nsgc

PERSPECTIVES IN GENETIC COUNSELING

newsletter of the National Society of Genetic Counselors, Inc.

Vol 14, No. 3 Fall 1992

ELECTION RESULTS

NSGC has experienced its first-ever tie vote for a major elected office, and full members have been asked to revote.

Did *your* vote count?

Joan Scott, Nominating Committee Chair, is pleased to announce the results of the first 1992/93 elections ballot.

President-Elect ... ... Karen Greendale

Secretary ... ...Tie

Regional Representatives

Region II ... ...Ann Happ Boldt

Region IV ... ... Kathy Delp

Region VI ... ... Robin Bennett

With appreciation to the 1992/93 nominating committee: Rosanne DiMaggio, Kathleen O'Connor, Bonnie LeRoy and Susan Schmerler.

in this issue...

TERATOLOGY RESOURCES FOR COUNSELORS

by Maureen Smith, M.S., University of Chicago, Chicago, IL and Beth Conver, M.S., University of Nebraska Medical Center, Omaha, NE

This article is in response to GeneBytes (PGC 14:2). In addition to the computer resource that was reviewed, the following article presents teratogen resources for our members' reference.

Responding to teratogen inquiries can be a daunting experience, particularly if this area was not emphasized during genetic counselor training or if the counselor is rarely asked to address this topic. While a genetic counselor's general knowledge of embryology and risk assessment will be helpful, complicated inquiries will require additional consultation with a genetic counselor, physician or health professional who specializes in assessing teratogenic risk.

Teratogen Information Services (TIS) are available to respond to inquiries from genetic counselors regarding potential reproductive risk. However, they request certain information for an accurate risk assessment. This includes the complete name of the agent and a list of all ingredients (spelled correctly, if possible!), dose, route and timing of exposure and the indication for or situation involved in the exposure. Most TISs do not charge for their services, but in return, ask that follow-up data be provided on selected agents.

A variety of other resources exist which can aid genetic counselors when seeking accurate information.

• continued on p. 4 •

EDITOR'S NOTEBOOK

by Vickie Venne, M.S., Editor-in-Chief

NOVEMBER. Leaves fall and Americans vote. This year, in addition to the general election, many genetic counselors will have a responsibility to vote on an issue of great importance to their professional lives.

The 68% of NSGC members who are ABMG Board certified will soon be called upon to vote to restructure the bylaws, allowing ABMG to be recognized by the American Board of Medical Specialties. An affirmative vote will result in the expulsion of master's level counselors. If restructuring occurs, a new American Board of Genetic Counseling (ABGC) would be established, and those holding ABMG certification would be invited to apply for membership. In the 1993 exam cycle, and in subsequent years, the general exam will remain the same for ABMG and ABGC candidates.

This is *not* a done deal. The ABMG membership vote will determine the final decision. Two opportunities for discussion have been scheduled in San Francisco. In addition, at our members' request, the NSGC Board has provided both points of view for your consideration of the issues within these pages.

Let this event be a process. Review these issues with colleagues. Critically evaluate all discussions. Listen to all, but make your own personal decision.

And don't forget to vote.

Ask a Colleague

When a History of Breast Cancer...

by June Peters, MS, Long Beach Memorial Breast Cancer, Long Beach, CA

"My mother has breast cancer. I'm frightened. What does this mean for me? What should I do?"

This question may arise more frequently now with media focus on leaky breast implants, rising cancer incidence and diagnosis of well known public figures. Genetic counselors may encounter questions about cancer risks in a variety of professional and personal settings. Many genetic counselors have not had specific training to provide comprehensive cancer risk counseling, an area that is fast becoming a subspecialized blending of genetic counseling, oncology nursing and health education. However, there are interventions that genetic counselors may find helpful.

Brief Counseling

Suppose the patient coming in for a specific reason (eg, prenatal diagnosis) is also worried about cancer. The counselor may address the concern with several options and interventions.

Information: Provide some basic facts. Breast cancer is common, and most cases are sporadic. The 11% baseline risk often quoted in the media is a lifetime risk to age 110. Most of a woman's risk for breast cancers occurs in her post-menopausal years.

Support: Commonly, feelings of grief over the loss of a mother, sister or close relative surface during pregnancy, a traditional time of female bonding in families. The woman may simply need the counselor to listen and witness her loss.

Referral: If the woman requests specific genetic risk counseling or has continued distress, this is an occasion for rescheduling or referral to a cancer genetic specialist, therapist or support organization.

The prudent counselor should be reluctant to provide risk estimates without first obtaining confirmation of diagnoses.

