PERSPECTIVES
in genetic counseling

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national society
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nsgc

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

www.nsgc.org

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Jessica Mandell, MS
Editor
jmandell@slc.edu

NSGC INTRODUCES SMITHBUCKLIN AS NEW EXECUTIVE DIRECTOR

Shannon Weiloch, MS

At the business meeting on November 13 at the recent Annual Education Conference (AEC) in Los Angeles, NSGC officially introduced the management firm SmithBucklin as our new executive directors. As of December 1, 2005, NSGC headquarters are located in Chicago IL, and SmithBucklin is running NSGC business. **Bea Leopold,** NSGC's first executive director, has stepped down after 18 years of service. The staff working under Bea's direction has not been moved to SmithBucklin.

BREADTH OF EXPERIENCE

SmithBucklin is the nation's largest association management firm. The firm has over 56 years of experience, with the vast majority of their clients in the health care and allied health care fields. With this background, NSGC is confident that SmithBucklin will assist the organization in obtaining the three major goals outlined in the current three-year Strategic Plan:

1. genetic service delivery models
2. visibility
3. improving the outlook for billing and reimbursement.

"After interviewing several different firms, we chose SmithBucklin because we believed they would work the hardest to make a difference to the long term vitality of NSGC. SmithBucklin prides itself on measurable outcomes and achievements and views common values as the most important aspect of a working relationship," said **Nancy Callanan,** NSGC President.

FIRST YEAR PROGRAM

NSGC will use SmithBucklin for one year, during which Senior Director **April Snyder** will act as executive director. NSGC also will develop a long-term plan of action, which may result in retaining SmithBucklin for an

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SUPPORT THE GENETIC COUNSELING FOUNDATION

Dawn Allain, MS

It is official! As of November 2005, the Genetic Counseling Foundation (GCF) has been incorporated and was formally opened to the public at the recent NSGC Annual Education Conference (AEC).

To date, 100% of your NSGC Board of Directors has made financial contributions to support the mission of GCF. This is an exciting endeavor for NSGC, but the GCF needs member support to succeed. We encourage you to contribute a tax-

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PRESIDENT'S BEAT

It was wonderful seeing so many of you at the Annual Education Conference (AEC) last month. I was excited to begin my term as NSGC President, and my first official activity was to recognize and applaud our past President, **Kelly Ormond.** Under Kelly's leadership, much progress was made toward meeting the goals in the 2004-2006 Strategic Plan. I hope you will join me in extending appreciation to Kelly for her commitment to NSGC.

A TIME OF TRANSITION

What an exciting time this is for NSGC as we transition to a new management company, SmithBucklin. Those of you at the AEC had a chance to learn about SmithBucklin and to interact with April Snyder, our Interim Executive Director, and others from the management team. A list of "Frequently Asked Questions" about the transition is available in the Member's Section of our website.

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- EDITOR: Jessica Mandell • jmandell@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; Sara Spencer, Kathryn Spitzer Kim; Kathryn Steinhaus French; Beverly Yashar
- NSGC EXECUTIVE OFFICE: c/o April Snyder, Executive Director, 4001 North Michigan Avenue, Chicago IL 60611; ✆ 312-673-4743; 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 **March 15***
*Submission deadline **February 11***

In contracting with SmithBucklin for a minimum of one year, the Board of Directors is adhering to the previously approved plan of action for this type of transition. During the next months we will evaluate this move, and I will appoint a committee, comprised of Board members, NSGC members and stakeholders, to examine long-range options for NSGC Administrative Office management. This will be done in the context of our upcoming Strategic Plan. Input from the membership will be sought during this process, and I hope that many members will weigh in on the issues.

BUSINESS AS USUAL

In the meantime, it is "business as usual" for NSGC. The Board of Directors had a productive meeting in LA at the close of the AEC. In October, Kelly Ormond, **Cathy Wicklund** (President-Elect) and I represented NSGC at the ASHG meeting. We met with the leadership of several organizations including ABGC, ACMG, ASHG, Genetic Alliance and ISONG. These meetings provided opportunities to give and receive updates on the activities of these organizations as well as to identify areas of collaboration.

STRATEGIES FOR STUDENTS

The first "Orientation for Students" was held at the start of the AEC this year, and it was well attended and received. In recognition of the importance of leadership development and outreach to students, a new Leadership Development Subcommittee of the Membership Committee has been established. This subcommittee will be led by the President-Elect and will include all six Regional Representatives. During the AEC, **Jolie Matheson,** Chair of the Membership Committee, met with the Association of Genetic Counseling Program Directors to discuss strategies for recruitment and encouraging students to become involved in NSGC.

Nancy Callanan

WE VALUE YOUR CONTRIBUTIONS

Our Genetic Counseling Foundation (GCF) was officially launched during the AEC (see article on p1). I encourage every NSGC member to promote the success of the GCF by making an annual contribution each time you renew your membership.

