PERSPECTIVES
in genetic counseling

Volume 27 Number 3 Fall 2005

national society
of genetic
counselors, inc.

nsgc

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

www.nsgc.org

TABLE OF CONTENTS

Jessica Mandell, MS
Editor
jmandell@mail.slc.edu

THE GENETIC COUNSELING FOUNDATION: A FOUNDATION OF THE NATIONAL SOCIETY OF GENETIC COUNSELORS

Dawn Allain, MS and
Kelly Ormond, MS

In June 2004, your Board of Directors voted to establish a foundation. To achieve incorporation status, a taskforce of individuals developed some baseline parameters, such as the foundation board structure, name, mission and budget. We are happy to announce that our work is complete, and the Genetic Counseling Foundation will be incorporated in September 2005.

ADDRESSING OUR NEEDS

The key initiatives of The Genetic Counseling Foundation will address needs within the field of genetic counseling which are guided by the National Society of Genetic Counselors' Mission, Vision Statements and Strategic Plan Initiatives.

The broad purpose of The Genetic Counseling Foundation is to:

- support innovative and timely research in the area of genetic counseling services
- provide education for genetic counselors, consumers and other health care providers
- actively participate in policy development as it relates to genetic counseling services
- support pioneering projects and collaborations within the field of genetic counseling.

The Genetic Counseling Foundation's founding Board of Directors is

...to page 9

BEA LEOPOLD RESIGNS FROM NSGC

On August 24, NSGC members received news that **Bea Leopold** will be leaving her position as Executive Director later this year. The eblast that was distributed is reprinted below. While the departure of such a longstanding and valuable member of our leadership team is a significant transition for NSGC, leaders in our organization are working hard to ensure that NSGC continues with smooth operations. NSGC will miss Bea as she moves on to new endeavors, and we wish her the best of luck!

Dear NSGC Membership,

I am emailing you with the news that our Executive Director, Bea Leopold, has submitted her resignation effective later this year. Bea has served the NSGC for 18 years and should be commended for her invaluable

...to page 5

PRESIDENT'S BEAT

As the leaves change and the weather cools down, fall brings many changes for us in our personal and professional lives. For me, fall has always been associated with going "back to school" and re-engaging in the learning activities that drive us through a large part of our childhood and early adulthood. I hope that you, as an NSGC member, will be joining us to further your own life-long learning efforts at the Short Course or Annual Education Conference in Los Angeles CA (November 10-15). The AEC is a great opportunity to update your professional knowledge, network with colleagues and join a committee or SIG and give some of your knowledge and enthusiasm back to our professional organization.

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

- EDITOR: Jessica Mandell • jmandell@mail.slc.edu
- DESKTOP PUBLISHER: Anne Greb • agreb@genetics.wayne.edu
- STAFF: Susie Ball; Janice Berliner; Jennifer Claus; Shelly Cummings; Kathleen Fergus; Nicole Fernandez; Angela Geist; Stephanie Herbert; Katherine Hunt; Sarina Kopinsky; Melanie McDermet; Kathy Morris; Whitney Neufeld-Kaiser; Claire Noll; Karen Potter; Roxanne Ruzicka; Faye Shapiro; Kathryn Spitzer Kim; Kathryn Steinhaus French; Beverly Yashar
- NSGC EXECUTIVE OFFICE: c/o Bea Leopold, Executive Director, 233 Canterbury Drive, Wallingford PA 19086-6617; ✆ 610-872-7608; FYI@nsgc.org

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

*Next issue **December 15***
*Submission deadline **November 11***

MORE B&R SUCCESSES

While the AEC may be our main "face time" with fellow members, the organization has been busy over the past quarter, working on initiatives related to our strategic plan.

With regards to billing and reimbursement, we held the first meeting of our external advisory committee to develop a long term plan. NSGC (working with the ACMG) undertook a survey this summer on time spent before, during and after genetic counseling sessions. This data will be presented later this month to the AMA's CPT Committee (by **Leslie Cohen,** working with **Deb Lochner Doyle** and the CPT Committee). We also provided final input into the SACGHS report on reimbursement and coverage, which was discussed at their June meeting.

THE GENETIC COUNSELING FOUNDATION

NSGC has recently incorporated a daughter entity, a 503c tax exempt "Genetic Counseling Foundation" (see Foundation article, page 1). As we initiate a member fundraising campaign this fall, I dream NSGC could announce that 100% of our membership made some level of contribution, whether small or large. I strongly encourage each of you to consider the Foundation as you plan your year-end gift giving – I've already written my check!

OTHER INITIATIVES

I am pleased that among the large tasks of the past year, NSGC has brought other projects to fruition. For example, a leadership initiative was enacted, the Health Disparities Work Group hosted a facilitated retreat to discuss the current culture of NSGC for underrepresented individuals and the Membership Committee collaborated with program directors to begin an active recruitment process into our profession. Additionally, NSGC is working with ABGC and other genetics organizations to collaborate on mutually relevant issues. I urge you to review our quarterly reports to learn more about each committee's activities.