Suspicions of Cancer Clusters

Another set of issues arises when the genetic counselor identifies multiple cases of cancer that are strikingly suspicious of a familial clustering. The family may or may not be concerned. It is important for the genetic counselor to address the health issues and acknowledge that more comprehensive cancer risk counseling is indicated in the future. *(See sidebar, sec. 3)* I might ask questions such as, "You may have wondered why so many of your relatives seem to have developed breast cancer. Would you like to talk with someone about that?" Recognizing pregnancy as a time of anxiety, I often follow-up with a statement such as, "I know you need to focus on your pregnancy now. After you have delivered the baby and recovered some of your energy, you may want to deal with other questions about your family health. In the meantime, I have referrals available if you have questions about changes in your breasts during pregnancy or lactation."

A stronger encouragement might be phrased "I notice that many of your female relatives have had breast cancer at relatively young ages. That concerns me because I recently learned that susceptibility for certain cancers can run in families. The medical community is learning more about prevention and early detection of breast cancer.

see next page

Dealing with a History of Breast Cancer

I. Identify the person at risk

All women are at risk for breast cancer. Most tumors are diagnosed in women who are >50 years old. The following are criteria that may increase risk:

- Breast or other cancer on either side of the family
- Bilateral breast cancer in a relative
- Early age of onset (before 50 years)
- Multiple primary tumors, eg, breast and ovarian
- Birth defects associated
- Ataxia telangiectasia or chromosome breakage syndrome
- Cancer syndromes evident
- Signs of pre-cancerous condition, eg, certain biopsy results

II. Brief counseling

- Document cancers in pedigree with sites, ages, bilaterality
- Supportive and/or grief counseling
- Reassurance about frequency of sporadic cases
- Referral for in-depth cancer genetic workup when indicated
- Health promotion (mammograms, diet, clinical, self exams)

III. Comprehensive Breast Cancer Risk Counseling

- Document all disease diagnoses by pathology report
- Provide background epidemiology
- Identify genetic syndromes
- Consider inheritance pattern
- Personal risk based on empirical data, pedigree analysis
- Consider DNA banking on affected relatives
- Coordinate DNA family linkage studies
- Psychosocial interventions (risk-notification, grief, decision-making, sexuality, coping processes)
- Liaison with comprehensive breast treatment team
- Follow-up, registries, prevention trials

...IS IDENTIFIED DURING A COUNSELING SESSION

You and your family may not be at an increased risk, but I don't have enough information at this point to assess your risk properly. I would like to refer you to a specialist who can explore your history in greater detail."

Naturally, each counselor will find a personal voice and style to convey these messages of concern comfortably.

ASSESSMENT FOR RISK COUNSELING AND TRIAGE

The following may help guide the genetic counselor:

- To triage the patient appropriately, the counselor must learn from the patient whether the issues are primarily genetic, medical, psychosocial, educational or epidemiological. Often, multiple referrals are required.
- The prudent counselor should be reluctant to provide risk estimates without first obtaining confirmation of diagnoses. Cancer diagnoses are notoriously inaccurate by self or family report and even on 50% of death certificates. Even when a pattern appears recessive or dominant, beware of prematurely offering a 25% or 50% risk of being affected.
- Clustering of sporadic and environmentally induced cases can mimic genetic inheritance patterns. Furthermore, penetrance may be low among those who have inherited specific genetic susceptibilities. Also, the risk may not be for breast cancer alone, but for other malignancies as well.
- Empirical risk estimates are available for certain breast cancer family types. Answers are not available for genetic risk in *all* families, and it is acceptable practice for the counselor to say that the pattern is not clear. The counselor can suggest that this is an area of current research, and thorough documentation is a good beginning. Should genetic testing for breast cancer become widely available, the groundwork will have been laid for the next stage of investigation and counseling.

COUNTERTRANSFERENCE

Becoming acquainted with the genetics of breast cancer can be both exciting and satisfying as a result of the rapid pace of discoveries.

However, cancers of all varieties are commonplace and may affect us, our colleagues or loved ones. We are just learning the impact breast cancer has on our personal as well as professional lives. Peer supervision, support of friends and therapy may help to deal with countertransference issues that inevitably arise with frequent encounters in breast cancer counseling.

EXPANDED ROLES

One of the current controversies in the medical genetics community is the extent to which counselors extend their area of concern beyond the initial reason for referral. Just as we debate whether CF screening should be offered to prenatal diagnosis couples who have no family history of CF, opinions differ about genetic counseling responsibilities to screen, inform and offer potential presymptomatic testing for more common conditions.

Many women present for genetic counseling simply because they are over age 35, a time when they become more aware of their breast cancer risk. Genetic counselors are in an ideal position to provide information about the American Cancer Society's recommendations for breast care.

Contact your local chapter of the American Cancer Society, their national office (800-227-2345) or the National Cancer Institute (800-4-CANCER) for information.