During my Presidential Address I encouraged all members to accept their personal responsibility for becoming engaged in NSGC activities so we can continue to live our vision and meet our mission. This is a time of tremendous opportunity for NSGC, and I look forward to working with the Board and the membership in developing our next Strategic Plan.

Best wishes to each of you for a happy New Year!

Nancy Callanan

Nancy P. Callanan, MS
2005-2006 President

For Your Practice

PROCEED WITH CAUTION: PRENATAL TESTING FOR ADULT-ONSET CONDITIONS

Julie Albertus, MS, Erica Stewart, MS and Erica Ward, MS

Prenatal testing for some adult-onset conditions exists. Yet few data are available on the outcome of this testing, and uptake of testing varies with age of onset and severity of the disease. As the public becomes more aware of genetic testing in general, requests for prenatal testing for adult-onset conditions are bound to increase. A survey conducted by the Genetics and Public Policy Center reported that 60% of the American public approved of prenatal testing for adult-onset conditions.[1] In light of growing interest, further research into this testing is necessary.

EXISTING GUIDELINES

NSGC formally adopted a position statement on "Prenatal and Childhood Testing for Adult-Onset Disorders" in 1995.[2] This document states that pregnant patients should be made aware of all clinically available testing for genetic diseases for which the fetus may be at-risk; that this should be offered regardless of whether an affected pregnancy would be terminated; that the patient should be counseled about the risks and benefits to the child, including genetic discrimination; and that genetic counselors may remove themselves from a case in which they feel uncomfortable. The statement closes by calling for pilot studies to assess the risks and benefits of this type of testing. These studies have not been done.

THE HD EXAMPLE

Huntington disease (HD) is frequently at the center of the debate on prenatal testing for adult-onset conditions. While not every couple at-risk to have a child with HD chooses prenatal testing, a British study found that from 1994 to 1998, 146 couples at increased risk to have a child with HD underwent prenatal diagnosis for this condition.[3] Of those pregnancies testing positive for HD, a small fraction were continued.

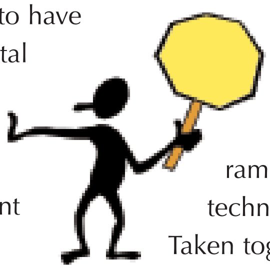
There are many concerns surrounding this testing practice:

- How are families affected by the knowledge that a child has the HD repeat expansion?
- Should the parents inform the child? If so, when?
- How does informing affect a child's concept of himself/herself and his/her future?
- What is the psychological impact of this information?
- What are the actual risks for insurance discrimination?

Without answers to these questions, counseling families about the potential risks and benefits of prenatal testing for adult-onset conditions can not be empirically-based.

EVIDENCE IS NEEDED

Further studies should examine the scale and scope of prenatal testing for HD and other adult-onset diseases and the factors influencing the decisions made by parents. Additionally, longitudinal studies could provide valuable information about long-term effects of this testing on affected children. Such studies will provide an evidence base for counseling about the actual risks and benefits to the child and family. There also are no studies on the societal effects of prenatal testing for adult-onset conditions and the ramifications of using genetic technology in this manner. Taken together, this work should assist in defining the best genetic counseling practice.



BALANCING ETHICS

Prenatal testing for adult-onset conditions can create conflict between the parents' rights to prenatal genetic testing and the child's right to genetic privacy. This issue may present a dilemma for genetic counselors on a personal level. Depending on the disease being tested, counselors may disagree with patients' choices regarding prenatal testing. Counselors should be mindful of the NSGC position statement and reflect on their own stance. In light of the lack of data surrounding prenatal testing for adult-onset conditions, genetic counselors involved in these cases should continue to exercise "extreme caution," as recommended in the 1995 position statement. ❖

1. "Reproductive Genetic Testing: What America Thinks." Released 2/18/05; http://tools-content.labvelocity.com/pdfs/6/66756.pdf
2. www.nsgc.org/newsroom/position.asp#adultonsetdis
3. Simpson, SA, Harper, PS and United Kingdom Huntington's Disease Prediction Consortium. 2001. Prenatal testing for Huntington's disease: Experience within the UK 1994-1998. *Journal of Medical Genetics,* 38:5;333-335.

“NONTRADITIONAL” IS THE NEW “MAINSTREAM” GENETIC COUNSELING

Nancy Steinberg Warren, MS, Nancy Callanan, MS and Bonnie Leroy, MS

The word “nontraditional” implies that something is outside of mainstream.[1] In genetic counseling, what is “traditional” and what is “nontraditional” with the diverse and changing roles performed by genetic counselors? Given current trends, nontraditional genetic counseling is the new mainstream, and the term nontraditional can be eliminated when discussing the scope of genetic counseling practice.

THE EXPANDED CLINIC

There are notable shifts in the clinical areas where genetic counselors work. The proportion of genetic counselors in prenatal or pediatric areas is decreasing, while counseling in cancer and other specialties is increasing.[2,3] Jobs focused on complex disorders like Alzheimer’s disease, thrombophilias and psychiatric illness require clinical and research skills. Primary work settings are changing; the percentage of counselors in University medical centers decreased from 47% in 1998 to 41% in 2004.[2,3] Experienced counselors are forming private practices and providing genetic counseling services under contract.