Kelly Ormond, MS

THANKS TO YOU

Finally, as my tenure as NSGC president comes to an end, I would like to thank you for the opportunity to serve you during this exciting time for our profession. But NSGC is not just about its president, so I would also like to thank every one of you for your hard work and enthusiasm. Whether you participated in a committee or SIG, gave a talk to a local community group or represented our organization as one of over 20 liaisons to outside groups, you have made a difference and worked to promote awareness of our profession, building a stronger foundation underneath our castles in the sky. I hope you will join me in welcoming our incoming president, **Nancy Callanan,** and in working with her throughout the next year to continue our organization's progress. ❖

Kelly E Ormond MS

Kelly Ormond, MS
2004-2005 President
k-ormond@northwestern.edu

For Your Practice

ADDRESSING MENTAL ILLNESS IN COUNSELING SESSIONS

Psychiatric Genetics Special Interest Group

Psychiatric disorders are complex diseases with a well-documented hereditary component. While all genetic counselors will inevitably encounter individuals with psychiatric diagnoses, many remain uncomfortable counseling about mental illness. The following case, presented by a second-year student, illustrates challenges and opportunities that arise regarding psychiatric disorders.

THE CASE

HB presented at 21 weeks of pregnancy to discuss age- and medication-associated risks. She was diagnosed with schizophrenia and type 2 diabetes, both reported as relatively well-controlled. HB saw a psychiatrist regularly. The father of the baby also had schizophrenia.

During the session, the student discussed amniocentesis, AMA, diabetes and medication during pregnancy. However, the student felt HB had issues beyond genetic counselors' training. After the session, the student identified that HB's psychiatric illness may affect her perception of her pregnancy, her decision-making and her ability to raise a child. The student, however, doubted her ability to respond appropriately and act an advocate. She also did not ask if HB wanted to discuss the fetus' risk for schizophrenia. Based on having two affected parents, the empiric risk of schizophrenia to this fetus is around 50% – higher than HB's other risks combined.

LEARNING FROM OUR FEARS

Many genetic counselors likely have had similar experiences. Genetic counselors, however, do have the necessary skills. Addressing the concerns of the student highlights ways for all of us to improve our genetic counseling services.

- **Feelings of Inadequacy**

Genetic counselors often have the same fears as the general public about individuals with psychiatric disorders. One way to improve comfort and competence is to gain exposure. Attend psychiatric grand rounds, visit a support group, speak to experienced colleagues and read books and journal articles.

> ***"Genetic counselors often have the same fears as the general public about individuals with psychiatric disorders."***

- **Lack of knowledge**

The same genetic principles apply to mental illness as to other complex disorders, including family-based variation surrounding genetic and environmental factors. Genetic counselors do not have to learn new concepts. In all cases it is important to analyze the family history to evaluate the applicability of empiric risks.

- **Fear of trying to develop a counseling relationship**

Genetic counselors may believe it impossible to develop a therapeutic relationship with someone with a psychiatric disorder. Such individuals usually can make informed decisions and even may be uniquely prepared to connect with the counselor if they have been in psychotherapy. Psychiatric symptoms may reduce capacity to understand complicated ideas, so provide straightforward information tailored to the needs of the patient, and ask a mental health professional about the patient's ability to provide informed consent.

- **Fear of inquiring about the illness**

Not asking about the patient's illness perpetuates the belief that psychiatric disorders are different or do not have a genetic basis. Regarding HB, a genetic counselor could say, "I noticed in your chart that you've been diagnosed with schizophrenia. Could you tell me how you are doing?" Other questions could address support system and the impact of her illness on her pregnancy. The post-partum period also can increase psychiatric symptoms, so counselors can help patients anticipate how to cope during this time.

- **Concerns about discussing familial recurrence**

Genetic counselors may hesitate from discussing empiric risks. Start by asking if the patient wants this information. Some are interested in a qualitative assessment or may be seeking anticipatory guidance. Patients suspect their offspring are at increased risk and can be empowered talking about early intervention and long-term outcome. Also, many find comfort in knowing treatments are expected to improve with research. ❖

☞ *Thanks to the student counselor for letting us learn from this case. To read more about psychiatric genetics, visit www.nchpeg.org/cdrom.*

NSGC ACCEPTS PARTNERSHIP WITH IQLM

Jessica Mandell, MS

NSGC has been selected to serve as a professional partner with the Institute for Quality Laboratory Medicine (IQLM). IQLM is a public-private organization designed to improve the quality, effectiveness and safety of laboratory tests and services.

IQLM was established by the Centers for Disease Control and the health management firm, Auburn Health Strategies LLC. More than 40 partners have joined the IQLM council, representing public health laboratories, technologists, physicians, accrediting bodies, hospitals, manufacturers and government agencies. "IQLM will be the first organization to bring these health care outlets together to enhance laboratory testing," said **Robin Stombler,** President of Auburn Health Strategies.

Objectives of the IQLM include:

- promoting laboratory practices that improve quality, safety and appropriateness of clinical care
- supporting research in the design and delivery of laboratory services
- facilitating communication between health care partners regarding laboratory services
- developing indicators for measuring the quality of laboratory tests
- translating laboratory research into strategies for improving health care
- developing educational programs to promote best practices.