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Send case reports, resources, materials and books for review to appropriate editors; address changes, subscription inquiries and advertisements to Executive Director; all other correspondence to Editor-in-Chief.
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Deadline for Submissions: November 13

SUGGESTED READING

Baker, NC (1991) *Relative Risk: Living with a Family History of Breast Cancer* NY: Penguin Viking.

Claus, EB, Risch, NJ, Thompson WD Age at onset as an indicator of familial risk of breast cancer. *Am. Epidem* 1990;131(6): 961-972.

Henderson IC What can a woman do about her risk of dying of breast cancer? *Curr Prob in Cancer* 1990; XIV(4) Suppl:163-1.

Hill, RB, Anderson RE Opinion: The autopsy in oncology CA *Cancer J Clin* 1992;42(1):47-56.

Kelly, P Breast cancer risk analysis. *JGC* 1992;1(2):155-167.

Kelly, P (1991) *Understanding Breast Cancer Risk* Phila: Temple Univ Press.

Li, FP Familial cancer syndromes and clusters. *Curr Prob in Ca* 1990 XIV(2):75-113.

Lynch, HT, Hirayama T (1989) *Genetic Epidem Ca* Boca Raton, FL: CRC Press.

Parry, DM, et al. Meeting Report: Strategies for controlling cancer through genetics. *Cancer Research* 1987;47:8914-6817.

TERATOGENS, from p. 1

Many textbooks address specific topics and provide assistance in understanding how a risk assessment can be made. Most journals dedicated to teratology research focus on animal research. Although they will provide updates, the information may be difficult to interpret.

Drug registries are often created by drug companies or others with particular interest in a medication when no previous formal research has been conducted regarding safety during pregnancy. While drug registries do not generally provide epidemologic information, they can provide case studies which may better define the potential problems associated with an exposure during pregnancy.

RESOURCES

- The Organization of Teratogen Information Services (OTIS) publishes a newsletter. For information, contact Susan Rosenwasser, 617-787-5834.
- *Reproductive Toxicology*, a journal of the Reproductive Toxicology Center, contains articles concerning human and animal research. Subscriptions and information about this journal are available from Pergamon Press, 914-592-7700.

CONFERENCES

- Genetic counselors interested in learning more about teratogens can attend the three-day, bi-annual conference on human teratogens sponsored by Massachusetts General Hospital and Harvard Medical School. For information, call 617-726-1742.
- OTIS holds an annual conference. The 1993 conference will be held in conjunction with the meeting of the Teratology Society in Tucson, Arizona, June 27 - 28.

Additional information about OTIS or the annual conference can be obtained by calling either Jane O'Brien, MD or Susan Rosenwasser MEd 617-787-5834 or Lynn Martinez 801-583-2229.

TERATOGEN RESOURCES...

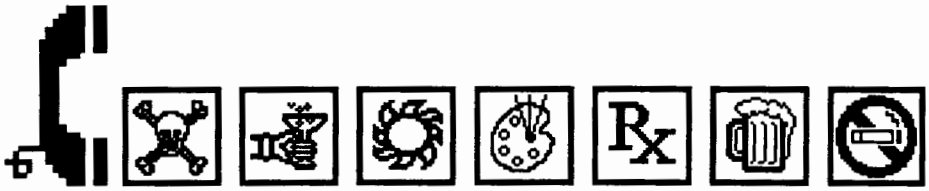
TERATOGEN INFORMATION SERVICES (TIS)

UNITED STATES

Arizona	AZ TIS	(AZ only)	800-362-0101
California	CA TIS	(CA only)	800-532-3749
Colorado	TIES	(CO only)	800-332-2082
		(WY only)	800-525-4871
Connecticut	CT Pregnancy Exposure Info Service	(CT only)	800-325-5391
Florida	TIS - Gainesville		904-392-3050
Georgia	CDC		404-488-4967
Illinois	IL TIS	(IL only)	800-252-4847
Indiana	IN TIS		317-274-1071
Iowa	Univ Iowa Prenatal Diagnostic Unit		319-356-3561
	University of Iowa TIS		319-356-2674
Kansas	Prenatal Diagnostic and Genetic Clinic		316-688-2362
Massachusetts	MA TIS	(MA only)	800-322-5014
Missouri	Columbia TIS		314-882-6991
	Genetics & Environmental Info Service		314-454-8172
Nebraska	NE Teratogen Project		402-559-5071
New Jersey	NJ Pregnancy Risk Info Service	(NJ only)	800-287-3015
New York	PEDECS		716-275-3638
	CUNY TIS		800-724-2454
North Dakota	University of North Dakota		701-777-4277
Pennsylvania	Pregnancy Healthline		215-829-3601
	Pregnancy Safety Hotline		412-687-SAFE
	Magee-Women's Hospital		412-647-4168
South Dakota	Teratogen and Birth Defects Info Project		800-962-1642
Texas	Genetic Screening & Counseling Service		817-383-3561
Utah	Pregnancy Riskline		801-583-2229
Vermont	VT Pregnancy Risk Information Service		802-658-4310
Washington	Central Lab of Human Embryology		206-543-3373
Wisconsin	TIS	(WI, MN, IA only)	800-362-9567
	WI Teratogen Project	(WI only)	800-442-6692
	Great Lakes Genetics		414-475-7400
	Eastern WI Teratogen Project		414-357-6555

