

PERSPECTIVES

in genetic counseling

Volume 20 Number 1

Spring 1998

**national society
of genetic
counselors, inc.**



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

TABLE OF CONTENTS

In Pursuit of Licensure	1
BC/BE Redefined.	1
Informed Consent Defined.	2
Billing Dilemmas: Reimbursement.	3
Duty to Warn	4
Fax Poll "Duty to Warn" Experiences	4
Calif Licensure Poll Results	5
On the Road: Judicial Education	6
Letters to the Editor	7
List Servings	8
Celebrate Ourselves	8
Student Corner.	9
Meeting Manager	9
Sickle Cell Meeting on Certification	9
The Making of a JEMF Project	10
Reflections of a JEMF Recipient	10
Research Network	11
Finance Committee Review	12
Annual Education Conference	12
Cancer SIG Profile	13
SIG Activities	13
Bulletin Board	14
Employment.	15

NSGC acknowledges Women's Health Care Services for a grant to support this newsletter.

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

TAKING CHARGE: LICENSURE ALTERNATIVES

Linda Robinson, MS & LuAnn Weik, MS

Billing, Licensure and Reimbursement (BL&R) Subcommittee

The ultimate need for licensure is to protect the public from harm. Improved reimbursement is a secondary benefit. Licensure represents a vehicle to establish a defined scope of practice, to set standards of care and practice ethics for which practitioners are held accountable. It allows for the assurance of at least basic essential qualifications necessary for

competent practice and continued proficiency.

The real question is not do we need state regulation, but rather how we find a way to implement this protection given our small numbers, potentially prohibitive costs, interstate mobility, etc. The answer lies in considering all the

...to p. 5

ACTIVE CANDIDATE STATUS CLARIFIED

Whitney Neufeld-Kaiser, MS

Since 1982, when genetic counselors were first certified by the American Board of Medical Genetics, the term "Board Eligible" has been used to refer to someone who had graduated from a master's degree program in genetic counseling but who had not yet passed the certification exams. It did not distinguish counselors whose applications to sit for the Board exams had been submitted and accepted from those who had not submitted an application or whose applications were not accepted.

Using this old system of nomenclature, a counselor could be "Board Eligible" indefinitely without ever sitting for the exams.

To clarify the distinction, the American Board of Genetic Counseling (ABGC) has adopted the terms "Active Candidate" and "Active Candidate Status." An *active candidate* is a counselor who

- has completed the requirements for certification established by ABGC
- has submitted credentials to ABGC for review in the form of the application for the Board exams *and*
- has credentials have been accepted by ABGC.

This counselor has *Active Candidate Status* and is able to sit for the next Board exams. *Active candidate status* is, by definition, temporary. Clinical cases can only be used for two exam cycles, after which a counselor must assemble 50 new cases and reapply to sit for the exams.

According to this new nomenclature, *Board Eligible* means that an individual has graduated from a master's degree program in genetic counseling and is therefore eligible *to apply to sit* for the Boards. ♦

Perspectives in Genetic Counseling
20:1 — Spring 1998

DEFINING AND ENSURING INFORMED CONSENT

Susan Schmerler, MS, JD, Chair &
Roberta Berkwits, MS, JD,
Member, Legal SIG

The concept of informed consent is derived from the principle of respect for an individual's autonomy, in other words, her control over herself. As part of that respect, the decisions for or against medical treatment should come from the client herself. To make the best decision, the client needs to have a clear understanding of the pertinent medical diagnosis, the procedures being offered and the potential consequences of those procedures. She has to be free from anyone else's control, and she has to then intentionally authorize a treatment.

A signature on a consent form is the end point of a dynamic interaction between the provider and the client that enables the client to make treatment decisions. Her signature documents that the informed consent process has occurred. For consent to be truly informed, five elements must be met.

COMPETENCY

The threshold element is competence — the ability to make a rational choice. To accomplish this, a client must understand the information, as well as the consequences of the available choices. She has to be able to communicate her choice. A physician can determine a person's capacity to make choices.

Competency has a legal meaning, and there is a continuum of competency. The criteria that is applied depends on the context of the task. An individual may be

considered competent to sign a will while at the same time not competent to make health care decisions. In health care, a person is presumed to be competent to make treatment decisions at 18 years of age. An

emancipated minor is also competent to make her own health care decisions. Whether or not a minor is determined to be emancipated is a matter of how emancipation is defined by that person's state statutes.

A person who is competent to authorize her own treatment is clearly also competent to refuse treatment. If the question of competency is raised, it is up to a court to assess the facts of the case.

INFORMATION ELEMENTS

Informed consent has two information elements. The first relates to *the amount and accuracy* of the information provided. The professional needs to discuss the possible benefits and risks of any intervention (chorionic villus sampling, for example). This element also includes the obligation to discuss the available alternatives (amniocentesis, triple screen, targeted ultrasound scan). All conceivable procedures, especially those that are not relevant to the situation, like first trimester testing when the client is in the second trimester, do not have to be included in the discussion. How much information is enough? As much as the client needs to understand the options and make a choice.

The second information element is the client's *understanding*. This element highlights all the barriers to

informed consent. Clients can be fearful, sick, uneducated, hold unscientific beliefs, or not speak the same language as the provider. It is the obligation of the provider to identify these barriers and endeavor to overcome them.

"The client's authorization has to be an active agreement, one that is more than a yielding to or complying with a suggestion by the provider."

CONSENT ELEMENTS

There are two consent elements to informed consent. The consent elements involve *voluntariness* and *authorization* by the client. As used here, voluntariness means the absence of control by others, which must be clearly demonstrated. The client's authorization has to be an active agreement, one that is more than a yielding to or complying with a suggestion by the provider.

There are exceptions to the need for informed consent. For more common, low-risk interventions where the risks and benefits are obvious, explicit agreement may not be required and consent is implied. In an emergency situation, it is a common assumption that the client is unable to make decisions about her care or to participate in her own care because of her pain and fear, her lack of understanding of the danger she may be in, or her unconscious state. An objective, "reasonable person" standard is applied in these situations. That is, if a reasonable person under the same or similar circumstances would consent to treatment, then consent is presumed.

Once the elements of informed consent have all been met, then it can be said that consent has truly been informed. ♦



BILLING DILEMMAS: OBTAINING REIMBURSEMENT FOR GC SERVICES

Rachel Baughman, MS

After attending the ACMG 1997 Annual Conference short course "Billing Collections and Compliance: Surviving the 90's," I returned to my academic prenatal diagnosis setting certain my colleagues and I would not survive. I left the conference with the impression that as a genetic counselor, I did not have sufficient independence or autonomy in the healthcare setting (i.e. CPT codes, HMO and other insurance reimbursement recognition) to generate income or justify my existence from a financial perspective. My listserv connection confirmed that many of us left the conference with similar feelings.

BILLING CODE DILEMMA DEFINED

I decided that the best way to overcome this feeling was to learn as much as I could about how my institution specifically bills for my service, and determine if our practice was within current guidelines. A year's work of investigation has found me wiser and more comfortable with the billing situation. Unfortunately, until board certified genetic counselors are "awarded" CPT codes, which specifically address our contribution, we will all have to investigate carefully our individual circumstances and ensure that our manner of billing is consistent with current guidelines.

NAVIGATING THE MAZE

I work at a university medical center as a prenatal genetic counselor. There are four prenatal genetic counselors and five perinatologists. Each patient referred to our center meets first with a genetic counselor before meeting the perinatologist. In this setting, we use the CPT

codes for office consultation *not* for a new patient. New patient visit implies that the patient was not referred to you and that the patient will receive regular care from you. If you keep records indicating that the patient was referred to you by another physician, you cannot use the new patient codes.

