings. Apply online at www.genzyme.com. Ref: Job Code #1368 c/o Amy Foster, Corporate Recruiter, Genzyme Corporation, 15 Pleasant Street Connector, PO Box 9322, Framingham MA 01701; @800-357-5744x 23728; amy.foster@genzme.com. EOE/AA
- UPLAND (PHILADELPHIA) PA: Immediate opening for PT BC/BE. Genetic Counselor. Exp pref, not req. Job share oppty within busy MFM prac on one main site & 2 satellite offices: partic in trng med & GC students & refer pts for AMA, triple screen, terat & family hx. Parris Reynolds, RN, Sr. HR Manager, Crozer-Chester Medical Center, One Medical Center Blvd, Upland PA 19013; Fax: 610-447-6366; parris.reynolds@crozer.org; www.crozer.org. EOE M/F/D/V
- PROVIDENCE RI: Immediate opening for BC/BE Genetic Counselor. Ability to work in independent environment req; exp pref. Join expanding GC staff at a busy PNDx Ctr.
- Debbie Owens RNC, MS, Professional Coordinator, Prenatal Diagnosis Center, Women & Infants Hospital Of Rhode Island, 79 Plain St, Providence RI 03903; @401-453-7510; Fax: 401-453-7517; dowens@wihri.org. EOE/AA
- NASHVILLE TN: Immediate opening for Genetic Counselor / Clinical Research Specialist. Exp desired: pt/fam ascertainment, cancer genetics risk assessment & educ, coord w/ regl physicians, tissue banks, tumor registries & IRBs. Independent specialist sought to conduct & coord pt-based genetic rsrch w/ team of physicians, clinical GC & physicianscientists studying the genetics of common cancer. IS Jeffrey R. Smith, MD, PhD, Div Genetic Medicine, Vanderbilt University Medical Center, 2200 Pierce Ave, 442 Preston Research Building, Nashville TN 37232-6304; @615-936-2171; Fax: 615-936-2661; jeffrey.smith@mcmail.vanderbilt.edu; dna.mc.vanderbilt.edu EOE/AA

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- DALLAS & HOUSTON TX: Immediate opening for Genetic Counselors in each location. Key characteristics: autonomy, compassion & abil to grow. Join cyto lab & clin offering GC to referring physicians. Jeffrey D. Franck, Operations Manager, Center for Medical Genetics, 7400 Fannin St #1150, Houston TX 77054; ©713-790-1990; Fax: 713-790-1903; ifranck@geneticstesting.com. EOE/AA
- HOUSTON TX: Immediate opening for BC/BE Genetic Counselor. Spanish pref. Join academic-based group in county hosp & outrch clins, primarily PND w/ some peds; abil to work independently a must. Katie Plunkett, MS, Baylor College of Medicine, 6621 Fannin CC 1560, Houston TX 77030; ©832-822-4295; Fax: 832-825-4294; plunkett@bcm.tmc.edu. EOE/AA
- HOUSTON TX: Immediate opening for BC Genetic Counselor, Faculty Associate level. Oppty to partic in the multidisc mngmt of pts w/ hereditary cancer, partic in clin research & conduct clin trials. Basic science rsrch opptys also available. Ssend a CV & 3 ltrs rec: Glenn A. Halff, MD, UTHSCSA, Dept of Surgery, 7703 Floyd Curl Dr, San Antonio TX 78229-3900. EOE/AA
- HOUSTON TX: Immediate openinf for BC/BE Genetic Counselor, Join a dynamic, expanding team in Clinical Cancer Genetics Program. Provide comprehensive GC svcs to diverse population of cancer pts.. Tremendous oppty for prof growth: publishing, rsrch, tchg and GC student trng. 🖙: Karen Copeland, University of Texas Health Sciences Center, 1515 Holcombe Blvd. Box 39, Houston TX 77030; @713-745-7391; ccg@mdanderson.org; or Kelly McDermott, Human Resources Dept., kmcdermo@mdanderson.org.EOE
- SALT LAKE CITY UT: Immediate opening for Laboratory Director. Doctoral degree, 6 yrs clin lab plus 2 yrs s'visory exp req. Direct team of lab techn groups in genomics lab: direct workflow, monitor competency/performance, ensure procedures/methods performed according to section protocol, provide technical expertise in use, calibration and maintenance of laboratory instruments, equipment, reagents and procedures, perform routine and specialized procedures as necessary. HR Manager, Sorenson Development, Salt Lake

City UT 84115; FAX: 801-461-9722; resumesubmit2002@yahoo.com. EOE/AA

- SALT LAKE CITY UT: Immediate opening for BC/BE Genetic Counselor. Independence; flexibility & excellent i'personal, verbal, written & org skills req. Join busy univ PN ctr & lab maternal serum scrng prog. Partic in conferences, tchg, rsrch & i'action w/ GCs from other depts.
- CV & 3 ltrs rec: Maureen Cantwell, MS, University of Utah Health Sciences Center, Perinatal Genetics, 50 North Medical Dr Room 2B200, Salt Lake City UT 84132; @801-581-7825; Fax: 801-585-2478; moureen.contwell@hsc.utah.edu. EOE/AA
- SALT LAKE CITY UT: Immediate opening for BC/BE Genetic Counselor. Cancer GC exp pref, not req. Abil to work independently as well as on team; initiative, writing & speaking skills req. Join univbased multidisc cancer genetics team incl GCs, oncologists, GIs & dermatologists. Provide clinic svcs w/oppty for rsch, prof & public outreach. Merlene Timmons, Univ of Utah, Huntsman Cancer Institute, 2000 Circle of Hope, Salt Lake City UT 84112; @801-585-3800; Fax: 801-585-9099. EOE/AA
- KIRKLAND WA: Immediate opening for per diem BC/BE Genetic Counselor. Assess risks & provide GC to clients w/ complex genetic issues. Human Resources, Evergreen Healthcare, 12040 NE 128th St, Kirkland WA 98034; Fax: 425-899-2510; Jobs@evergreenhealthcare.org. EOE/AA
- MORGANTOWN WV: Immediate opening for BC/BE Genetic Counselor. Abil to work independently req. Join 4 MFMs to provide c'hensive PNDX svcs (serum scrng, AMA, abn U/S, fm hx, terat, CF scrng etc.) to WV & surrounding area, expand cancer risk assmt & infertility work-ups. Opptys for tchg & rsrch. New grads encouraged to

Devereux Saller, MD, Robert C. Byrd Health Sciences Center, PO Box 9186, Dept Ob/Gyn, Morgantown WV 26506-9186; ©304-293-5553; Fax: 304-293-2131; dnsoller@hsc.wvu.edu. EOE/AA ❖