CANADA

Ontario		
Hamilton	Safe Start Program	416-521-2100 x6788
London	Fetal Risk Assessment/Maternal Exp	519-685-8293
Toronto	Motherisk Program	416-813-6780
British Columbia		
Vancouver	University of British Columbia	604-975-2157
Vancouver	BC Drug & Poison Info Center	604-682-2344 x2126



...Directory for Counselors

Miscellaneous Resources

- **Arts, Crafts, Theater Safety** **212-777-0062**
  Resource center for artists regarding safe work environments, chemical composition of art materials and reproductive hazards.

- **Center for Safety in the Arts** **212-227-6220**
  Information for artists and others with focus on work environment safety, chemicals used in art and exposure to art chemicals during pregnancy.

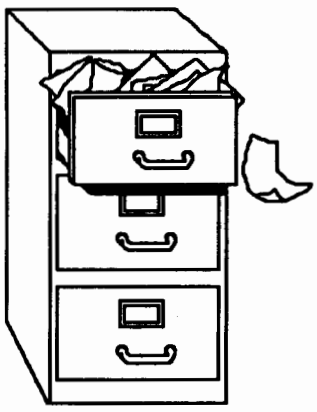
- **CDC** **404-639-3311**
  Information about infectious diseases, disease epidemics and vaccinations. Some information about exposures during pregnancy.

- **NIOSH** **513-841-4382**
  Health hazard evaluations.

- **Occupational & Environmental Reproductive Hazards Center**
  General information about occupational exposures. **508-856-6162**

- **Regional OSHA and Occupational Medicine Specialists**
  Both can be sources of information about occupational exposures. These centers do not specialize in drug and chemical exposures during pregnancy. However, they can often provide information about ingredients in a specific drug, mechanism of drug action, safe exposure limits, side effects of a chemical or drug, route of entry into the body of a particular chemical and strategies which are available to minimize risk of exposure.

- **Computer Databases**
  On-line computer services accessible for yearly subscription. Contain summaries of chemical, drugs and some maternal diseases and infections.
  Reprotox **202-293-5137**
  Contact: Kay Padgett
  Teris **206-543-2465**
  Contact: Dr. Janine Polifka



- **Nat'l Pesticide Hotline** **800-858-PEST**
  Will identify chemicals contained in many pesticides and insecticides as well as decipher difficult chemical names. Can provide information about types of exposures that are hazardous with a particular chemical or class of chemicals, how a chemical is absorbed into the body and helpful guidelines about exposure to particular pesticides.

- **Local Poison Control Centers**
- **Local Drug Information Centers**
  These centers, usually located at major universities, help identify the chemicals contained in most medications and chemical products. They can identify toxic level limits and side effects of drugs. Drug information centers also insist on identification of foreign medications.

Drug Registries

Mefloquine (Lariam)
Contacts: Susan Rosenwasser or Jane O'Brien 617-787-4957

Acyclovir (Zovirax)
Contact: Burroughs Welcome Co. 800-722-9292 or 919-248-8465

Fluoxetine (Prozac)
Contact: Eli Lilly Co., David Goldstein, MD 317- 276-7047
or in Utah, Prozac Registry 801-584-8488

Lithium
US and Canadian Collaborative Project, Contact: Ann Pastuszak 416-598-6780

Zidovudine (AZT)
Contact: Burroughs Welcome Co. 800-722-9292 x8465

Alprazolam (Xanax)
Contact: Upjohn Co. 616-329-3686

ACE Inhibitors
Teratogen Information Services Collaborative Project, Coordinator
Pregnancy Riskline 801-583-2229

Methotrexate
Investigating maternal and paternal use, preconceptual and prenatal. Pregnancy Healthline 215-829-3601

Supplemental Reading

- *Drugs in Pregnancy and Lactation*, 3rd ed, 1990, GG Briggs, RK Freeman, SJ Yaffe.
- *Chemically Induced Birth Defects*, 1985, JL Schardein.
- *Handbook of Perinatal Infections*, 2nd ed, 1989. JL Sever, JW Larsen, JH Grossman.
- *Peace of Mind During Pregnancy*, 1989, C. Kelly-Buchanan.
- *Reproductive Hazards of Industrial Chemicals*, 1982, SM Barlow, F Sullivan.
- *A Clinical Guide to Reproductive and Developmental Toxicology*, 1992, AR Scialli.
- *Catalog of Teratogenic Agents*, 6th ed, 1989, T. Shepard.
- *Occupational and Environmental Reproductive Hazards: A Guide for Clinicians*, 1992, M Pauli.