In this setting, the genetic counselors fall into the Health Care Financing Administration (HCFA) classification of "incident to." Medicare regulation 2050.1 states "incident to a physician's professional services means that the services are furnished as an integral, although incidental, part of the physician's personal professional services in the course of diagnosis or treatment..." This includes services of auxiliary personnel employed by the physician and working under his/her supervision such as nurses, psychologists, technicians, therapists, etc. In this circumstance, when the individual is employed to assist the physician in rendering services (e.g., genetic counseling prior to a procedure), the physician may include charges for this individual's services in his/her own charge.

Be careful of the definition of office: if your clinic or department is paying rent to a hospital or some other entity, you can be classified as an office. Alternatively, "incident to" would not apply to an in- or outpatient hospital setting where genetic counseling is provided.

FACE TO FACE WITH PATIENTS

Another key factor in using CPT codes is time spent by the physician and genetic counselor. To use these codes properly, the physician must see or talk with the patient face-to-face for at least 50% of the time billed. In my setting, the consultation charge includes the genetic

counseling and the consultation/discussion (often in the ultrasound room) between the physician and the patient. I am fortunate that >95% of the time, any patient I meet with is also scheduled to meet with a perinatologist. This circumstance, very workable in my situation, may be difficult to achieve in other non-academic or non-obstetric settings.

ALTERNATIVE BILLING OPTIONS

Another option, put forth by Debra Lochner Doyle via NSGC's listserv, is to contract specifically with the physician or medical center to reimburse the genetic counselor at a set rate and let the physician or institution decide how to actually bill insurance for the genetic counseling services. Other options, such as a facility fee (e.g., include the genetic counseling fee in with overhead such as electricity, supplies, etc.), V codes (poor reimbursement) or using other "incident to" circumstances may generate income from genetic counseling. Many of these other options fail to recognize that genetic counseling services are provided by professionally-trained and certified health care providers.

WHAT DOES THE FUTURE HOLD?

Continuing to work towards CPT codes for our services is probably our best option to gain financial autonomy, secure our longevity in the health care food chain and justify our existence. In the meantime, it is critical to work with our administrators and insurance liaisons to use billing and coding methods that not only comply with HCFA requirements, but also recognize our services as professional. ♦

DUTY TO WARN: THE ROLE OF THE GENETIC COUNSELOR

This is the first of a two-part piece regarding an issue that genetic counselors probably face frequently. Part one discusses the background of the professional duty to warn. Part two will be a collection of comments and experiences from the membership and a lawyer's perspective.

Chantelle Wolpert, MBA, PA-C

Just as medical genetic information and technology are evolving, so are policy issues and legal determinations that may affect genetic counseling practice. Within the medical genetics community, discussion is ongoing on one such issue — the duty to warn at-risk relatives, also known as third parties, about their genetic risks.

For purposes of this discussion, a third party does not refer to an insurance company or an employer. The outcome of these discussions and case law decisions may ultimately compel genetic counselors to incorporate formally the duty to warn third parties into their clinical counseling practice. Consequently, genetic counselors need to be aware of this potential professional duty.

BACKGROUND

In our society, individuals who create risks to others are expected and often legally mandated to warn unaware individuals or third parties who may incur those risks. There are many tangible examples of this broad and implicit duty to warn. For instance, signs such as “wet floors” or “beware of dog” may suffice to shift responsibility for potential injury from the party creating the risk to the party assuming the risk. Similarly, a professional performing a job is expected to warn someone subject to risks. An obvious example is a surgeon telling a patient about the risks associated with a surgical procedure; this risk

disclosure is an element of the informed consent process.

However, the duty to warn third parties is clearly distinct from the informed consent process. In duty to warn...

- The patient, not the professional, by virtue of shared genetic traits, imparts the risks.
- These risks threaten third parties rather than the patient.
- The third parties are not directly involved in the patient/professional relationship.

DEFINING THIRD PARTY

Third parties can include anyone outside the patient/professional relationship whose risk of foreseeable harm may be disclosed as a direct result of this relationship. In medical genetics, this includes biological relatives and future generations who may be at-risk for having or developing a genetic disorder. Also, some circumstances may place non-biological relatives at-risk. For instance, the spouse of someone with Huntington's disease may have the right to know that his or her spouse has a condition predisposing to violent or psychotic behavior. Also, the general public may be the third party if a driver's license is not revoked from an individual deemed medically unfit to drive.

In the health care setting, this concept of duty to warn third parties has been defined primarily through case law decisions. The precedent-setting case is the Tarsoff case (Tarsoff v Regents of University of California; Macklin 1976). In this court decision a psychotherapist was found liable for violent acts his

patient committed. Specifically, the patient revealed to the psychotherapist that he planned to kill his girlfriend, a scheme which he later carried out. The court found that, “the therapist failed to act with reasonable care [by warning the girlfriend] when he knew, or should have known, of the patient's dangerous propensity to violence.” Therefore, when professional health care work reveals a potential danger to a third party, the Tarsoff case and other similar cases oblige some health professionals to weigh the patient's privacy versus a duty to warn the third party. One court opinion stated, “privacy ends where public peril begins.” (Tarsoff)

However, despite this landmark court decision and some current genetic counseling practices, it is still undetermined how the duty to warn third parties (at-risk relatives) might apply in genetic counseling practice. This is, in part, because there are not yet any clinical practice standards or consensus documents regarding this matter in the genetic counseling community. ♦



**E-mail/ FAX
Poll**



DUTY TO WARN:

RESPONSIBILITY OR OPTION

Do you have an opinion or specific case in which you dealt with the duty to warn in a genetic counseling setting?

Fax or EMail your thoughts, comments or anecdotes to:

Chantelle Wolpert, MBA, PA-C
FAX# 919-681-7043

chantell@dnadoc.mc.duke.edu

Indicate whether or not you want your name to be used. ♦

TAKING CHARGE: LICENSURE ALTERNATIVES *from page 1*

alternative mechanisms for pursuing licensure. There are legislative and non-legislative routes. One option is to have a state senator or assembly person introduce a bill to the legislative council or contact the legislative committee on health related issues. Once the bill is passed, regulations are written. This entire process can take years. The State Health Department can submit these regulations, which require extensive documentation such as the fiscal impact of the bill. Another avenue is directly petitioning the State's Department of Consumer Affairs or Department of Licensing and Regulation. The latter determines the requirements for licensure of a profession. The agency will need

documentation on why licensure is needed. California, New Jersey and New York have developed all the documentation necessary to support these efforts, which could serve as models for other states.

To make a stronger case for a "compelling state's interest," some healthcare providers have banded together. For example, an allied health board or a professional counselors board could include a section dedicated specifically to the licensing of genetic counselors. Alternatively, an arm of an existing board could be created or an examining counsel could be created as a subset of the medical examining board in a particular state.

Most of what has been discussed relates to practice acts, e.g., only authorized persons with proven qualifications and competencies can practice.

Another alternative may be registration acts. Registration acts authorize a listing or roster of individuals performing certain acts. Those not on the roster could not practice. This is the least restrictive type of licensing; however, rosters typically do not require any qualification or entry tests for inclusion.

Perhaps it could be stipulated that only professionals who are board eligible or board certified and members of NSGC can register within the state. This could serve as a mechanism for consumers and health insurance carriers to verify that a qualified practitioner, bound by NSGC's Code of Ethics, provided the service. It could also serve as a repository for consumer complaints adding another measure of accountability.

No matter what licensing route is pursued, there is a precedent for national certification exams to be recognized by states. There is also a movement to standardize licensure requirements among states making the license potentially more portable.

Once licensure for genetic counselors is approved in one state, it will open the door for others. Before pursuing licensure in your state, contact NSGC's BL&R Subcommittee to obtain background information ...and please report to the subcommittee your experiences with any attempts at licensure, both positive and negative. ♦

CALIFORNIA COUNSELORS POLLED ON LICENSURE

Trisha Brown, MS and Melisa Siegler, MS

Recently, Linda Foley, MS and Sara Goldman, MPH surveyed 220 genetic counselors in California to ascertain information needed to develop and implement a licensure program. Both work for the California Department of Health Services, Genetic Disease Branch (GDB).