BEYOND PATIENT CARE

There also are practice changes in nonclinical settings. Many genetic counselors work in industry, in research facilities and in testing laboratories. In education and advocacy, genetic counselors direct graduate training programs and work for the National Coalition for Health Professional Education in Genetics, the Genetic Alliance and the Centers for Disease Control. Genetic counselors work in health policy and administration in state genetics programs or as newborn screening coordinators. In 2004, 54% of the NSGC membership reported primary roles in teaching and 32% in research.[3]

> ***“Eliminate the term ‘nontraditional’ genetic counseling, and include genetic counselors practicing in diverse areas and settings within ‘mainstream’ genetic counseling.”***

GRAD TRAINING: STICK TO THE BASICS

Genetic counseling programs are preparing students for diverse jobs, and graduates are taking advantage of new prospects. So as not to overwhelm students with too much content by cramming more into the curriculum, training programs need to “get back to basics” by teaching students to think like genetic counselors.

Students can apply their learning to expanded settings and roles after they:

- have acquired the skills of listening, critical thinking, assessment, interviewing and counseling
- are able to assess reliable information resources
- have honed their interpersonal and psychosocial skills.

The American Board of Genetic Counseling clinical competencies defines the minimum skills required for graduates of accredited programs.[4,5] By designing curricula to support these competencies, graduate programs provide students with the exposure and core skill set needed to apply this learning to diverse settings.

IN WITH THE NEW

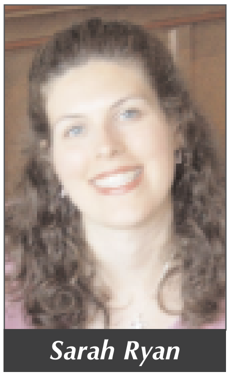
Other allied health professions are experiencing “graying” as baby boomers fail to be replaced by a younger generation, but our profession is experiencing a vibrant infusion of new graduates. There are so many possibilities for innovative and motivated genetic counselors to establish new positions and write their own job descriptions. Let’s encourage this! Eliminate the term “nontraditional” genetic counseling, and include genetic counselors practicing in diverse areas and settings within “mainstream” genetic counseling. ❖

1. Wolinetz, C. 2005. *The Scientist* Vol 19, no 15, August 1.
2. Parrot, S and Clark, C. 2004. National Society of Genetic Counselors, Inc. Membership Trends 1980-2002.
3. Parrot, S and Manley, S. 2004. National Society of Genetic Counselors, Inc. Professional Status Survey 2004.
4. Fiddler, MB, Fine, BA, Baker, DA and ABGC Consensus Development Consortium. 1996. A Case-Based Approach to the Development of Practice-Based Competencies for Accreditation of and Training in Graduate Programs in Genetic Counseling. *JGC* 5:3;105-112.
5. Fine, BA, Baker, DL, Fiddler, MB and ABGC Consensus Development Consortium. 1996. Practice-Based Competencies for Accreditation of and Training in Graduate Programs in Genetic Counseling. *JCG* 5:3;113-121.

STUDENT CORNER

A DEFINING MOMENT…

Sarah E. Ryan, BS


Sarah Ryan

An 18-week fetal ultrasound for a couple I saw recently reported "ambiguous genitalia." At first I wasn't sure how to interpret this diagnosis, but I soon learned that "ambiguous genitalia" could range from nothing at all to a number of genetic diseases. The couple had amniocentesis, which revealed a normal 46,XY karyotype.

I prepared for my next meeting with the couple. What did the finding mean? What did they need to know? I became nervous about seeing them. I had never shared such sensitive information like this before.

I met with my supervisor to plan for the return visit. She helped me figure out the important details of the finding, how it related to the amniocentesis results and what the next steps would be. It was nice to know she would be there to assist me.

LEARNING ON THE JOB

The following week, the couple had a repeat ultrasound. Each clinician took a look at the baby. I found myself hoping for a new outcome, but in the end the finding was the same. The clinicians just couldn't tell the gender.

Although I had practiced what to say, when the time came to talk to the couple, I froze. I just didn't know what to do. I had prepared myself for something like this to happen, so it felt natural to let my supervisor take the "reins," which she did seamlessly. The couple did not notice this transition and took the information from my supervisor well.

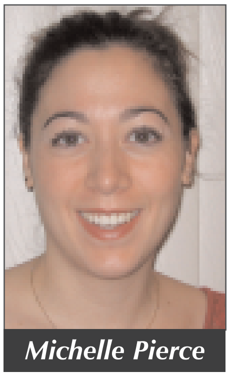
REALITY HITS

The most profound part of this interaction was the reality that part of my job will be giving uncomfortable news that may leave a patient confused and upset. I knew this intellectually, but so far I had only given good news. From this experience I realized the depth and complexity of the career I have chosen. Since cases like this will be a part of my job, it's good to be prepared and to ask for help when you find yourself stuck. ❖

Sarah is a 2nd year graduate student at the University of California at Irvine.