Human Genome Project Update

James Watson Steps Down

James D. Watson, MD, resigned from the National Center for Human Genome Research directorship on April 10, a position he has held since October 1989. He will return to serve as director of Cold Spring Harbor Laboratory. NIH Director Bernadine Healy appointed Michael Gottesman, MD, a molecular geneticist and cancer researcher, to serve as NCHGR Acting Director. He was formerly Chief, National Cancer Institute's Laboratory of Cell Biology.

Wanted: Genetic Mentors and Good Teachers

Debra Collins is recruiting genetic counselors, clinical geneticists, researchers, ethicists, lawyers and sociologists to serve as local mentors for biology and science teachers (grades 7-12) as part of a national human genome education project. Mentors will be expected to meet with teachers a few times each year, serve as a local resource and help with local teacher programs. Names of resourceful biology/science teachers with leadership qualities and knowledge of teacher networks are also being solicited. More information or applications are available.

Send names to Genetic Education, Univ Kansas Medical Center, 4043 Wescoe, 3901 Rainbow Blvd, Kansas City, KS 66160-7318; 913 588-6043.

Gene Pinpointed

The gene for myotonic dystrophy is located on chromosome 19. The structural defect associated with myotonic dystrophy may grow larger with each generation, and the increase in size is associated with the severity of the disease. The enlarged gene area consists of a CTG repeat usually copied 5 to 30 times that of people without the disorder. These findings are similar to those found in Fragile X syndrome.

Genome Mapping Documents Now Available

Two HGP documents have recently been produced and are available at no charge.

"Genome Report Card" provides an overview of progress toward the five year goals of the HGP for chromosome mapping and sequencing. Information includes data in the Genome Data Base, GenBank and primary publications. "Index Marker Catalog" summarizes the progress of NCHGR's Index Marker Project, an ongoing program geared to produce a high-resolution genetic linkage map of the human genome.

For copies, contact the NSHGR, 301-402-0911; fax 301-480-2770.

What's Ahead?

- October 5-6: *Protecting Human Subjects in Research Involving Families*, Bethesda, MD. Contact: E. Langfelder, 301-402-0911.
- November 4-8: *Genetics of Cancer*, Hilton Head, SC. Contact: Amer Acad Cancer Research, 215-440-9300.
- November 12-13: *Impact of Molecular Genetics on Treatment of Genetic Diseases*, Bethesda, MD. Contact: R. Abizaid, 301-230-0052.

JoAnn Inserra, M.S.

Society Adopts Two Resolutions

The last issue of *PGC* (14:2) included a ballot insert to all Full members. Of the 788 ballots mailed, 407 responded, representing a 52% response rate. Our membership has passed both resolutions: **Prenatal Substance Abuse** with a 97% affirmative vote, and **Fetal Tissue Research** with a 96% affirmative vote. With appreciation from the Social Issues Committee for your acknowledgement of these important issues and for your thoughtful comments and editorial corrections. A current listing of the NSGC's Position Statements and Resolutions follows for your reference.

Shane Palmer
Chair, Social Issues Committee

Position Statements

Access to Care: The NSGC supports individual access to appropriate genetic services regardless of racial or ethnic background, socioeconomic status, disability, ability to pay for services or method of payment. Access to care for families with genetic concerns is also necessary in the areas of prenatal care, family planning services, pediatric care and psychological counseling. *(Adopted 1991)*

Nondiscrimination: The NSGC opposes discrimination against an individual with regard to eligibility for or maintenance of employment, insurance coverage or medical benefits on the basis of the results of genetic testing. Consideration of testing information is appropriate only when used to protect the individual's best interests. *(Adopted 1991)*

Confidentiality of Test Results: The NSGC supports individual confidentiality regarding results of genetic testing. It is the right and responsibility of the individual to determine who shall have access to medical information, particularly results of testing for genetic conditions. *(Adopted 1991)*

Disclosure and Informed Consent: The NSGC supports an individual's right to full disclosure of all appropriate medical options regarding reproductive testing and management of genetic diseases and birth defects. It is the care provider's responsibility to provide effective communication of all available options and to obtain informed consent for procedures involving risk to the individual or fetus. *(Adopted 1991)*

Resolution

Reproductive Freedom: The NSGC, as an organization, publicly supports a woman's right to reproductive freedom, including her right to prenatal diagnosis and access to safe and legal abortion. *(Adopted 1987)*