The survey revealed that 90% of the 70 respondents were in favor of licensure, citing an improved billing/reimbursement structure and a higher quality of genetic services. Respondents also cited numerous cases of consumer injury due to alleged negligence or inadequate genetic counseling, including failure to recognize a significant family history, inadequate explanations regarding abnormal ultrasound findings and recurrence risks, communication of inaccurate or incomplete information which influenced reproductive choices and failure to obtain informed consent.

The GDB survey also ascertained examples of consumer populations currently *not* utilizing the services of qualified genetic counselors, such as those pursuing prenatal diagnosis with private obstetricians, patients in oncology settings, those obtaining information via the Internet and patients restricted to centers without genetic counselors. A public demand for licensure was reported to exist, with respondents indicating that

- HMOs and PPOs wish to identify licensed genetic counselors prior to contract negotiation
- patients seeking genetic counseling from *qualified* providers.

The current status is that the Board of Consumer Affairs concluded that there are not enough individuals to warrant licensure. However, Senator Patrick Johnston introduced a bill (FB1800) which would give the Department of Health authority to issue licenses to qualified genetic counselors. ♦



with Edward M. Kloza, MS

NEW ENGLAND JUDGES LEARN GENETICS

How interested can a room full of justices be about genetics?

This is the question I asked myself when I accepted an invitation to be part of "Preparing Our Judges for the 21st Century," the educational component of the 1997 Maine, New Hampshire and Vermont Judicial Conference. We decided to use a case presentation approach, and we selected *Chances' Choices*, a genetics curriculum unit for high school biology classes, as the vehicle. As creator of *Choices*, I was chosen to present the cases.

I was part of a team that included Philip Reilly, MD, JD from the E.K. Shriver Center in Waltham MA; Dr. Richard Doherty, Director of Medical Genetics at Foundation for Blood Research (FBR); Dr. James Haddow, FBR Medical Director; and Paula Haddow, Director of FBR's Education Division, who was instrumental in developing *Choices*.

WALKING THROUGH GENETICS

The cases were presented as if they were taken from the Genetics Division files: I related that when little Michelle Chance was born with PKU, her father wondered how such testing could take place without his expressed consent, how he sought to blame his daughter's condition on his wife's side of the family and about his reluctance to listen to information about the importance of a life-saving diet. It was a genetic counselor who was not only able to identify and deal

with the father's perceived loss of control, but also explain the public health concerns that prompted the passage of legislation mandating newborn screening. Dr. Doherty followed with a discussion of the clinical aspects of PKU and newborn screening. He made clear the dilemma of maternal PKU effects. Dr. Reilly then added impor-

tant information about case law and anecdotes about his experience managing a woman with PKU who refused diet during pregnancy.

In the next scene, Michelle's 6 year old brother was diagnosed with Factor VIII deficiency after hurting his knee playing basketball. By this time the justices had become intrigued with the range of genetic disorders and types of transmission — not to mention the options for treatment. When I shared with them the mother's refusal to notify her sister (who had three young daughters) of the risk of her carrying a gene for hemophilia, murmurs were clearly evident.

MORE THAN ONE PATH

Genetics was becoming more than research, laboratories and science fiction — its impact on families and society was becoming evident. The creative genetics staff found a way to inform the sister without breaching confidentiality. Drs. Reilly and Doherty followed with essential clinical and legal insights.

The resumption of the program saw Michelle's father, age 36, fall victim to a heart attack. Familial hypercholesterolemia was (of course!) diagnosed, and so a dominantly inherited condition was added. The minor children

were considered for testing, and a further problem arose when Michelle's mother expressed concern that her husband might not have fathered the oldest of the three children. Paternity testing and DNA analysis — now here was something

the justices could identify with! A discussion of technology, legality and ethics, along with the accuracy and reliability of DNA testing, followed.

"Paternity testing and DNA analysis — now here was something the justices could identify with!"

WALK THE WALK; TALK THE TALK

By the end of the program there was no question that this was an appreciative and attentive audience. Far from the technical jargon that they may be dealing with in the courtroom, this case presentation approach caught their attention and encouraged them to think about the implications that genetics had on law and justice. We also wanted to introduce them to the types of genetics professionals whose testimony may be a part of the judicial process. This is not a role that many genetic counselors may think is part of their domain; indeed, many counselors may prefer never to be in front of a judge. But our future is dependent upon raising the awareness of genetics among the public including those involved with legislation, prosecution and adjudication. ♦

HAVE YOU BEEN 'ON THE ROAD'?

We're looking for creative genetics and genetic counseling education experiences. If you've been somewhere interesting or unusual, why not share it with us? Shy about writing? We can help. Contact Karen Eanet ☎410-828-3312; keanet@gbmc.org ♦



LETTERS TO THE EDITOR



SECOND LOOK URGED FOR CARE MARKETING MESSAGE

To the Editor:

We are writing to express our concerns about the marketing message proposed by the GeneAMP Managed Care Team (*PGC* 19(4):4, 1997). We recognize the effort put forth by the team members and the research that led to the message draft. However, prior to the adoption of a message for widespread use in representing the genetic counseling profession, its limited content, the format and the finite process by which it was developed should be further addressed by NSGC.

In our opinion, the format of the message represents a first step for a work in progress. It incompletely represents the work genetic counselors do within their client relationships. It omits, perhaps, our most important area of expertise, that of counseling. NSGC and the profession have worked hard to establish our level of professional excellence. It is our understanding that counseling was omitted because managed care is not as likely to reimburse for psychosocial services. We ask you to consider, are we leading efforts to map the future of our field, or are we following someone else's lead?

While our knowledge of clinical and molecular genetics will remain essential to our work, new and efficient means of communicating information are upon us and suggest it is our counseling skills that will sustain our professional growth.

Further, there is a paucity of data to support the claim that genetic counseling is cost effective.

How will we help to shape our future in these changing times if we merely respond to economic pressures and the ideas of others?

We propose that any public communication drafted by the NSGC be subject to an active and rigorous peer review, as was done with the Code of Ethics. While it is critical for the NSGC to take the leadership role in marketing the

profession and its membership, this is our opportunity to get it right! We believe the NSGC and the profession deserve a creative and precise message that will expand and promote future directions for the field. ♦

Judith Benkendorf, MS

Helen Travers, MS,

& Barbara Bowles Biesecker, MS

ASHG MEMBERSHIP BENEFITS ...

To the Membership:

The genetics community has often boasted of the multifaceted composition of our patient care team. Genetic counselors play an important role that has been positively described in many publications.

As an active member of NSGC, I have become concerned about counselors who have limited their participation in this team effort. I firmly believe that it is important for every practicing genetic counselor to be a member of NSGC and American Society of Human Genetics (ASHG).

ASHG is the only professional genetics organization which allows genetic counselors, scientists and physicians equal membership. ASHG has an active role in the future of genetic healthcare in the United States. I have found the leaders to be genuinely interested in the opinions and ideas of genetic counselors. Voting members have more impact than commentators.

In 1996, I was appointed to ASHG's nominating committee by Dr. Judy Hall. While on the committee, I was impressed by the

desire of the committee members to have genetic counselors play an active role in the organization. But I was shocked by the limited number of counselors (less than 60% of full NSGC members) who were members. Genetic counselors constitute less than 12% of ASHG membership.

Genetic counselors were nominated to the

ASHG Board of Directors in 1996 and 1997, but neither candidate received sufficient votes for election. Currently the total number of genetic counselor ASHG members is less than the number needed to carry a board seat. Only a small increase in membership would be required to change this.

I propose the following suggestions:

1. Join ASHG if at all possible.
2. Take an active role and vote.
3. Encourage your physician and scientist associates to consider voting for the genetic counselor candidates. ♦

Andy Faucett, MS

"Genetic counselors constitute less than 12% of ASHG membership."