FIRST TIME AT THE NSGC ANNUAL CONFERENCE

Michelle Pierce, BS


Michelle Pierce

As a 2nd year student at Sarah Lawrence College, I looked forward to attending my first NSGC meeting for two reasons: 1) it was in my hometown of Los Angeles and 2) it was another step toward becoming a genetic counselor.

USEFUL ORIENTATION

I enjoyed this year's orientation for first time attendees. The orientation started with a greeting from Board members who described not only their area of leadership within NSGC but also their stories of how they became involved. Students then formed small groups with Board members to ask questions and discuss the future of NSGC. Interacting with the Board highlighted the inner workings of the Society.

A SENSE OF CROSSING OVER

I experienced a crossing over from being a student to being a professional. In watching colleagues, I saw how the skills I learn in school are put to practice, and I gained a new confidence and pride about my chosen profession. The enthusiasm of my colleagues inspired me to help our society strive for excellence and take our role as genetic counselor into nontraditional areas.

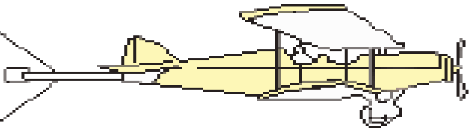
I also appreciated the opportunities at the conference to network with others. Attending committee and Special Interest Group meetings increased my desire to volunteer. Meeting students from various programs and seeing former supervisors was a bonus.

TAKE TIME FOR FUN

The NSGC meeting is an opportunity for students to learn and to have fun. Use the job board as a means to make connections and meet the individuals with whom you may one day work. It also is great to take time out from the meeting to enjoy the city and available activities. ❖

Michelle is a 2nd year graduate student at Sarah Lawrence College.

MEDIA WATCH



By Angela Geist, MS and Roxanne Ruzicka, MS

September 19 – *The Daily Sparks Tribune,* “Genetic testing leads woman to surgery”

An interview and a front-page picture of **Robbin Palmer** graced this article about a patient found to have a BRCA mutation. On September 16, public radio station KUNR aired a segment about this patient and Robbin.

October – NBC, ER

For its 2005 “Tied to the Cause” breast cancer awareness initiative, Ford Motor Companies enlisted support from the women of this hit medical drama for its annual celebrity ad campaign. A three-part series followed a patient at risk for cancer because of a BRCA mutation, and one of the ER doctors finally faced her family history of cancer and decided to have a mammogram. The episodes dealt with the issues of fear, prophylactic mastectomy, body image and relationships. There was no mention of the option of cancer risk counseling.

October 3 – *Wall Street Journal,* “Agonizing choice: A brother's survey touches a nerve in abortion fight”

This feature story explained how several families were informed about their child's diagnosis of Down syndrome. While the article was fairly balanced and informative, it referred to information coming from “doctors.” Genetic counselors were never mentioned.

October 6 – ABC, Extreme Makeover: Home Edition

A two-hour episode focused on a woman with seven adopted daughters with different disabilities: two with no legs, one with fetal alcohol syndrome, one with arthrogryposis, one with spina bifida, one badly burned in a crib fire and one with epidermolysis bullosa that had passed away. The Extreme Makeover team built a great house for these kids and showed the audience how important it is to the children to be treated like any other child.

October 10 – NPR, “All Things Considered”

In editorial style, this radio show discussed direct to consumer marketing of DNA testing and the lack of availability of genetic services. Genetic counseling was not mentioned.

October 13 – NPR, “On Point: Down syndrome and doctors”

A reporter reviewed medical student Brian Skoto’s study about delivering news to parents expecting a child with Down syndrome and the Prenatally Diagnosed Condition Awareness Act (legislation to ensure parents receive accurate information). Genetic counselors were mentioned but not recognized as an important part of the process. The segment included an interview with a perinatologist, a patient who was found to carry a pregnancy with Down syndrome and a high-functioning adult with Down syndrome.

November 9 – *The Daily Sparks Tribune,* “Genetic counselors translate genomic science into practice”

Robbin Palmer wrote this article, with subtitles of “What is a genetic counselor?” and “What is genetic counseling?” to advocate for genetic services in her community.

November 13 – *The San Francisco Chronicle,* “Pre-vivor: A personal voyage into the strange new world of genetic testing”

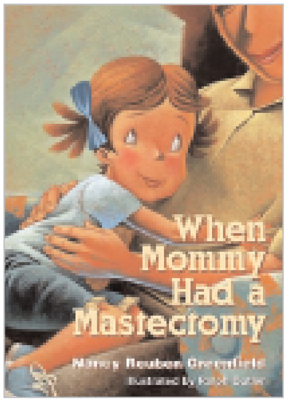
A woman depicted her own journey after she discovered she had a BRCA2 mutation. She discussed the ambiguity of being physically healthy while being at increased risk to develop breast and ovarian cancer. The author mentioned her genetic counselor a few times but did not describe their counseling session. The article included a reference to the NSGC.