The IQLM will not be a regulatory body. It will not approve medical devices or set standards for practice. ❖

☞ www.iqlm.org

NEW POSITION STATEMENT APPROVED BY NSGC

Elinor Langfelder Schwind, MS, Chair, Genetic Services Committee

The NSGC Board of Directors approved the following Preconception/Prenatal Genetic Screening Position Statement on May 25, 2005. Thanks to the members of the Prenatal SIG who developed this statement: **Renee Chard, Debra Duquette, Carrie Haverty, Christine Koil, Renee Laux, Kathleen O'Connor** and **Michelle Strecker,** and to **Heather Ferguson,** GSC liaison.

PRECONCEPTION/PRENATAL GENETIC SCREENING

Laboratory screening tests that identify individuals who are at increased risk for having offspring with a genetic condition or structural birth defect are increasingly available. Counseling by a Board Certified/Board Eligible genetic counselor/geneticist or a professional with equivalent experience is an essential component of any screening program. The NSGC supports the following recommendations.

1. Individuals/couples seeking preconception/prenatal care should be offered genetic screening tests after clinical research trials have been satisfactorily completed and the individuals:
    a. have a family history of a specific genetic condition for which screening is available
    b. have reason to suspect a family history of a genetic condition for which screening is available
    c. are members of a high-risk subpopulation or
    d. are members of a low-risk population when the clinical and analytical validity and utility of a genetic screening test has been established.
2. Screening is ideally performed prior to conception or as early as possible once pregnancy is confirmed in order to maximize reproductive options.
3. Individuals/couples considering screening should be provided with accurate, balanced information about the condition for which screening is being offered. They should be informed of the specificity, sensitivity, accuracy, risks, benefits and limitations of the screening tests offered and of any follow-up diagnostic tests, as well as their reproductive options, given a positive diagnostic test result.
4. Pilot studies to explore the scientific, educational, counseling, social and ethical aspects of screening should be completed prior to instituting large scale screening programs.
5. When choosing a laboratory, providers should consider the specificity, sensitivity, accuracy, risks, benefits and limitations of testing.
6. Genetic counseling should be offered to individuals/couples identified to be at increased risk for a specific condition by a screening test and should be available to any individual/couple that desires detailed counseling before screening.
7. Genetic counselors should take an active role in educating primary health care providers about appropriate use of screening tests. ❖

VOICES OF OUR COMMUNITY

Diversity Series, Issue Four

This is the last installment of our year-long series, Voices of Our Community. In this issue, we feature a veteran genetic counselor, ***Daniel Riconda,*** *who writes an eloquent narrative of the choices he has made in his 17 year career.*

Taking Chances, Making Choices

Daniel Riconda, MS

In the Spring of 1986, I interviewed, with trepidation, at Sarah Lawrence College as a prospective student for the Genetic Counseling Program. At the time, I was not certain if genetic counseling was going to be my vocation. During the interview, I was informed I might need more volunteer experience if I was not accepted. Fortunately, I was accepted and began my journey into a dynamic and sometimes daunting field.

Dan Riconda, MS

The First Job

As I think back over the last 17 years since completing graduate school, I realize how important your first job is in determining your development as a genetic counselor. Whether you are employed in an academic center with other counselors and geneticists or as the lone counselor with limited direct contact with colleagues, your job helps define how you will evolve professionally. My first job was in the latter category, requiring me to work independently and take initiative. After four years, I took on my current position in a medical center where I have remained 13 years and counting.

A Fork in the Road

Early in my career, I was encouraged by three senior genetic counselors in the Southeast region to get involved in an *ad hoc* committee investigating the issue of licensure in genetic counseling. I was in awe of the colleagues I met, some who were very well established in our profession. I asked myself, “What do I have to contribute to this group?” Little did I know that I would spend much of my spare time 10 to 15 years later heading the committee for licensure in Florida. The pursuit of licensure has proven to be a paradox. Although it has been one of the most satisfying experiences of my career, it also has been one of the most disappointing (our licensure bill was vetoed in 2004).

Outside the Box

The professional choices we make have a profound effect on our future. The decision to take a job where I was forced to be a self-starter (which at the time I believed was not my normal disposition) gave me the courage to join the licensure committee. This in turn set me down a path that also has included serving on the NSGC Ethics Committee and getting elected to the American Board of Genetic Counseling. I do not know where this path will lead me in the future, but I would encourage any counselor, no matter where you are in your career, to take a chance doing something professionally that is outside your character. You just might be surprised! ❖

☞ **Katherine Hunt, MS**
Voices Coordinator
hunt.katherine@mayo.edu

Leopold resigns, *from page 1*

contributions to our organization's growth, leadership and direction.

I would like to assure you that your Board of Directors is working to ensure that our organization continues to move forward in this time of change. We have activated our Executive Office succession plan, and in accordance with that plan, I have appointed a committee to select an interim management company to assist us in this transitional time. We will alert you as to our progress and provide further details when a company has been selected. We also will begin the process of determining the long-term direction for NSGC as it relates to the Executive Director position and will solicit input from stakeholder groups, including our own membership. The committee will conduct an exit interview with Bea to gain insights and recommendations.