LISTSERVINGS: PASS THE INFORMATION, PLEASE

Lyn Smith Hammond, MS

Recent discussions on our general Listserv revolved around the issue of resources for adoptions of children with Down syndrome. In usual form, members contributed a wealth of resources. **HELPFUL HINT:** Inquire about enforced policies when exploring or coordinating these services.

- ADOPT A SPECIAL KID
©800-246 1731; aasktoledo@aol.com
<http://www.aask.org>
- ADOPTION AGENCIES FOR CHILDREN WITH SPECIAL NEEDS
Janet Marchese, National Down Syndrome's A Kids Exchange, 56 Midchester Avenue, White Plains, NY 10606; ©914-428-1236
- ADOPTION EXCHANGE
Coordinates open adoptions in which both families remain in touch. <http://nac.adopt.org/me6.html>
- ADOPTION OPTIONS
<http://www.cx1.com/options>

GENETICS CURRICULA FOR ELEMENTARY THROUGH HIGH SCHOOL STUDENTS DEVELOPED

Another recent listserv discussion focused on resources for teaching younger children about genetics. NIH has announced the development of a major science education initiative aimed at elementary through high school science classrooms. Phase one, geared to high school biology courses, includes genetics, cancer and infectious disease. Information is available by accessing these home-pages: Office of Science Education at www.science-education.nih.gov and Biological Sciences Curriculum Study (BSCS) at www.bscs.org. ♦

- ADOPTION QUEST
Helps people parent children with developmental disabilities. <http://nac.adopt.org/adopt/issues/indexdev.html>
- DOWN SYNDROME ASSOCIATION OF GREATER CINCINNATI
Waiting list; a policy against placing babies in group homes. Robin Steele, ©513-554-4486
- THE JEWISH CHILDREN'S ADOPTION NETWORK
Finds Jewish adoptive parents for babies, disabled or not, nationwide. ©303-573-8113
- Shattered Dreams - Lonely Choices: Birthparents of Babies with Disabilities Talk about Adoption by Joanne Finnegan.
Appendix lists adoption resources for disabled babies and children. Greenwood Publishing Group, Westport CT, ©800-225-5800
ISBN 0897892860
- POST ADOPTION DEPRESSION SYNDROME
<http://www.adopting.org/pads/html>
No decision is anxiety-free!

CELEBRATE OURSELVES

NSGC THANKS JEFF SHAW

"CONGRATULATIONS!

Your site: <http://members.aol.com/nsgcweb/nsgchome.htm> has been selected as a featured site in StudyWeb as one of the best educational resources on the Web by our researchers. It can be found in our Genetics section. StudyWeb is one of the Internet's premier sites for educational resources for students and teachers. Since 1996, our expert reviewers have scoured the Internet to select only the finest sites to be included in StudyWeb's listing of educational links. ...StudyWeb updates are provided to media and educational resources around the world." Members can check us out StudyWeb at: <http://www.studyweb.com>

Jeff, we couldn't have said it better!

GREENDALE TO EDIT JOURNAL

Karen Greendale has been named Editor for Genetic Counseling of American College of Medical Genetics' journal, *Genetics in Medicine*. She is one of nine editors under Richard A. King, MD, PhD, Editor-in-Chief. Here's another opportunity to submit articles on your genetic counseling research.

ELSI GRANT INVOLVES COUNSELOR INPUT

The Vermont Human Genetics Initiative was awarded an ELSI grant to look at the social, ethical, and legal issues of the Human Genome Project. Genetic Counselors Wendy McKinnon, Leanne Haskin Leahy and Denise Lintner will be involved in the project.

RESTA INVITED TO SPEAK IN LONDON

Bob Resta has been invited to speak in September by the Galton Institute in London on the "Social, Ethical and Technical Implications of Pedigree Construction: What the Maps Tell Us About the Mapmakers." His talk will focus on the historical and social aspects of pedigrees. Way to go, Bob!



STUDENT CORNER

Jessica Mandell, MS

The 1998 graduating class commemorates Sarah Lawrence College's (SLC) 28th year bestowing Masters in Science Degrees in Human Genetics to new genetic counselors. Just as the first students in 1969, this year's 25 students are busy preparing their master's theses, comprising a detailed review and/or independent research on a significant topic in human genetics and genetic counseling. Specialists on each thesis topic serve as mentors, and completed theses are critiqued and graded by three clinical geneticists.

The following is a list of representative thesis projects currently underway at SLC's Class of '98:

- Rajani Aarte — "Hereditary Non-Polyposis Colorectal Cancer: Clinical Aspects of
- Danielle Hanna — "22q11 Deletion Syndrome and its Association with Psychosis: Schizophrenia, ADD, ADHD and Bipolar Depression"
- Allyson L. Norris — "The Past, Present and Future of Fetal Surgery"
- Kristi Page — "Preimplantation Diagnosis in the U.S. and Abroad: Where Do We Stand?"
- Molly Hogan Stieglitz — "Prevention of Unnecessary Tragedy: Recognizing MCAD & LCHAD"
- Jennifer Williamson — "The Genetics of Alzheimer Disease: Association with Apolipoprotein E 4 Allele"
- Anne Yesley — "Informed Consent in the Context of Prenatal Diagnosis." ❖



MEETING MANAGER

APRIL 30 - MAY 2 • BOSTON MA

Harvard Medical School course on Human Teratogens.

Contact: Course Administrator ☎617-432-1525; hms-cme@wareen.med.harvard.edu

MAY 15 - 16 • WASHINGTON DC

University of Michigan and Michigan State University's Center for Ethics and Humanities, "Genome Horizons: Public Deliberations and Policy Pathways," Contact: Tahnee Hartman: ☎734-936-1226

JUNE 8 - 11 • LOS ANGELES CA

9th International Conference, "Prenatal Diagnosis & Therapy," sponsored by Cedars-Sinai Medical Center in cooperation with International Society for Prenatal Diagnosis, Wayne State University, Baylor College of Medicine and March of Dimes. Contact: Lawrence D. Platt, MD: ☎310-855-7433; Fax: 310-967-0142. Abstract Deadline: April 1

JUNE 19 - 21 • DENVER CO

Huntington's Disease Society of America (HDSA) 13th Annual Convention, "Reaching New Heights." Contact: Amy Schoenberg: ☎212-242-1968x18

JULY 26 - 29 • ASHVILLE NC

International Fragile X Meeting. Contact: Allyn McConkie-Rosell, ☎919-684-2036.; mccon006@mc.duke.edu

JULY 9 - 11 • FT WALTON BEACH, FL

21st Annual Southern Genetics Group Meeting. Contact Lisa Abear: ☎706-721-2809

CERTIFICATION IS TOPIC AT SICKLE CELL MEETING

Andy Faucett, MS

The Sickle Cell Disease Association of America (SCDAA) held an ad-hoc committee meeting in Los Angeles in February to discuss establishing national certification for undergraduate level hemoglobinopathy counselors. I attended as the appointed NSGC representative; Bill Herbert represented ABGC. Representatives from SCDAA, CORN, several comprehensive sickle cell centers and the Sickle Cell Counselor's Society (SCCS) also participated.

SCDAA convened this meeting because of their concern that the quality of counseling and information provided by hemoglobinopathy counselors varies greatly. Major issues discussed were:

- POSITION TITLE — sickle cell v. hemoglobinopathy and educator v. counselor. SCDAA is interested in a certification process for individuals who can adequately discuss all hemoglobinopathies and provide family support. Hemoglobinopathy counselor was recommended.
- CERTIFICATION — Consensus was reached that for this effort to succeed, current hemoglobinopathy counselors must play the primary role in creating the certification process. This committee recommended that SCDAA fund an interim board, consisting of active hemoglobinopathy counselors from SCCS and an ex-officio representative from SCDAA. This Board is charged with developing the certification process. SCDAA, CORN, newborn screening programs, NSGC and ABGC will serve as consultants. ❖

Perspectives in Genetic Counseling
20:1 — Spring 1998

CREATING A JEMF PROJECT: FROM IDEA TO REALITY

Judith Benkendorf, MS

& Michele Prince, MS

Three years ago, Judith heard the best-selling author Deborah Tannen, PhD, interviewed about her book, *Talking from 9 to 5: Women and Men in the Workplace*. Dr. Tannen is Professor of Linguistics at Georgetown University, where we work. Dr. Tannen's observations are intriguing, as they substantiate the work of educational psychologist Carol Gilligan, whose theories underpin the NSGC Code of Ethics.