November 13 – ABC, Grey’s Anatomy

After learning that she carried the “cancer gene” found in her family, an unaffected young woman sought the help of her surgeon friend to obtain a prophylactic mastectomy and oophorectomy. Her husband struggled to be supportive, fearing that she would lose her sexuality by losing her breasts and entering premature menopause. Female residents questioned if surgery was really worthwhile or if it was better to live without the burden of genetic knowledge. There was no mention of genetic counseling. ❖

WHEN MOMMY HAD A MASTECTOMY

Author: **Nancy Reuben Greenfield**
Illustrator: **Ralph M. Butler**
Publisher: Bartleby Press, Maryland, USA, 2005, 40 pp., $14.95
Reviewed by: ***Karen Heller, MS***



When Mommy Had a Mastectomy is a beautifully illustrated children's book that explains breast cancer and mastectomy simply and sensitively. The book is ideal for four to eight year-old girls, though it also could be appreciated by boys and children of any age. The theme centers on the difficulty of "hugging my mommy" as she recovers from mastectomy. Together, mother and child find ways to express their love and closeness during this stressful time.

WRITING FROM EXPERIENCE

Author **Nancy Reuben Greenfield** was diagnosed with breast cancer in her late 30s. She wrote the book as she recovered from bilateral mastectomies while raising her young children. **Wendy Harpham, MD,** author of *When a Parent Has Cancer,* comments, "*When Mommy Had a Mastectomy* is masterful in its direct and loving tone and its focus on fun and hope." The book is small and inexpensive enough for cancer genetic counselors to have on hand and give to patients or to recommend for patients to purchase. ❖

☞ www.mommyhadamastectomy.com

LEAN ON ME: CANCER THROUGH A CARER'S EYES

Author: **Lorraine Kember**
Publisher: Success Print, 2005, Hardcover, 130 pp.
Reviewer: ***Scott M. Weissman, MS***

Lean on Me: Cancer Through a Carer's Eyes is the true account of one woman's journey as a caregiver for an individual with terminal cancer. The book was written by **Lorraine Kember,** the primary caregiver for her husband, Brian, after he was diagnosed with pleural mesothelioma 35 years into their marriage.

AN ACCURATE ACCOUNT OF GRIEF

Lorraine guides the reader through the challenges she faced during Brian's two-year battle, using a combination of narrative, poems and excerpts from her diary. Lorraine documents her passage through shock, denial, anger, bargaining, depression and, finally, acceptance of her husband's impending death. Her words are poignant and could serve as examples of the feelings lived during the grief cycle.


Lorraine and Brian Kemper three months before Brian passed away

LESSONS LEARNED

Lorraine describes the vital role family and friends play while caring for an individual with a terminal illness. She discusses the importance of proximity to family and friends but also how these individuals can, unknowingly, get in the way at times.

Another focus of her book deals with pain management for cancer patients. Lorraine explains how she and Brian came to work with their hospital's palliative care team, a vastly significant factor in her husband's quality of life as well as her own. She advises on how to use the pain scale and administer medications and the benefits of journaling this information for healthcare professionals. Lastly, she presents a rational dialogue on the benefits of dying at home versus in a hospital bed.

NO GENETICS NEEDED

Though *Lean on Me* has nothing to do with genetics, this book offers an authentic insight into the world of caregivers. Genetic counselors can take Lorraine's words and better offer anticipatory guidance to caregivers and the terminally ill alike. *Lean on Me* would be a wonderful resource to our patients, but because of the raw emotion of the book, careful patient selection is warranted. ❖

☞ www.cancerthroughacarerseyes.jkwh.com/

RESEARCH NETWORK

✓ CONGENITAL HEART DEFECT STUDY

Dr. Elizabeth Goldmuntz at The Children's Hospital of Philadelphia is recruiting research participants with structural congenital heart defects. Families with more than one affected member are of particular interest. The study seeks to identify changes in specific genes and chromosomes that might lead to heart malformations. To participate, individuals with the heart defect and family members (parents, grandparents and siblings) are asked to give a blood sample. Pregnancy, medical and family history will be taken by phone. ❖

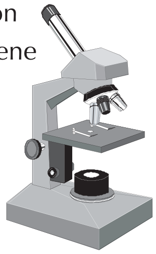
☞ **Shannon Wieloch,**
✆ 215-590-5644;
wieloch@email.chop.edu

Jennifer Garbarini,
✆ 215-590-1473;
garbarini@email.chop.edu

Stacy Woyciechowski,
✆ 267-426-7484;
woyciechowski@email.chop.edu

✓ HIRSCHPRUNG DISEASE GENE STUDY

Dr. Aravinda Chakravarti's laboratory at Johns Hopkins University has been investigating the genetics of Hirschsprung disease (HSCR) for nearly 15 years. HSCR disease is a great model of complex, multigenic inheritance.