NSGC will have its Annual Educational Conference as previously planned, and this event will continue to be staffed by our current executive office staff. We strongly encourage you to attend.

On behalf of our entire Board, we look forward to continuing to lead our organization through this next "developmental stage," and I welcome your input as we move forward.

Kelly E Ormond MS

Sincerely,
Kelly Ormond, MS
2004-2005 NSGC President
k-ormond@northwestern.edu

NONDIRECTIVENESS: WHAT DOES IT MEAN?

Lauren Hickson, BS, Allison Lawrence, BS, Karen Metzler, BS and Gwenn Sickles, BS

Nondirectiveness is an inconsistently defined and widely-debated issue in the field of genetic counseling. There is a significant amount of literature that criticizes, explores and questions the exact meaning of the term and the role it plays or should play. To assess the importance of nondirectiveness, we have attempted to examine its current definitions and to provide a resolution to its current misrepresentation.

TWO TENENTS

Two concepts common to most definitions are patient autonomy and value neutrality. We define autonomy as helping to ensure that the patient's choices regarding genetic diagnoses are informed and voluntary, reflecting their own values and interests[1]. We define value neutrality as expressing no value judgments about the medical procedures or tests the patient may choose or about the personal values, goals and beliefs the patient considers in making a choice.

We believe that patient autonomy should always be a central tenet of our profession due to our eugenic roots. Embracing this concept results in putting the patient and counselor on equal ground, which helps facilitate patient-driven decision-making.

In contrast, we disagree with value neutrality being part of the definition of nondirectiveness. We believe that this concept causes some of the confusion and debate among genetic counselors.

- *Is maintaining value neutrality really possible?*


(left to right) Lauren Hickson, Gwenn Sickles, Allison Lawrence and Karen Metzler

Much of what genetic counselors do in a session reflects what we know and what we think about what we know, i.e., our information and biases. For example, could the act of simply offering prenatal testing be construed by the patient as an endorsement to pursue testing? Another example is the way we present risk information. If we give the negative risk (risk of disease) before the positive risk (risk of not having the disease), are we implying that the former risk is more important and serious? Even if we attempt to use value neutral language, does the fact that we are discussing risks/chances indicate a bias?

- *Does a genetic counselor need to be value neutral to promote patient autonomy and informed decision-making?*

Although it can be detrimental to impose values on a patient through certain types of advice giving[2], we may express our values inadvertently. Does this value "leakage" really have an effect on a patient's ability to make an independent decision? We argue that it does not.

AUTONOMY IS ENOUGH

We believe that nondirectiveness, defined in terms of both patient autonomy and value neutrality, is an outdated concept. The term should instead be replaced by the concept of patient autonomy alone. Patient autonomy, though, is not an outcome; it is a process in which we provide information for patients to make their own choices and we facilitate decision-making by helping patients explore their values and beliefs. In order for the field of genetic counseling to move forward and expand, it seems essential to reach a timely consensus regarding the debate over nondirectiveness. ❖

---

[1] Wachbroit, Robert, Wasserman, David (1995) Clarifying the goals of nondirective genetic counseling. Report from the Institute for Philosophy and Public Policy; vol 15.

[2] Veach, P.M., LeRoy, B.S., & Bartels, D.M. (2003). Facilitating the Genetic Counseling Process: A Practice Manual, New York: Springer.

☞*Lauren, Allison, Karen and Gwenn are second year students at the Wayne State University Program.*

FREE TIME IN LA? SUGGESTED ACTIVITIES AT THE NSGC 25TH AEC

The Logistics Committee has organized some enticing activities for everyone at the upcoming AEC in Los Angeles. Here are a few highlights with contact information:

- Hosted dinners – Groups will be arranged to try out two or three local favorite restaurants on Sunday evening, 11/13. Sign up at registration or during the conference.
- City tour – We are working on arranging a city tour for Saturday morning, 11/12. One option is a private bus tour ($43/adult) of Santa Monica, Chinatown, Rodeo Drive, the Hollywood sign, plus stars' homes with stops along the way to window shop and take pictures.

☞ **Barbara Corey, MS**
bcorey626@charter.net

- TV show tapings – Attending a taping of a TV show can be fun! Anyone interested in this should check out the following websites: www.tvtickets.com, www.TVTix.com, www.ocatv.com

☞ **Jonathan Saari, MS**
jonathan.saari@csun.edu

- Museums – There are several great museums in the area. The King Tut exhibit at the Los Angeles City Museum of Art, which closes 11/15, requires advanced booking. If interested, order tickets ASAP (about $25 – www.lacma.org/art/exhibition/Tut2005/tuttickets.htm).
- Theater – Local theaters include the Mark Taper Forum, the Ahmanson, the Dorothy Chandler and Disney Hall. Current plays and performances will be listed at the AEC, but you might want to book ahead.