After reading *Talking from 9 to 5*, Judith wondered about elements of our work-day talk, such as directness in communicating ideas, requests and authority, balancing the asymmetry of power through conversation and how a mismatch of conversational styles can undermine professional encounters.

EVOLUTION OF AN IDEA

The relevance of Dr. Tannen's research to genetic counseling seemed obvious. Most genetic counselors are women. Does our inherently indirect conversational style promote value-neutrality? Do male and female genetic counselors talk to clients differently? Is the genetic counselor/client relationship subject to the asymmetry of power seen in the doctor/patient relationship?

Six months later, Judith returned from the JEMF Grantsmanship Seminar with inspiration from the discussion of qualitative research methods and the concept of packaging and marketing a dream. This was the critical turning point.

Judith discussed her ideas with Dr. Tannen and was introduced to

Heidi Hamilton, PhD, Director of the internationally renowned Sociolinguistics Program at Georgetown. Dr. Hamilton has had ongoing personal and research interests in medical communication. Because of our shared reflective approach to genetic counseling and love of writing, Michele joined the project, and we made a commitment to submit a JEMF proposal.

Judith audited Dr. Hamilton's graduate level Seminar on Discourse and Medicine, and we submitted a protocol and proposed consent form to our IRB for permission to audiotape our sessions for linguistic analysis. The linguistics graduate students in the seminar observed us counseling and transcribed the audiotapes. Through the analysis of our conversations with clients, we saw evidence of the enactment of genetic counseling principles and were convinced that this project had tremendous potential.

LET THE WORK BEGIN

We have begun by studying discourse analysis through readings, graduate courses, tutorials with Dr. Hamilton and research group

meetings with sociolinguistics graduate students. For a year, we have been taping our genetic counseling sessions to obtain primary data for discourse analysis. Most genetic counseling research has been conducted by outsiders; through this collaboration we have the luxury of combining the best of the insider/outsider worlds. As we become more aware of our own conversational styles and how our language choices facilitate or hinder the effectiveness of our counseling interactions, we are establishing a model for practicing counselors to sharpen their counseling skills in a process similar to clinical supervision.

Finally, we are developing two products: a textbook on the application of discourse analysis to our practice and professional principles and an accompanying audiotape. Both will be distributed to genetic counseling programs and NSGC members.

New challenges and ideas for future work continue to emerge, and we are deeply grateful to Mr. Alfred B. Engelberg and the JEMF Advisory Board for making this opportunity possible. ♦

JEMF AWARD RECIPIENT REFLECTS ON EXPERIENCE

Throughout my years of work in clinical genetics, I was always fascinated by how families and individuals adjust to and cope with the presence of genetic risk or a family member with an inherited or congenital disorder. Receiving the Jane Engelberg Memorial Fellowship Award allowed me to complete a post-graduate certificate program in systemically based couples and individual psychotherapy. In addition to completing coursework, I had the opportunity to complete several hundred hours of supervised therapy with individuals and couples.

Every part of my clinical and academic work since then has been positively affected by the additional training. I have begun to formulate possible answers to my original questions about adjustment and coping. I have begun to consider what the universal human experiences of genetic risk are and their implications for genetic counseling. These developing theories and thoughts have been invaluable in my work as a trainer of genetic counselors and as a therapist working with families who have been touched by genetic risk. ♦

— Deborah L. Eunpu, MS

RESEARCH NETWORK



PRENATAL STUDIES

CVS AND BIRTH DEFECTS

The Chorionic Villus Sampling Birth Defects Registry is obtaining information about CVS exposed children with any type of birth defect or hemangioma. The study will send a health care provider to the family's geographic area. The painfree examination will consist of a physical, fingerprints, finger molds and a photograph.

☛ Caroline McGuirk, MPH,
Coordinator, ☎888-287-0738;
mcguirk.caroline@mgh.harvard.edu.

SKELETAL STUDIES

CRANIOFACIAL SYNDROMES

Research is underway to determine if there is a clinical correlation between the specific genotypes and phenotypes of a number of craniosynostosis syndromes. Investigators at Children's Hospital of Philadelphia and others have identified responsible mutations in fibroblast growth factor receptors (FGFR1, 2 and 3) and the transcription factor TWIST and have developed rapid sensitive assays for mutation detection and molecular diagnosis.

☛ Lynn Godmilow, MSW,
☎800-669-2172;
godmilow@mail.med.upenn.edu.

ADULT STUDIES

SLEEP DISORDERS

The National Narcolepsy Registry (NNR), a National Sleep Foundation project, is collecting demographic and clinical data and DNA from individuals and families with narcolepsy to assist research into this possibly inherited, adult onset disorder.

Two studies are underway:

- A search for the gene(s) involved in narcolepsy

- A study of the possible correlation between HLA-DQB1*0602 and the degree of cataplexy.

The Registry seeks large families with at least two affected relatives, as well as isolated cases with two unaffected parents.

☛ Helen M. Temple, MS,
☎718-920-4841; HMTemple@aol.com.

ALZHEIMER; PARKINSON; MACULAR DEGENERATION

Family ascertainment and clinical research on Alzheimer and Parkinson diseases and age related macular degeneration is being conducted at Vanderbilt University. The linkage studies are free, have open enrollment and are not limited to any geographical area.

☛ Amy Bazyk, MS, ☎888-717-4219;
amy@ruth.mc.vanderbilt.edu.

OTC DEFICIENCY

Heterozygous females or partially deficient males age 18 - 65 are being recruited by Hospital of University of Pennsylvania for a study requiring an 11-day hospital stay. Travel funds are available.

☛ Donna McDonald-McGinn, MS
or Margaret Rose, ☎215-895-3584;
mrose@childrens-seashore.org.

CANCER STUDIES

BREAST CANCER AND COUNSELING IMPLICATIONS

A New Jersey collaborative effort is examining the effects of genetic counseling and genetic testing for BRCA1 (185delAG and 5382insC) and BRCA2 (6174delT) mutations in the Ashkenazi Jewish population. This study follows eligible individuals for eight months, examining:

- changes in knowledge and attitudes before and after counseling
- factors that motivate or discourage individuals from testing

- emotional responses to test results or the decision not to test
- changes in health behaviors after genetic counseling and/or testing

Eligible participants must be seen in either Newark or New Brunswick for genetic counseling. Genetic testing is *not* required.

☛ Monica Magee, MS,
☎973-972-3304; mageeml@umdj.edu.

NY BREAST CANCER STUDY

The University of Washington and Sarah Lawrence College continue their collaboration on The New York Breast Cancer Study, an epidemiological investigation of BRCA1 and BRCA2 mutations in the Jewish population.

Directed by Mary-Claire King, PhD, the study provides free genetic counseling and testing for three mutations.

The study includes Jewish individuals in the New York metropolitan area who have been diagnosed with breast cancer since 1994 and who may or may not have a family history of cancer.

All participants receive pre- and post-test genetic counseling via collaboration with several tri-state institutions. Participants are given the option of receiving their results; all must complete an environmental questionnaire detailing their lifestyles and medical histories. Free counseling and testing is offered to all family members of participants found to carry a mutation.

☛ Jessica Mandell, MS, Sarah
Lawrence College; ☎914-395-2239;
jmandell@mail.slc.edu. ♦

NSGC BUDGETS: HOW WE PLAN TO SPEND AND SAVE!