We are currently focused on exploring RET, the major gene implicated in HSCR, and identifying additional modifying genes that influence whether a particular individual develops HSCR. For this study, we seek families that have one or more affected individuals. Both non-syndromic and syndromic (including Down syndrome) cases are welcome. We ask for blood samples from the individual(s) affected with HSCR and his/her parents. We currently do not disclose individual results, although MEN2-associated mutations would be disclosed. ❖

☞ **Julie Albertus,**
✆ 410-502-7541;
hirschsprung@igm.jhmi.edu

✓ STUDIES OF CHEMOTHERAPY EXPOSURE

Participants are needed for two studies at the University of Oklahoma and its Registry of Pregnancies Exposed to Chemotherapeutic Agents.

PRENATAL CHEMOTHERAPY IMPLICATIONS FOR CHILD DEVELOPMENT

This project is looking at children exposed to chemotherapy during pregnancy that have no congenital malformations. It includes ongoing developmental assessments using standardized physiological, cognitive and psychosocial measures. The information will be correlated with specific exposure and timing, and results will be shared with those who keep in touch.

PRENATAL CHEMOTHERAPY: IMPACT ON COGNITION, HEALTH BEHAVIOR AND FAMILY PLANNING

This study is seeking adults prenatally exposed to chemotherapy to assess cognitive functioning, their believed level of cancer risk, their actual cancer risk and any differences from the general population in cancer-related behaviors and life choices.

☞ **Susan Hassed,**
✆ 405-271-8685;
susan-hassed@OUHSC.edu

✓ CHARACTERIZATION OF PMS2 GENE MUTATIONS

Researchers at The Ohio State University are currently looking for individuals with potential mutations in the PMS2 gene, which are associated with Lynch syndrome (Hereditary non-polyposis colorectal cancer syndrome; HNPCC). We are currently accepting individuals who have:

- MSI positive colon or endometrial tumors
- absence of PMS2 only on immunohistochemistry or
- normal immunohistochemistry staining for MLH1, MSH2 and MSH6 but no staining for PMS2. (This may have occurred in some cases before PMS2 staining routinely was offered.)

The study requires informed consent, a blood sample and, in some cases, slides from the tumor tissue to perform PMS2 staining. Samples may be requested from family members to better characterize identified mutations.

☞ **Leigha Senter-Jamieson,**
✆ 614-293-7369;
leigha.senter@osumc.edu

Meet Your NSGC Board of Directors

Below are the new (*) and returning leaders for NSGC in 2006. All of these people have been selected by YOU – the membership – and they want to hear from you. Keep this list handy in the coming year to email your leadership with your questions, ideas and accomplishments.

Officers/Executive Committee (elected)

Nancy Callanan; Nancy_Callanan@uncg.edu..................................President

Cathy Wickland*; catherine.a.wicklund@uth.tmc.edu..............President Elect

Angela Trepanier; atrepani@med.wayne.edu...................................Secretary

Susan Manley; smanley@myriad.com...Treasurer

Kelly Ormond; k-ormond@northwestern.edu............................Past President I

Dawn Allain; dawn.allain@phci.org ....Past President II

Committee Chairs (appointed)

Aubrey Turner; aturner@wfubmc.edu..................................Communications

Susan Schmerler*; schmerler@sjhmc.org.......................................Education

Jennifer Farmer; farmerj@uphs.upenn.edu...Finance

Elinor Langfelder Schwind; elinorlang@verizon.net..............Genetic Services

Jolie Matheson; jolie.matheson@bhs.org....................................Membership

Maria DelVecchio; mdelvecchio@rics.bwh.harvard.edu.....Professional Issues

Jill Fonda Allen; jfonda@ahm.com...Social Issues

Regional Representatives (elected)

Renee Chard*; chardr@mmc.org...Region I

Ellen Schlenker; ellen.schlenker@genzyme.com...............................Region II

Claire Singletary*; cnsingle@richmed.medpark.sc.edu....................Region III

Aimee Walter; awalter@myriad.com...Region IV

Karen Copeland*; karenlcopeland@hotmail.com..............................Region V

Emily Burkett; eburkett@lhs.org..Region VI

Genetic Counseling Foundation, *from page 1*

deductible donation. Donations can be made with the renewal of your dues or by submitting a check to our Executive Office made out directly to the Genetic Counseling Foundation.

Addressing Our Needs

Details of the GCF were outlined in the Fall issue of *Perspectives in Genetic Counseling*. The broad purpose of the GCF is to:

- promote innovative research in the area of genetic counseling services
- help educate genetic counselors, consumers and other health care providers
- participate in genetic counseling services policy development
- support pioneering projects and collaborations in the field of genetic counseling.

These initiatives address unique needs within the field of genetic counseling, which are guided by NSGC's Mission and Vision Statements and Strategic Plan Initiatives.