☞ **Ellen Knell, MS**
eknell@ix.netcom.com

- Wellness activities – We plan to host a variety of wellness activities including yoga/meditation, kickboxing and run/walk groups. We are looking for people to help lead some of these programs.

☞ **Erica Ramos, MS**
Erica.Ramos@genzyme.com

☞ **Amy Powers, MS**
alrpowers@bellsouth.net

- Roommate match – Do you need a roommate?

☞ **Christina Chimera, MS**
chimeracm@upmc.edu.

We look forward to a wonderful conference. Safe and easy travels! ❖

Roxanne Ruzicka, MS
AEC Logistics Committee Chair

LEADERSHIP IS ALL AROUND US

At the 2004 AEC, NSGC President **Kelly Ormond** encouraged us to dispel the misconception that leadership within NSGC was confined to a small number of individuals. She challenged all NSGC members to take on a leadership role to strengthen the genetic counseling profession.

In particular, there is a need to reach out to students and younger members of NSGC. Almost half of the respondents to the most recent Professional Status Survey (PSS) had less than five years experience. A survey conducted by **Melissa Stillberger, MS,** from UNC Greensboro, revealed that students and recent graduates lack awareness of NSGC activities and how to learn about volunteer opportunities. Students and recent grads also often feel too inexperienced to contribute to committees. (Stillberger's findings will be presented in a poster at the upcoming AEC.)

As part of NSGC's Leadership Development Initiative, an Orientation Session for students is planned for the upcoming AEC. The session will highlight opportunities for NSGC involvement, as well as tips for getting the most out of attending the conference. The goal of this session is to welcome our student colleagues and facilitate their engagement in NSGC activities.

This program follows previous activities of the Leadership Development Initiative this year, including speakers on various leadership topics at three regional meetings and creation of the "Volunteers Needed" column on the NSGC website.

The strength of the NSGC lies in the commitment of its membership (that's you!) to work towards achieving the NSGC Mission and the goals in the Strategic Plan. Let this be the time that you make a commitment to be an active player in our professional organization.

Leadership Development Initiative Working Group: **Nancy Callanan,** President-Elect, **Maria DelVecchio** (Region I), **Ellen Schlenker** (Region II), **Lynn Holt** (Region III), **Aimee Walter** (Region IV), **Karin Dent** (Region V) and **Emily Burkett** (Region VI) ❖

CALLING ALL PEDIATRIC PRACTITIONERS

If you work in pediatric genetics or just have an interest in pediatric counseling, the Pediatric SIG is looking for you. Our SIG is reorganizing and revitalizing, so now is the time to join.

We are recruiting new members and encouraging existing and former members to get involved. Our goals include developing Educational Breakout Sessions (EBS) and creating our own web page within the NSGC website. We also are formulating other projects to benefit our profession, our patients and ourselves as individual practitioners, such as:

- developing practice guidelines for common pediatric genetic conditions
- investigating billing and reimbursement issues for pediatric genetic counselors and
- writing articles or EBS proposals regarding the introduction of newborn screening by tandem mass spectroscopy.

We are looking for ideas, energy and the manpower to make this a truly useful, and fun, SIG. Please contact us for more information, or look for our meeting at the AEC in November. ❖

☞ **Sue Moyer, MS,** 415-476-9321; sue.moyerharasink@tenethealth.com

☞ **Michelle Strecker, MS,** 215-427-4294; streckerm@peds.ucsf.edu

INTRODUCING: *LEGISLATIVE NEWS* FROM THE SOCIAL ISSUES COMMITTEE AND LEGISLATIVE SUBCOMMITTEE

Jill Fonda, MS

The Legislative Subcommittee of the Social Issues Committee is pleased to announce the launch of, *"Legislative News,"* NSGC's new bulletin on state, national and international legislative activity. We hope this bulletin increases awareness of legislative events that may be relevant to your patients and practice. The bulletin will be posted every other month under the Social Issues Committee on the NSGC website. Take a look below at some exciting features from our first issue. Congratulations to the Subcommittee for a job well done!

CORD BLOOD BANKING

A recently introduced bill on cord blood banking could directly impact genetic counseling. Originally introduced by **Rep. Christopher Smith** of New Jersey, the Umbilical Cord Blood Bill (HR2520) passed 431 to 1 in the House of Representatives in May. A version of the bill, the Bone Marrow and Cord Blood Therapy and Research Act of 2005 (S1317), has since moved to the Senate. The White House has indicated support for this legislation.

The purposes of HR2520 and S1317 are to provide for the collection and maintenance of human cord blood stem cells for patient care and research and to authorize the C.W. Bill Young Cell Transplantation Program, a national cord blood stem cell banking system. The legislation has implications for cord blood and bone marrow transplantation, sickle cell disease, leukemia and others. For the practicing genetic counselor, this legislation presses us to inform our patients about the importance of cord blood banking and the potential of transplant therapy for genetic diseases – perhaps the only time patients will hear of these opportunities.