Lisa Amacker North, MS

Finance Chair

& Kristine Courtney, MS, Treasurer

Ever wonder how NSGC's Board of Directors decides to spend the money it receives in dues and other income? Your organization is different than your personal or for-profit business accounts whose goals are to make money. NSGC's goals are to provide services and benefits, using the members' dues in the most efficient and effective manner and to have sufficient reserves in fund equity to finance future growth.

NSGC's budgeting process also runs differently from your personal household budget and bank accounts. A tax-exempt organization like NSGC runs on a fiscal accounting system called cash basis. Revenue (dues, grants, income) and expenses (labor, supplies, postage, computers, telephone, etc) are planned for in an annual budget.

The Finance Committee is responsible for creating an annual budget that details what money will be available from dues, grants, products NSGC sells and bank interest. Given the available revenue, the budget also details what projects will be funded that year.

Every summer, individual committees, SIGs, the Executive Director and members of the Board of Directors make requests for money for projects they would like to accomplish in the upcoming year. Certain projects are budgeted not to cost NSGC money, but to break even (like the Jane Engelberg Memorial Fellowship) or bring in a small amount of income (job connections, mailing lists, Annual Education Conferences or regional conferences).

Other projects are prioritized by the requesting Board member. The Finance Committee oversees a preliminary prioritizing of these expense requests to bring a budget to the Board of Directors for final discussion and vote of approval at the fall Board meeting. The budget is designed so that the year's revenue equals the year's expenses.

Another aspect of the cash basis accounting system is that budgeted income and expense are actually received and spent during the year. Any budgeted project must be completed within that fiscal year. If a project needs to be continued into another year, new budgeting must occur. We do not accrue income for projects like GeneAMP and SIG projects from year to year.

Lastly, balancing the financial reserve needs of NSGC with the operating realities is a difficult process. Our financial reserves, which have built up over the lifetime of our organization, are generated when NSGC earns excess revenues over

expenses in a given year, and are used to:

- offset the effect of inflation on our assets
- ensure financial growth (GeneAMP, and computer equipment in '97),
- accumulate funds for expansion (expanded services and executive office in future)
- help us weather short-term adversity, such as the Annual Education Conference having low attendance and losing money. We are trying to maintain a reserve of 60% - 100% of our annual budget.

Thanks to Andy Faucett, past Treasurer and Finance Chair, we have in place the systems needed to meet our current financial needs. Ahead is continued expansion and growth of our profession with its growing financial demands. We are a young, financially secure organization. We need to watch our pennies and someday we will be able to own our own executive home. ♦

ANNUAL EDUCATION CONFERENCE — FEEL THE ENERGY

Every year, we end our Annual Education Conference thinking we have reached a new height in planning and programming. NSGC's 17th Annual Education Conference promises to be such a year! Let's preview some of the highlights:

- 12 WORKSHOPS to challenge you, among them: Creating a Marketing Plan: Strategies for Genetic Counselors; Developing Your Retirement Portfolio; Eureka! Using Research to Discover New Truths About Counselees With Mental Retardation; Educational Tricks: A 'Show and Tell' Approach; Establishing Programs of Community; and Professional Awareness and Education about Genetics Experience with an Ashkenazi Jewish Population; Family Dynamics in Genetic Counseling
- 8 PRACTICE-BASED SYMPOSIA sponsored or facilitated by leaders and innovators in the field of genetic counseling, among them: Fetal Diagnosis and Therapy; Non-Traditional Jobs in Genetic Counseling: Experiences of Recent Graduates; Infections During Pregnancy: Impact on the Fetus; Prophylactic Surgery: Implications for Cancer Genetic Counseling; Molecular Genetic Diagnostic Technology in the 21st Century.

Look in your mailbox for the Information and Registration Brochure and be sure to take advantage of early registration without penalty! ♦

THE CANCER GENETIC COUNSELING SPECIAL INTEREST GROUP

Charlene Schulz, MS

The Cancer Genetic Counseling Special Interest Group (CGC-SIG) grew from the former Familial Cancer Risk Counseling Alliance (FCRCA), a multidisciplinary group whose mission was to maintain and foster relationships among professionals in cancer risk counseling. Our CGC-SIG is currently composed of greater than 250 members, making it the largest NSGC Special Interest Group in 1998, as it was in 1997.

SIG STRUCTURE

The CGC-SIG is composed of co-directors who serve alternating two year terms and one member who serves as secretary/treasurer for one year. These individuals are elected by the entire SIG membership. Five committees add to the structure, with a majority of

members sitting on one or more committees. These committees include: Communications, Education, Liaison, Practice Issues and Research. Each is headed by co-chairs, who serve a two year term and are elected by their committee members. The Steering Committee is the governing body, consisting of the co-directors, secretary/treasurer and co-chairs from each committee.

The CGC-SIG has been highly active — sponsoring a business meeting, practice-based symposium and workshop at NSGC's Annual Education Conference. SIG members have been involved in creating fact sheets, position statements, directories and short courses. Many members are active in research.

LIAISON COMMITTEE

In 1996, June Peters was appointed as liaison between the FCRCA and the newly formed CGC-SIG. June modified the FCRCA directory and introduced it online into the NCI CancerNet homepage and the Physician's Desk Query (PDQ). A new liaison committee was created in 1997 and is currently working on the following:

- surveying NCI Cancer centers about the use of genetic counseling and referrals
- distributing cancer genetics packets to oncologists as marketing tools
- coordinating efforts to take our exhibit to oncology meetings.

COMMUNICATIONS COMMITTEE

This committee is responsible for internal communications within the SIG, including the well used CGC-SIG listserv. The committee has posted monthly abstracts of recent and relevant journal articles and lay press article reviews. A quarterly calendar of pertinent

meetings and events are also posted on the listserv. A quarterly CGC-SIG newsletter summarizes list serv activity for members who are not online. Future plans include a link of SIG news and abstracts to the NSGC webpage.

EDUCATION COMMITTEE

This committee was responsible for the successful Cancer Genetic Short Course in 1997 and will continue to be involved at Annual Education Conferences. Members are working on the final draft of the "Starter Packet" for genetic counselors new to cancer genetic counseling services.

PRACTICE ISSUES COMMITTEE

This committee is charged with the development of practice guidelines for cancer genetic counseling which will be used as an educational and marketing tool and for setting standards. The committee will also consider consistency of their document with other published practice guidelines.

RESEARCH COMMITTEE

This committee's goals include:

- developing a list of ongoing research projects
- fostering collaboration among researchers
- Mentoring genetic counselors interested in research.

Plans for 1998 include surveying the CGC-SIG membership to develop a directory of ongoing research projects and testing laboratories to facilitate collaboration. The committee also plans to write a proposal to the American Cancer Society requesting that the Society create a grant line specifically for the area of cancer genetic counseling. ♦

ACTIVITIES OF OTHER SIGS

DNA Diagnostic Lab

- Created listserv
- Organizing a practice-based symposium for 17th Annual Education Conference
- Investigating possibility of writing guidelines for student internships and rotations in a DNA/Diagnostic lab
- Updating Molecular Genetics Lab Questionnaire

Assisted Repro Technologies

- Presenting workshop at ACMG
- Developing slide program for students to address the role of genetic counselors in this field

Connective Tissue

- Conducting needs assessment on clinical research and support for connective tissue conditions
- Studying psychosocial issue of adults with Marfan syndrome
- Creating natural history sheets of 10 skeletal dysplasias



BULLETIN BOARD



PERSPECTIVES EDITOR NAMED

Janice Berliner has accepted the post of Editor, *Perspectives in Genetic Counseling*. The official appointment was made in early March by President Maureen Smith. Janice serves on the *Journal of Genetic Counseling* Editorial Board, spearheaded and continues to chair the Education Committee's Education Modules Subcommittee and was NSGC Treasurer, 1995 - 1997. Abounding with energy and enthusiasm, she follows the footsteps of Deborah Eunpu, Joe McNerney, Ed Kloza, Vickie Venne and Liz Stierman.