Prenatal Substance Abuse: The NSGC supports an increase in prevention efforts and treatment services for alcohol and drug dependent women and their children. Treatment services have proven to be a successful way to overcome both drug and alcohol abuse and this prevent prenatal exposure to these agents. These services are far preferable to punitive sanctions brought against alcoholic and drug dependent women solely because they were pregnant when they used alcohol or drugs. *(Adopted 1992)*

Fetal Tissue Research: The NSGC supports fetal tissue research (within strict medical guidelines) as a legitimate and important area of scientific investigation and as a vital avenue of research toward treatment of genetic conditions. *(Adopted 1992)*

Commentary from the Presidents

As a result of our commitment to keep our membership informed, PGC identified several issues regarding the ABMG restructuring plan. Current ABMG President, Dr. Anne Spence, agreed to address the following points.

PGC: At last year's NSGC meeting during the International Congress of Human Genetics, you stated that the ABMG Board would not go forward if it meant disenfranchising the genetic counselors. Please comment.

AS: It is correct that I made that statement, and I meant it. Initially, the Board expected that the process would include several negotiation steps. We anticipated ABMS would demand that the ABMG Board agree not to certify master's level individuals, and we were prepared to negotiate that issue. In fact, the Board was naive about the process. Instead of negotiations, we received official word that we had already been approved for ABMS recognition, pending what ABMS viewed as minor bylaws changes. Final recognition was contingent upon those changes being made. ABMG bylaws were to be changed to time limit credentials and not certify anyone except doctoral-level individuals.

This presented a dilemma for the Board in that it had not anticipated such quick action. After years of unbelievable delays in accepting and processing the application, quite simply, we were caught unprepared.

As the Board reflected on the *fatt accompli*, several points were considered. Formal recognition by ABMS is crucial for a medical speciality competing in the current medical environment. In addition, a case could be made for the appropriateness of genetic counselors becoming more self-directed and moving to a level of recognition with their own Board. The Board decided that these points were of sufficient magnitude that they should be presented and discussed prior to a vote by the diplomates for a bylaws change.

The Board voted to accept the ABMS invitation, which we felt could be withdrawn if we hesitated. Then, the Board called for a vote of the diplomates to determine if the required two-thirds concurred with this decision.

PGC: Is an appeal to COCERT a real option?

AS: The ability of the ABMG Board to appeal to a group known as COCERT (Committee on Certification, Subcertification and Recertification) within the ABMS structure to authorize certification of non-doctoral level individuals has been raised. This is an interesting Catch 22 in that only ABMS members can appeal to COCERT. Therefore, if the ABMG membership rejects the ABMS recognition, this option would not be open to us. If our membership accepts the ABMS recognition and we continue as an ABMS recognized Board, this is an option open to us, but only in the future.

PGC: What happens if the bylaw changes are defeated? Should ABMG re-approach ABMS with the genetic counselors as a part of the Board?

AS: The original application included MDs, PhDs, and MS diplomates. ABMS did not acknowledge the MS diplomates in their official approval. Nothing more could be gained by resubmitting an equivalent application.

If the bylaw changes are defeated, ABMS will most likely remove our recognition. It is necessary to have permission from the ABMS to apply for recognition. It took the Board years to obtain that permission initially. Our best guess is that if recognition is removed, permission to reapply would not be given to ABMG in its current structure.

From NSGC's President...

On September 6, the NSGC Board of Directors held a conference call to discuss the latest information regarding the proposed ABMG restructuring. Diane Baker, who with Debra Collins represents genetic counseling on the ABMG Board, updated the NSGC Board and answered our questions.

The Board then discussed whether it should ask the ABMG to file an appeal to the ABMS for inclusion of master's level genetic counselors in the ABMG application. Because information regarding the availability of this appeal process has been ambiguous, the Board instructed me to seek clarification from ABMG president, Dr. Anne Spence. To paraphrase, Dr. Spence responded that because the ABMG is *not* an ABMS-recognized Board, an opportunity to file such an appeal does not currently exist. If the ABMG is restructured, it will have an opportunity to use the COCERT process. Dr. Spence feels, however, that the appeal is sure to be denied.

In other action, at the request of the membership, the Board polled its members to determine their current positions on the proposed restructuring. The poll was neither binding nor an attempt to direct those NSGC members who are ABMG delegates to vote in any specific way. The Board also understood at the time of the poll that details of the restructuring proposal are subject to change at the time of the actual vote. The most current information prior to the actual vote, as it is planned now, will be made available at two open forums at the upcoming NSGC and ASHG conferences. One will be held immediately at the conclusion of the NSGC Annual Education Conference, 5:00pm, on Sunday, November 8; the other has been scheduled for Friday, November 13, at 11:30am. Exact locations will be posted.

Results of the NSGC Board poll on restructuring are on page 8.