☞ National Marrow Donor Program, www.marrow.org/NMDP/position_on_cell_therapy_act_hr2520.html

GENETIC NON-DISCRIMINATION

Successful passage of the Genetic Information Nondiscrimination Act (HR1227, S306) in Congress requires commitment to a sophisticated, aggressive strategy. The Coalition for Genetic Fairness has the plan.

☞ www.geneticfairness.org

SPEAK OUT!

Your contributions to the bulletin, the Social Issues Committee or the Legislative Subcommittee are welcome. Contact the Co-Editors or Chairs, visit the Social Issues Yahoo group or attend the open Social Issues Committee meeting at the AEC. ❖

☞ **Jill Fonda, MS,** Social Issues Committee Chair, jfonda@ahm.com

☞ **Sarah Burton, MS,** Legislative Subcommittee Co-Chair, Social Issues Yahoo group, sarah.burton@gallaudet.edu

☞ **Sara Pirzadeh, MS,** Legislative Subcommittee Co-Chair, Co-Editor, *Legislative News,* sap9022@nyp.org

☞ **Janine Lewis, MS,** Co-Editor, *Legislative News,* jlewis@aspensys.com

Foundation, *from page 1*

currently being put into place. It will be comprised of members of the NSGC Board of Directors, NSGC members at large and non-NSGC members.

Founding Board

The NSGC Board members who will be on the Foundation Board are **Dawn Allain** (as Past President), **Angela Trepanier** (as Secretary) and **Jennifer Farmer** (as a finance representative). NSGC members are **Robin Bennett, Susan Dickinson** and **Joan Marks**. Other members of the Board will be **William Rusconi** from Myriad Genetics (who will chair the Board), **Katie Buck** from Affymetrix, and two other pending members representing various non-NSGC stakeholders in genetic counseling and education.

This is an exciting endeavor for NSGC, but it needs member support to succeed. We encourage all members to help by pledging funds and volunteering to make The Genetic Counseling Foundation a success. ❖

Revised Ethics Casebook Coming Soon

Logan Karns, MS, Myra I. Roche, MS and Beverly Yashar, PhD, MS

An Ethics Casebook for Genetic Counselors, written by **Dr. Julie Maley** in 1994, was the first NSGC publication of its kind. Used by practicing genetic counselors and training programs, the still popular *Casebook* has sold over 340 copies in the last five years. The success of the *Casebook* is a testament to the value that genetic counselors place on addressing ethical issues.

Times Are Changing

The preface of the original book states that “social and ethical implications of advances in genetics are receiving heightened public attention.” A decade later, the growth of clinical genetics has created new categories of ethical dilemmas. Position papers from NSGC, ASHG and ACMG highlight the challenges generated by technical advances (preimplantation genetic diagnosis, assisted reproduction and frozen embryos), new practice areas for genetic counselors (research, neurology and cancer) and a broader understanding of genetics in common diseases. It is crucial to our profession that we continue to explore ethical issues and develop tools for use by genetic counselors.

Update on Its Way

As tenured members of the NSGC Ethics Subcommittee, we recognized the need to revise the *Casebook* to include contemporary cases and issues. To this end, we applied for and received an Audrey Heimler Special Projects Fund Award to author a second edition. Tentatively entitled, *An Ethics Casebook for Genetic Counselors, 2nd Edition: Ethical Discourse for the Practice of Genetic Counseling,* this book will include chapters on:

- ethical theories
- the history of the Code of Ethics
- ways to identify moral dilemmas
- the elements of case analysis.

Case examples and discussions will illustrate three areas of potential ethical conflicts – confidentiality, truth telling and disclosure – as well as informed consent and autonomy. Dr. Maley has agreed to author the foreward of the book.

The book will be available to the NSGC membership in the near future. We hope it will be a valuable resource to those entering the field as well as to practicing genetic counselors. ❖

Speaker’s Bureau Now Online

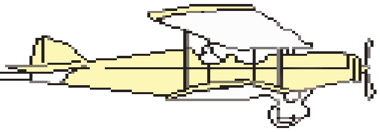
Kristie Morrell, MS

Does it inspire you to see genetic counselors highlighted as keynote speakers at national meetings? Are you looking for ways to enhance your professional development? The Professional Education Subcommittee of the NSGC Education Committee is excited to introduce online access to the NSGC Speaker’s Bureau. This search engine will allow consumers to search for NSGC speakers by topics of interest, event locations, audience size and type of venue.

When you register, specify your preferences: would you like to speak to small local groups? large audiences? or something in between? You also choose from a list of over 50 topics to speak on, ranging from specific subjects like “neural tube defects” to broad subjects like “the Human Genome Project.”

The Speaker’s Bureau promises to be a valuable resource and will be marketed externally to many professional organizations including ASHG, ACMG, March of Dimes and NCHPEG. The Speaker’s Bureau is live on the NSGC website. ❖

MEDIA WATCH



By Angela Geist, MS and Roxanne Ruzicka, MS

April, 2005 – *SmartMoney* magazine, "It's in your genes"

The multitude of genetic tests now available bear promise and limitations, especially when interpreting test results and navigating direct-to-consumer marketing and Internet-based genetic testing. To help consumers decide which tests to pursue or skip, the article emphasizes the importance of discussing options with a genetic counselor. **Susan Estabrooks Hahn** is quoted.