The GCF's Board of Directors is comprised of the following individuals: members of the NSGC Board of Directors **Dawn Allain** (as Past-President), **Angela Trepanier** (as Secretary) and **Jennifer Farmer** (as a finance representative); NSGC members **Joan Marks, Susan Dickinson** and **Robin Bennett; E. Robert Wassman, MD** from Genzyme, **Katie Buck** from Affymetrix and **William Rusconi** from Myriad Genetic Laboratories (as Board Chairman).

☞ For more information on the GCF, go to www.nsgc.org

SMITHBUCKLIN, *from page 1*

extended period or hiring a solitary executive director.

In speaking with Ms. Snyder, specific tasks were outlined for the upcoming year. "During the first three months, SmithBucklin will engage in obtaining a complete understanding of the genetic counseling profession: its vision, beliefs and values. We will work to increase our knowledge of the NSGC while guiding the organization through the best use of SmithBucklin resources, including public relations, finance and marketing, to name a few."

In the longer term, SmithBucklin will focus on the new National Society of Genetic Counseling Foundation (see article on page 1). SmithBucklin will work to raise funds, increase awareness and coordinate staffing for the Foundation.

LOOKING TO THE FUTURE

NSGC extends a heartfelt thank you to Bea and her entire staff for their years of dedication and service. Please note that NSGC is accepting suggestions for future executive directors and headquarter locations. Emails should be directed to President Nancy Callanan or any Board member. ❖

☞ April Snyder, Senior Director
SmithBucklin Corporation
4001 North Michigan Avenue
Chicago IL 60611
✆ 312-673-4743
fax 312-527-6658
aprilsnyder@smithbucklin.com

SPECIAL INTEREST GROUPS IN 2006

SIGs are a way for members who share professional interests to network with each other. Here is a list of active SIGs for 2006. Please contact SIG leaders for information on current projects and how to get involved.

ART/Infertility	**Jodie Asher;** jlasher@emory.edu
Cardiovascular Genetics	**Heather MacLeod;** hmacleod@uchicago.edu **Nicole Johnson;** njohnso5@jhmi.edu
Clinical Supervisors	**Monica Barth;** mbarth@lumc.edu
Familial Cancer Risk	**Scott Weissman;** sweissman@enh.org **Nancie Petrucelli;** petrucel@karmanos.org
Industry	**Cynthia Frye;** cfrye@myriad.com; **Kathleen O'Connor;** Kathleen.O'Connor@genzyme.com
Legal	**Sandra Factor;** engravitas@aol.com
Metabolism/Lysosomal Storage Disorders	**Juliann Stevens-Harvey;** JMSHarvey@aol.com
Neurogenetics	**Jill Goldman;** jgoldman@MEMORY.UCSF.EDU **Alison La Pean;** lapeana@ninds.nih.gov
Pediatrics	**Sue Moyer;** sue.moyerharasink@tenethealth.com **Michelle Strecker;** streckerm@peds.ucsf.edu
Prenatal	**Sarah Noblin;** Sarah.J.Noblin@uth.tmc.edu **Jen Hoskovec;** jennifer.e.malone@uth.tmc.edu
Private Practice	**Kelly Donahue;** kelly_donahue@pediatrix.com
Psychiatric Disorders	**Jehannine Austin;** jcaustin@interchange.ubc.ca **Holly Peay;** hlpeay@nchpeg.org
Public Health	**Suellen Hopfer;** sxh343@psu.edu
Research	**Kelly Taylor;** ktaylor@chgr.mc.vanderbilt.edu
Telegenetics	**Angela Arnold;** arnola@gosh.nhs.uk **Becky Butler;** bbbutler@uams.edu

BULLETIN BOARD

MARK YOUR CALENDARS FOR NSGC REGIONAL MEETINGS

Regional meetings serve to keep you up-to-date on the professional and legislative activities in your area of the country and within the genetic counseling profession. They offer education, networking and CEUs. Below are the NSGC regional meetings for 2006 so you can mark your calendars.

REGION I

March 31, Royal Plaza Hotel and Conference Center, Marlborough MA

"Genetic Counseling in 2006:
New Technologies, Challenges
and Opportunities for
Professional Development"

Agenda and registration available mid-January at www.nsgc.org; 0.80 Category 1 CEUs available.

Meeting Co-Chairs: **Allison Cirino;** acirino@partners.org and **Erin Linnenbringer;** erinlp@bu.edu

☞ Representative: **Renee Chard;** chardr@mmc.org

REGION II

April 28, Sarah Lawrence College, Bronxville NY

Volunteers needed! If you are interested in helping plan the conference, please contact Ellen.

Meeting Co-Chairs: **Ellen Schlenker** and **Janice Berliner**

☞ Representative: **Ellen Schlenker;** ellen.schlenker@genzyme.com

REGION III

September 28-30, Atlanta GA

To be held with the SERGG meeting; plans to be announced.

☞ Representative: **Claire Singletary;** cnsingle@richmed.medpark.sc.edu

REGION IV

April 7-8, Kensington Court Hotel, Ann Arbor MI

Agenda will showcase local genetic counselors and guest speakers discussing various areas of genetics and current professional issues; more information available at www.nsgc.org in January and February.