Edward M. Kloza, M.S.
September 18, 1992

YES. In 1979 and 1980, when the ABMG was being formed, many genetic counselors were adamant that certification should be available through the same organization to all professionals involved in the provision of clinical genetic services, regardless of training. At that time, master's level genetic counselors were just beginning to gain acceptance in the arena of what then was organized medical genetics. NSGC had only recently formed, and there were many hurdles to overcome before counselors were accepted as integral participants in the provision of services and the governing professional organizations. Therefore, certification by the same agency as that for our MD and PhD colleagues offered a definite advantage.

Times and circumstances have changed. Genetic counselors have grown in maturity, experience, respect and number. Through our professional society, we have developed guidelines for continuing education programs and established a presence in the community at large. Counselors have assumed leadership roles in many training programs and in formulating training guidelines. We have been active in the ABMG as directors and exam writers.

During the same time, the specialty of clinical genetics has also changed. An explosive growth in the demand for services has resulted from scientific and technological advances. Despite these advances, clinical genetics remains relatively underdeveloped as a recognized medical specialty. Many of us realize that our activities do not finacially support our programs adequately. The potential to increase reimbursement by improving CPT codes has been frequently cited as a reason for joining ABMS. Given the political structure of the governing bodies, CPT code changes are not likely to become a reality for quite some time.

Nonetheless, in this country's medical system, it is the *only* way to have a legitimate chance to change current reimbursement practices.

ABILITY TO SELF DIRECT

Arguably, the more important reason to support restructuring pertains to the future of the professional group called genetic counselors. The time has come for genetic counselors to define and confer certification on their own professional colleagues. What other professional group is certified by a board that is not composed entirely of its peers? If restructuring is approved and a separate certification process is established through an American Board of Genetic Counseling, we will gain in autonomy. We will shape our own future. Those who are concerned about losing recognition through restructuring can take some reassurance from the current plans which provide that all genetics professionals, including counselors, will continue to take the same general examination.

When the NSGC was formed, many thought this action would constitute the dissolution of the collegial atmosphere in clinical genetics. There were even some who said the NSGC would only be a union. If anything, establishing a separate professional society has afforded genetic counselors a richer level of participation in collaborative activities with our colleagues. Just as we have gained strength, autonomy and respect through our professional society, we have an opportunity to do the same through assuming responsibility for our own certification. The best long term interests of genetic counselors will not be served by continuing to obtain certification by a board that is part of an organization whose history does not include certifying *any* professional at the master's level. In addition, by providing our own certification, we will also be in a better position to shape certification for genetic professionals who have not attained a master's degree.

It takes courage to embrace an unknown future, but the risks are worth it.

NEGOTIATING OPPORTUNITY IS STRONGEST NOW

There are practical reasons to support the restructuring plans now. We are in a strong negotiating position and would likely realize a healthier financial distribution if the restructuring is accomplished sooner rather than later. It is most likely that the question will be raised again if it does not pass now. A delay will only serve to weaken our negotiating position. Prompt resolution of the question will also be beneficial to our ongoing work with our MD and PhD colleagues.

Restructuring the ABMG and the subsequent formation of an independent board to certify genetic counselors is a positive choice which will lead to new growth. Genetic counselors now have the knowledge, expertise and professional maturity to oversee our own certification.

It takes courage to embrace an unknown future, but the risks are worth it.

BOARD POLL ON RESTRUCTURING THE ABMG

I SUPPORT THE ABMG RESTRUCTURING PLAN

Barbara Bowles Biesecker
Deborah L. Eunpu
Andrew Faucett
Jill Fonda Allen
Bill Herbert
Edward M. Kloza
Marsha Lanes
Linda Nicholson
Shane Palmer
Janice Cox Palumbos
Joan A. Scott
Carol Strom
Laura Turlington
Wendy R. Uhlmann
Vickie L. Venne

I DO NOT SUPPORT THE ABMG RESTRUCTURING PLAN

Beth Balkite
Betsy Gettig
Linda Lustig
Liz Stierman

poll conducted week of September 7

...Support the Restructuring of ABMG?

No. For over 20 years, the clinical genetics community has enjoyed the unique nature of a multi-disciplinary team of genetic professionals: masters level counselors, PhD geneticists and MD geneticists. We have established a mutual respect for one another's roles and strengths. To fragment the ABMG now will undermine the strides we've made to unite our profession and provide optimal delivery of genetic services.

High among our unanswered questions is why anyone believes that certification of genetic counselors by a separate board will suffice in the outside world. The current ABMG and ASHG have considerably more stature than a board representing only one type of professional. If they are not sufficiently accepted in policy making areas such that recognition by the ABMS is crucial, how can certification by a separate genetic counseling board be expected to provide the kind of recognition necessary to maintain the status of genetic counselors?