May, 2005 – *Mpls. St. Paul* magazine, "Facing high risk head on"

Evaluating family history is important in determining which individuals most benefit from genetic counseling and testing for hereditary breast cancer. **Mary Ahrens** explains the features that suggest a genetic form of cancer and screening/ treatment options for mutation carriers.

May 5, 2005 – *Wall Street Journal*, "Gene test could help indicate cancer treatment"

A study performed through Ohio State University illustrates how family history and MSI testing for HNPCC can help determine which individuals could benefit most from genetic testing. **Heather Hampel,** lead author of the study, is quoted.

May 12, 2005 – *Chicago Tribune*, "Keeping marriage all in the family"

The oft-referenced *Journal of Genetic Counseling* article on consanguinity from 2002 was quoted in this story about first cousins who decided to marry. The couple's home state of Pennsylvania forbids first cousins from marrying, primarily due to concerns for birth defects in offspring, but the author points out that the risk is relatively low.

May 22, 2005 – Grey's Anatomy (ABC)

Several genetics references appear in this medical drama. One man dies of heart/liver problems related to "hematomachrosis," found after an unauthorized autopsy. A second man has a bladder tumor that turns out to be an ovary and a blind-ending vas deferens. He is found to have a 46,XX karyotype. There is no mention of genetic counselors.

June 26, 2005 – *Chicago Tribune*, "Genes: Your body's crystal ball"

This story discusses the increasing availability of genetic tests and the concern about genetic discrimination. **Kelly Ormond** is quoted, along with a gastroenterologist who states: "Genetic counselors are in short supply, and we're going to need more of them to help us understand how to interpret risk and what to do with it."

June 27 – *Boston Globe*, "Test reveals gender early in pregnancy"

A newly unveiled home gender test called "Baby Gender Mentor" reportedly can determine fetal sex as early as five weeks of pregnancy using dried blood, with results available in 48 hours. The article includes ethical issues of sex selection.

August 15, 2005 – *Dragonfire* (online publication of Drexel University), "Destiny Defied: What you should know about genetic testing"

Chock-full of genetic tests, this feature reviews carrier testing for cystic fibrosis, prenatal testing, preimplanation diagnosis, newborn screening, predictive testing for conditions like Alzheimers disease and susceptibility testing for breast and ovarian cancer. **Emily Hardisty, Jennifer Williamson** and **Jessica Mandell** are quoted.

August 24 – *Edmonton Journal*, "The Cooking Gene: Is it nature or nurture that makes some people comfortable in the kitchen?"

Deepti Babu and her mother, **Dr. Tula Babu,** are featured in this culinary story about a possible inherited inclination for cooking. This article begins with Deepti's profession as a genetic counselor and ends with intriguing recipes from her family's home in India.

Summer, 2005 – *Ward Rounds* (Northwestern University School of Medicine quarterly magazine)

A six-page cover story reviews **Kelly Ormond's** achievements as director of the Northwestern Genetic Counseling program, her goals as NSGC President and the field of genetic counseling. ❖

RESOURCES

EXPERIENCES OF DONOR CONCEPTION: PARENTS, OFFSPRING AND DONORS THROUGH THE YEARS

Author: **Caroline Lorbach**
Publisher: Jessica Kingsley Publishers Ltd, London, England, 2003, 203pp., $19.95
Reviewed by: ***Melody White Perpich, MS***

Experiences of Donor Conception presents first-hand accounts and unique perspectives of donors, patients, their partners and donor-conceived children. **Lorbach,** who herself had three donor-conceived births, shares her personal experiences as well.

The book is highly readable and addresses many issues. It is not meant to educate on assisted reproductive technologies. Instead, it uses interviews to illustrate the nuances of donor conception including:

- male and female perspectives on infertility
- making decisions about donors – the pros and cons of using friends or family members
- donors' motivations
- if, when and how to tell donor-conceived children about their origins
- experiences of donor children
- experiences of single women and lesbians.

Interestingly, the topic of male couples seeking reproductive technologies is not included in the book.

This book is a useful guide for navigating the murky waters surrounding assisted reproductive technologies. The personal accounts are particularly helpful for those who find it easy to learn from others' experiences. A valuable addition would be a "key points" list after each section to facilitate discussion among participants in donor conception. ❖

TERATOLOGY PRIMER

Editors: **Adrienne Fugh-Berman, Barbara Hales, Anthony Scialli** and **Melissa Tassinari**

Publisher: The Teratology Society, 2005, 98pp.; Free to genetic counseling training programs and students; $10 to genetic counselors and other professionals;
Available at TSHQ@teratology.org
Reviewed by: ***Beth Conover, MS***

The Teratology Primer is a collection of 30 chapters covering basic principles of teratogen action, identification of birth defects and teratogenic exposures and examples of concern-causing agents. Each chapter is only a few pages long with references for further exploration. The list of expert authors reads like a "Who's Who in Teratology." Skillful editing smooths out individual differences in format and tone and avoids redundancy.