☞ Representative: **Aimee Walter;** awalter@myriad.com

REGION V

No meeting scheduled.

☞ Representative: **Karen Copeland;** karencopeland@hotmail.com

REGION VI

April 27-30, the McMenamins Edgefield, Portland OR

Highlights will include "dazzling speakers, fantastic food and time to catch up with old friends in the retreat atmosphere that has been the hallmark of past Region VI conferences."

☞ Representative: **Emily Burkett;** eburkett@lhs.org

NSGC 25TH ANNUAL EDUCATION CONFERENCE: CALL FOR ABSTRACTS

It's not too early to think about the next NSGC Annual Education Conference planned for fall 2006 in Nashville TN.

Abstracts of interest to the genetic counseling profession and related fields are being accepted for consideration as platform or poster presentations at the 2006 AEC. Abstracts can be submitted from April 3 through June 2, 2006. Students, non-members and full members are encouraged to submit abstracts.

Monetary awards will be presented for best full member and best student member abstracts. Guidelines and instructions for submission can be found at www.nsgc.org using a link to the Abstract Submission Form. ❖

☞ 2006 NSGC Abstract Committee Co-Chairs:

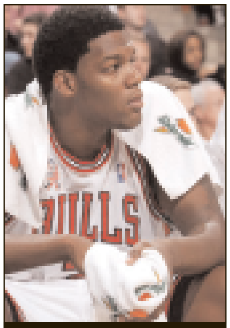
Stephanie Brewster;
✆ 617-355-2499;
stephanie.brewster@childrens.harvard.edu

Sara Cooper;
✆ 404-778-8536;
scooper@genetics.emory.edu

LETTER TO THE EDITOR

GENETIC NONDISCRIMINATION LEGISLATION: FULL COURT PRESS NEEDED

Eddy Curry is a true champion in my book. I have to admit I have never seen him play basketball, but from what I have read he is quite a superstar. Being recruited to the NBA's Chicago Bulls straight out of high school must have been a boyhood dream come true for this young man from Illinois.



Eddy Curry

THE ULTIMATUM

Mr. Curry was recently given something of an ultimatum from the Bulls, however: Give us your DNA or pack your bags. It seems that Mr. Curry received a diagnosis of hypertrophic cardiomyopathy, and the Bulls wanted him to have genetic testing for the condition to determine how much risk this condition posed for him on the court. Various newspaper articles out of Chicago suggested the team would just do this testing as part of his routine physical. The Bulls' coach recently revealed more specifics of the team's proposal. Curry could take the DNA test, and if it was negative, he could play for the team with a four-year contract of $32 million. If the test came back positive, they would pay Curry $400,000 each year for 50 years, but he could never wear the team uniform again. Mr. Curry would not have this, rightly arguing that such testing was a violation of his privacy.

TESTING DOESN'T TELL ALL

There is no question that tremendous advances in recent years have unraveled the genetic underpinnings of hypertrophic cardiomyopathy. What the Bulls failed to understand, however, is that this testing is not so straightforward and may not give them any more information than whatever clinical details were available on Mr. Curry. Only his cardiologists can give him the best advice on the implications of his career to his wellbeing. I am sure to a professional athlete these are not so easily separated.

Mr. Curry was ultimately traded to the NY Knicks and cleared to play with the team this season. The Knicks will not require him to undergo genetic testing; they are relying solely on his clinical findings. Unfortunately, should Mr. Curry succumb to any complications from his heart condition that will end his career, he has no insurance covering him in this regard since the league's insurance carrier will no longer insure him. While the implications of this real life story are rather troubling, there was recent encouraging news from the IBM Corporation which announced that they will not use genetic testing information to determine whether someone is hired or for what positions they may be eligible.

Whether or not you are an NBA fan, may Eddy Curry serve as an inspiration and encourage you to contact your Senators and Congressman and urge them to enact tough Genetic Nondiscrimination Legislation. It has been far too long in coming.

Deborah A. McDermott, MS
Weill Medical College of
Cornell University, New York NY

PARTING THANKS FROM BEA LEOPOLD

Dear NSGC Membership,

Last month, at the Annual Education Conference, the Board presented me with a generous travel gift certificate as an expression of gratitude from the membership for my service to NSGC. What a wonderful surprise! Norm and I plan to go to one of the internationally-renowned film festivals – location to be determined at this time.

Lisa and Audrey also asked me to thank you for your generous parting gifts.

As well, I would be remiss if I failed to thank you again and publicly for 18 years of your allowing me to walk along side of you and provide staff-side leadership. Your notes, cards, emails and calls since my announced departure have helped me see with clarity the level of value you have placed in both my leadership and friendship.

I always will treasure your expressions of care and the many, many friendships I have gained when I think back on the years that I spent with NSGC.

My best, Bea

Bea Leopold, MA, President
BL Communications
233 Canterbury Drive
Wallingford PA 19086
✆ 610-872-8730
fax 610-872-1192
Bea.BLCommunications@comcast.net