DEADLINES

March 20	Call for Award Nominations
April 3	Call for Board of Directors Nominations
May 1	Jane Engelberg Memorial Fellowship Proposals
May 15	Special Projects Fund
May 15	Call for Abstracts 17th Annual Education Conference
mid May	Professional Status Survey mailed to Full members
June 15	Professional Status Survey due

NEW NATIONAL WOMEN'S HEALTH INFORMATION CENTER NOW OPEN FOR TESTING

The US Public Health Service's Office on Women's Health has opened a National Women's Health Information Center, (NWHIC). Through a toll-free number and the Internet, NWHIC acts as a federal "Woman's Health Central" for the public, health care professionals, educators, researchers and women in the military.

For questions about women's health in general or about a specific program, concern or disease, call ©800-994-WOMAN or visit <http://www.4woman.org>.

REVIEW COURSES FOR BOARD EXAMS SET FOR '99

NSGC and the University of Pittsburgh have again teamed together to co-sponsor a Board review course in 1999. Identical courses will be offered on both coasts — April 30 - May 2 in Pittsburgh and May 14 - 16 in Oakland. Information will be available on our voice mailbox #6; brochures will be mailed to persons approved to sit for the exam.

For any type of information related to the Boards, *do not contact NSGC*. Rather, call ABGC directly, ©301-571-1825.

ACMG SOLICITS WORKSHOPS

American College of Medical Genetics is soliciting workshop proposals for the 1999 Joint Clinical Genetics Meeting, to be held in Miami in March. Priority will be given to interactive workshops. Proposals are due by April 24. Contact Melanie Gross-Greenfield, ©301-571-1825 or mgross@genetics.faseb.org.

BECOME INVOLVED IN CONFERENCE PLANNING

The 1999 Annual Education Conference Planning Committee is looking for members. The theme is Reproductive Genetics; the conference will be held in Oakland California, October 16th — 19th. We are particularly seeking individuals with novel concepts to work on the Program, Workshops and Practice-based Symposia Committees.

CONFERENCE CO-CHAIRS

Laura Thomson 315-464-7610[E]

Thomsonl@mailbox.hscsyr.edu

Linda Robinson 510-883-6027[P]

lrobinson@genetic.dhs.cahwnet.gov

PROGRAM COMMITTEE

Kathryn Murray 541-686-7419[P]

murrayk@ohsu.edu

WORKSHOPS

Kelly Ormond 312-908-6478[C]

kormond@nmh.org

Lyn Hammond 803-792-7541[E]

hammondl@muscc.edu

PRACTICE-BASED SYMPOSIA

Dawn Allain 312-633-7768[C]

Heather Hampel 614-293-6694[E]

Hampel-2@medctr.osu.edu

RESOURCE CENTER

Michael Banke 412-624-0133[E]

mbanke@helix.hgen.pitt.edu

ABSTRACTS

Leah Hoechstetter 513-636-4351[E]

hoec10@chmcc.org

Karen Wcislo 408-972-3306[P]

Karen.Wcislo@ncal.kaiperm.org

COMMUNICATIONS

Denise Tilley 704-355-3149[E]

dtilley@carolinas.org

LOGISTICS

Kimberly Barr 415-202-2996[P]

kimberly.barr@ncal.kaiperm.org

Contact the corresponding Chairs to volunteer.

Key: [E] Eastern Time; [C] Central Time; [P] Pacific Time

EMPLOYMENT OPPORTUNITIES



BERKELEY CA

Civil Service Exam to be given June/July '98 for 2 Genetic Disease Program Specialists (GDPS IV & GDPS III). GDPS IV req 4 yrs admin in pub health genetic prog w/ rsrch, coun or tchg in genetics, genetic disease or closely related field; GDPS III req 3 yrs exp in same. GDPSIV: \$4139 - \$4994/mo; GDPS III: \$3770 - \$4547/mo. GDPS IV serves as sec-tion chief of major statewide PN prog scrng approx 350,000 women/ yr; develop & monitor standards for PNDx ctrs, cyto & molec biology labs; assist Chief in develop, implement, eval genetic disease prevention & control prog & policies. GDPS III provides consult & prog developmt to med community re: hereditary & congenital disease preven progs; devel prog objectives & stds, eval proj effectiveness, liaison & coord w/ lab svcs.
CONTACT: For app & annmt re: Civil Svc Exam, Maxie Spears, Genetic Disease Branch, Berkeley CA; ☎510-540-2613. [TDD 916-657-3042]. Applicants must have return postmark by April 3. EOE/AA

MOUNTAIN VIEW (PALO ALTO AREA) CA
Immediate opening for BC/BE part-time/full-time Genetic Counselor. Ability to work independently, high motivation req; exp pref; Spanish a plus. Join 2 GCs in a busy expanding PN practice; work independently at satellite locations. Multi-ethnic backgrounds served.
CONTACT: Frannie Roche, MS, Peninsula Prenatal Diagnosis, 1580 W El Camino Real, Mountain View CA 94040; ☎650-938-6066; Fax: 650-964-1522. EOE/AA

SAN FRANCISCO CA

Temp opening for BC/BE Genetic Counselor (4/1-10/19/98). Some travel to satellite clin in Marin & Santa Rosa. Busy PNDx ctr w/ broad range pt population: AMA, + Exp AFP results, abnl U/S, terat & fam hx of birth defects/genetic disease. Active CF scrng prog; exploring cancer coun. Multi ethnic & economic pt population.
CONTACT: Katie Braverman, MS, CPMC Prenatal Diagnosis Center, 3700 California St Ste G330, San Francisco CA 94118; ☎415-750-6400; Fax: 415-750-2306. EOE/AA

SOUTHERN CALIFORNIA

Immediate opening for BC/BE Genetic Counselor. Exp & bilingual (English/Spanish) pref. Provide primarily PN svcs to diverse pt population; AMA, XAFP (TMS), teratogen, DNA referrals on team supporting one of the largest providers of genetic svcs nationwide.
CONTACT: Beth Bronstein, Genzyme

Genetics, PO Box 9322, Framingham MA 01701-9322; Fax: 508-872-5234. EOE/AA

STANFORD CA

Immediate opening for energetic BC/BE Genetic Counselor. Fluency in Spanish desired w/ abil to work independently. Provide GC in PNDx ctr: AMA, XAFP, abnl U/S, DNA dx, family hx, & terat. Primary site in Stanford w/ satellite clin in San Mateo & Mountain View.
CONTACT: Robbie Tung, MS, UCSF-Stanford Health Care, Dept OB/Genetics, HF 306C, Stanford CA 94305; ☎650-723-5198; Fax: 650-725-2878. EOE/AA

DENVER CO

Immediate opening for BC/BE Genetic Counselor. Busy dept svg CO & WY, incl 5 GCs, 1 MSW, & 4 MD geneticists. Coordinate presymp tstg clin & partic in pediatric & adult genrl genetics clin in Denver & outreach. No PN clin.
CONTACT: Eva Sujansky, MD UCHSC/The Children's Hospital, 1056 E 19th Ave B300, Genetic Svcs, Denver CO 80218; ☎303-861-6395; Fax: 303-861-3921; Sujansky.Eva@TCHDEN.ORG. EOE/AA

DENVER CO

Immediate opening for BC Genetic Counselor. Exp req. Join 3 GCs & 2 OB/geneticists in busy PNDx prog: CVS, amnio, terat, triple screen.
CONTACT: Kathleen O'Connor, MPS, Reproductive Genetics Center, P.C., 455 S. Hudson St Level Three, Denver CO 80246; ☎800-399-5577.

NEW HAVEN CT

Immediate opening for Genetic Counselor or Clin Nurse Specialist. ABGC; State certified RN; or BSN w/ clin experience & formal training in rsrch & analysis. Exp pref; self motivated graduates w/ strong interpersonal skills considered. Join active established multidisc specialty clin for Hereditary Hemorrhagic Telangiectasia, Coord inpt & outpt visits & admissions for pts w/ HHT & other vascular malformations. Compile thorough fam hx; provide educ & follow-up; perform data collection & analysis for rsrch.