The *Primer* is not intended as a reference book on specific agents. It was developed as an introduction to the science and practice of teratology and is intended for use by medical students, genetic counseling students and health professionals.

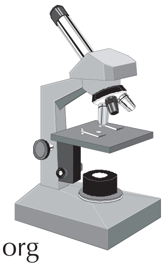
The *Primer's* brevity is both a strength and weakness. It introduces an admirable array of topics like, "Does the placenta protect against insult or is it a target?" "Do experimental animal studies predict human risk?" and "Is stress a developmental toxicant?" One of the highlights is the chapter by **Melissa Tassinari** titled, "How are new drugs evaluated for reproductive risk?" Some chapters, however, have an overly simplistic tone and struggle to cover complex topics.

The *Teratology Primer* is a valuable adjunct to the Clinical Teratology Educational Modules often used in genetic counseling training programs. It also provides a quick survey of teratology for practicing counselors. For those of us who specialize in teratology, the writings offer a glimpse into the thoughts of pioneering researchers who have helped mold the genetic counseling profession. ❖

CELEBRATE OURSELVES

Congratulations to genetic counselor and associate professor **Myra Roche** for the publication of her chapter, "Genetic Counseling Considerations in Molecular Diagnosis" in the second edition of the book, *Molecular Diagnostics: For the Clinical Laboratorian*. The 19-page chapter discusses the clinical and counseling applications of molecular genetic testing and includes 292 references. Electronic copies of the chapter are available at www.humanapress.com. The book is published by Humana Press and edited by **W. B. Coleman** and **Greg Tsonglis**. ❖

Research Network



Epidemiologic BRCA 1/2 Study

Cedars-Sinai in Los Angeles seeks to identify factors influencing cancer risk, prevention and surveillance strategies in those with BRCA1 and BRCA2 mutations. Participants must be men and women, 18 years or older, with documented mutations. They must have undergone genetic counseling. Participation is open regardless of geography. Participants will complete questionnaires every two years and provide medical records related to a cancer diagnosis. Participants may donate a blood sample for research.

☞ **Raluca Nedelcu, MS,** 310-423-9917; raluca.nedelcu@cshs.org

Assessing Screening Efficacy in BRCA 1/2

The Gilda Radner Ovarian and Breast Cancer Detection Program is conducting a study to assess the efficacy of standard and experimental screening methods to detect ovarian or breast cancer in women who carry mutations in BRCA1 and BRCA2. Participants must be 18 years or older with documented BRCA mutations and must have undergone genetic counseling. Participants may or may not have had cancer and must have a personal physician to provide routine care. Participants in the Los Angeles area will receive screening at Cedars-Sinai twice a year. Participants living outside the area may visit Cedars-Sinai annually with intervening screening from their local physician. Yearly questionnaires will be collected. ❖

☞ **Tony Braswell, MBA, MHA,** 310-423-5800; anthony.braswell@cshs.org

Study of Ocular Anomalies

The Human Developmental Genetics Laboratory at the Medical College of Wisconsin is recruiting patients with ocular anomalies for genetic studies. Diagnoses include: Axenfeld-Rieger spectrum (syndrome or isolated anomaly), SHORT syndrome, Peters plus syndrome, anterior segment dysgenesis, congenital/pediatric glaucoma, congenital cataract, microphthalmos/anophthalmos, optic atrophy, optic nerve hypoplasia, pathologic myopia and other ocular abnormalities without environmental causes.

The study is investigating the genes PITX2, PITX3 and FOXE3 and may identify additional genes involved in ocular development through linkage analysis. Participation requires a blood or buccal sample and clinical and family history information. Test findings will be communicated to participants. ❖

☞ **Linda Reis, MS,** 414-456-7645; lreis@chw.org

Genetic and Psychosocial Study of Hemophilia

Dr. Donna DiMichele and researchers at the Weill Cornell Medical Center are conducting a multi-site study on females with moderate or severe hemophilia A or B (factor VIII or factor IX less than 6%) through hemophilia treatment centers across the US. The study is assessing clinical, genetic and psychosocial issues unique to this population. To learn more about the study or to enroll a patient, contact your local hemophilia treatment center or a researcher below. ❖

☞ **Connie Gibb, MS,**
212-746-3972;
cog2005@med.cornell.edu

☞ **Jacqueline Lefkowitz, MSW,**
212-746-4337;
jlefkowi@nyp.org

Last Chance to Vote on *PGC's* Online Format

Last year, *Perspectives in Genetic Counseling* moved to an online format, responding to the results of a membership vote. The paperless system saves money, and the online format provides visual enhancement (color, photos and improved graphics).

Is the online format meeting your needs? Are you more inclined to read the online or paper format? We conducted an online survey last spring and summer to answer these questions, but the response was insufficient to generate meaningful results.

Thank you to the NSGC members who responded. The rest of you have one more chance! A hardcopy version of the survey will be distributed at the upcoming Annual Education Conference. Please take five minutes to provide feedback to the hardworking editors and staff of *PGC*. ❖