CONTACT: Ms. W McNeil, Yale University Medical School, Dept HR, 153 College St, PO Box 9168, New Haven CT 06532-0168; Mail CV w/ salary req or Fax: 203-785-3165. EOE/AA

ATLANTA GA

Immediate opening for Genetic Counselor w/ min 2 yrs exp in PN/Perinatal dx ctr setting req. BC pref; BE considered. PN &

preconceptional GC for AMA, abnl scrng results, abnl U/S & family history.

CONTACT: Beth Bronstein, Genzyme Genetics, PO Box 9322, Human Genetics Framingham MA 01701-9322; Fax: 508-872-5234. EOE/AA

GAINESVILLE FL

Immediate opening for BC/BE Genetic Counselor. PNDx couns exp pref. Provide PNDx svcs for Women's Health group in tchg hospital/clin setting; tchg & rsrch.
CONTACT: Gayla Rye, Womens Health Group, Univ Florida, Box 100347; Gainesville FL 32610; ☎800-325-0367; Fax: 352-395-7898. EOE/AA

OAK LAWN IL

Immediate opening for BC/BE Genetic Counselor. Part-time w/ potential for full-time; some travel in Chicago req; exp pref. Busy MFM section: amnio, CVS, triple screen, abnl U/S, fam hx, some peds.
CONTACT: Cristina Ruiz, MS or Deborah Oleskowicz, MS, Hope Children's Hospital/Christ Hospital & Medical Center, 4440 W 95th St #3141, Oak Lawn IL 60423; ☎708-346-2529; Fax: 708-346-4446. EOE/AA

IOWA CITY IA

Immediate opening for Program Consultant w/ master's in genetic counseling, genetics, nursing, preventive medicine & environmental health, public health, human genetics or related field/equivalent. BC/BE highly desirable. Coordinate activities of Statewide Regional Genetic Consultation Service with Birth Defects Institute: provide genetic evals & counseling; partic in total quality management; coord training.
CONTACT: Janine McBride-Rahn, (Attn: #05), Dept Pediatrics, University of Iowa, 200 Hawkins Dr, Iowa City IA 52242-1083. ☎319-356-8154; Fax: 319-356-4855. EOE/AA. Women and minorities strongly encouraged to apply.

DETROIT MI

Immediate opening for BC/BE Genetic Counselor w/ min 2 yr PN exp req. Join 4 active GC's in busy PN ctr: CVS, amnio, PN & ethnic scrng, dx U/S, terat, fetal therapy. Oppty for rsrch, publctn, & tchg.
CONTACT: Eric Krivchenia, MS, DMC Hutzel Hospital, 4707 St Antoine Blvd, Detroit MI 48201; ☎313-745-7067; Fax: 313-993-0153. EOE/AA

See next page

233 CANTERBURY DRIVE • WALLINGFORD PA 19086-6617

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc. Send articles and correspondence to the Executive Office.

- GUEST EDITOR: Janice Berliner
- STAFF: Lisa Brown; Jennifer Claus; Kris Courtney; Shelly Cummings; Rich Dineen; Karen Eanet; Katherine Hunt; Sarina Kopinsky, Jacquelyn Krogh; Jessica Mandell; Melissa Patterson; Trisha Peters Brown; Trisha Page; Toni Pollin; Melisa Siegler; Kathryn Steinhaus; Wendy Uhlmann; Cathy Wicklund; Elaine Wu; and Beverly Yashar
- NSGC EXECUTIVE OFFICE: c/o Bea Leopold, Executive Director, 233 Canterbury Dr, Wallingford PA 19086-6617; ☎610-872-7608; Fax: 610-872-1192; NSGC@aol.com

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 11



Printed on 100% Post-Consumer Waste Recycled Paper

EMPLOYMENT OPPORTUNITIES

... from previous page

KANSAS CITY MO

Immediate opening for BC/BE Genetic Counselor. Good public speaking & writing skills a must. Independent, creative, self-starter desired. Join 2 GC's in busy Perinatal Ctr: 50% PN GC/50% in new educ/outrch project to improve PN care provider assessment of birth defects risk. CONTACT: Susan Mundt, MPH, St. Luke's Perinatal Center, 4401 Wornall Rd, Kansas City MO 64111; ☎816-932-5967; Fax: 816-932-2381; smundt@saintlukes.org EOE/AA

PARAMUS NJ & ENVIRONS

Immediate opening for part-time Genetic Counselor. MS or RN req. w/ exp in OB &/or Peds. Strong written & verbal skills essential. Own transportation req. Join priv Medical Genetics Ctr. Flex hrs Mon-Fri 8am-5pm. Travel to OB offices in Paramus NJ & environs. Send cover letter & CV. CONTACT: GeneCare Medical Genetics Ctr, PO Box 4270, Chapel Hill NC 27515-4270.

GREENVILLE NC

Immediate opening for BC/BE Genetic Counselor w/ Faculty position. Wide range of GC opptys: Peds, PN & specialty clins; partic in satellite clins. CONTACT: O.J. Hood, MD, East Carolina Univ School Medicine, Brody Medical

Sciences Bldg, Rm 3E140, Greenville NC 27858-4354; ☎252-816-2525. EOE/AA. Accommodates individuals w/ disabilities. Applicants must comply w/ the Immigration Reform & Control Act.

BRONX NY

Immediate opening for BC/BE Genetics Counselor. Fluency in Spanish pref. Abil to work w/ team req. Diverse oppty in genrl genetic svcs: PN, peds & adult clins, svg culturally diverse population. CONTACT: Philip F. Giampietro, MD, PhD, Lincoln Hospital, Pediatrics-Genetics, 234 E. 149th St, Ste 4-4 Bronx NY 10451; ☎718-579-5295; Fax: 718-579-4640. EOE/AA

NEW YORK NY

June 1 opening for BC/BE Genetic Counselor. Highly motivated, independent personality req. Fluency in Spanish strongly pref. Join active team in estab, comprehensive genetics prog in Univ-based medical ctr. All aspects of PN, pediatric & cancer genetic counseling. CONTACT: Send CV & 3 ltrs recom to Harry Ostrer, MD, Director, Human Genetics Program, New York University Medical Center, 550 First Ave, MSB136, New York NY 10016; ☎212-263-5746; Fax: 212-263-7590 EOE/AA

OKLAHOMA CITY OK

Immediate opening for BC/BE Genetic Counselor w/ min 1 yr exp. Parental coun

& assistance w/ genetic evals in outrch clins based at Chapman Inst, Children's Med Ctr. CONTACT: Human Resources, Hillcrest Healthcare, 110 W. 7th St Ste 105, Tulsa OK 74119-1101; ☎918-579-7645; Fax: 918-579-7875. EOE/AA

HOUSTON TX

Immediate opening for BC/BE Genetic Counselor. Independent, self-starter; ability to speak Spanish req. Join PN group in an academic setting: provide GC in clins for underserved population. CONTACT: Katie Leonard, MS, Baylor Prenatal Genetics Ctr, 6550 Fannin, #921, Houston TX 77030; ☎713-798-4363; Fax: 713-798-4187; kleonard@bcm.tmc.edu EOE/AA

SALT LAKE CITY UT

Immediate opening for Genetic Counselor w/ MS from accredited prog or equiv req, BC/BE req. Partic in genrl genetics clin w/ oppty for growth & specialization. Salary Range: \$34,361-\$51,540, dep on bkgrd & exp. Info: Bonnie Baty, MS, ☎801-581-8943; Fax: 801-585-7252; bonnie.baty@hsc.utah.edu

CONTACT: App review begins 2/20/98. Send ltr, resume & names, addresses & telephone #'s of 3 work related references to: Chair, Search Committee c/o Kenya Fail, Univ Utah, Human Resources (KP-1097), 1901 E South Campus Dr, Rm 101, Salt Lake City UT 84112. EOE/AA