Given that there is a great deal of confusion...it is hard to understand the need for a vote right now.

Status May Be Diminished

In addition to salary increases, some counselors have used ABMG certification to achieve faculty appointments in medical schools. While it is attractive to think that an American Board of Genetic Counseling will eventually establish itself, will certification by this new board allow opportunities similar to those available from the current ABMG certification?

Already, public perception of the counselors' status is being questioned. The CF screening booklet from Office of Technology Assessment (OTA) states "Until 1992, graduates [of genetic counseling training programs] were eligible to sit for certification... by the ABMG, but the continuing certification of these individuals by this body is unclear." The August 1992 issue of *The Scientist* headline reads "Genetic Counselors Struggle for Status."

Loss of Opportunities

Like it or not, we work in a physician-controlled medical care delivery system. To think we are better off disassociating ourselves from it may be a naive perspective. Will there be less opportunity to sit on physician-driven boards of the Institute of Medicine or the OTA?

The argument has been made that clinical genetics services will generally benefit by being recognized as a *bona fide* medical specialty. With representation in ABMS, medical geneticists can be involved in setting regulations and fees. CPT codes for genetic services could be written by geneticists, not physicians from other specialties. However, it is unclear that geneticists would have sufficient voice to affect this change. Would genetic counselors or our patients benefit at all? Are there benefits to being "on the inside" to witness a process that may continue to ignore the needs of clinical geneticists?

Lack of Commitment

The ABMG has shown little commitment to the genetic counselors in the ABMS application process. Although we were told that we would be included in the entire process, we are being asked to vote on a bylaws change that would remove counselors from the organization entirely. This serious breach of trust was reflected in other activities during this process. As an example, many issues surrounding ABMS recognition were never discussed at ABMG membership meetings. The ABMG may have been able to route their formal application through COCERT, an option which was not explored.

ABMG has stated that they would provide financial support to establish our own Board. Concerns about the high cost of the certification process will only grow if the number of individuals participating is decreased, which is likely with an American Board of Genetic Counseling. This will incur an additional financial burden on eligible candidates. One would hope we would have a written commitment outlining specific dollar amounts and a plan to guarantee financial stability of a new board before disenfrachizing from an existing structure.

Unanswered Questions

Beyond the specific unanswered questions about the end result of such a change is the anxiety which is generated when communication is not clear to all members of the ABMG. Given that there is a great deal of confusion about this issue, it is hard to understand the need for a vote right now. Why can't ABMG delay the application until the many unresolved points are clarified?

Without discussion and clarification of these issues, many genetic counselors may be left without any alternative but to vote *no* on restructuring the ABMG.

Alphabet Soup

ABGC... ... ... American Board of Genetic Counseling
ABMG... ... ...American Board of Medical Genetics
ABMS... ... ... American Board of Medical Specialties
ACMG ... ... American College of Medical Genetics
ASHG ... ... American Society of Human Genetics
CMGS ... ...Council of Medical Genetic Societies
NSGC ... ...National Society of Genetic Counselors

GeneBytes

HGP Gets With the Program

by Robert Resta, M.S. and Karen Wcisło, M.S.

We admit from the start that the potential benefits of the Human Genome Project have been exaggerated by a few of its supporters. But we're practical enough to realize that there will be some concrete benefits from all that money and research.

Access to the Latest Genome Data

One immediate benefit for genetic counselors is the Human Genome Data Base and Online Mendelian Inheritance in Man (GDB/OMIM). This online database is a project of the Howard Hughes Medical Institute, the Johns Hopkins University School of Medicine and the William H. Welch Medical Library. GDB/OMIM allows public online access to the latest human genome mapping data (GDB) as well as to McKusick's classic compendium (OMIM).

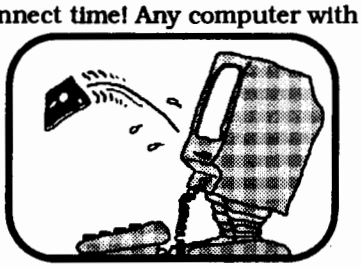
GDB allows users to look up any area of the human genome to determine which genes, if any, have been mapped to that region. Alternatively, the database can be searched to determine if a particular gene or enzyme has been mapped and which DNA probes are available. Information about DNA polymorphisms and their population distributions are provided, along with references, abstracts and the names and addresses of those responsible for providing the locus/probe information. If a particular locus or enzyme has been associated with a Mendelian disease, the user can easily access the appropriate entry from OMIM. Users can ask questions like "Has the gene for Rett Syndrome been mapped?", "What genes map to 21q21.2?" or "What probes exist for exons of the CFTR locus?"

OMIM is a full-text database of Mendelian Inheritance in Man and will probably be more useful than GDB for most genetic counselors. Entries are updated almost daily by Dr. McKusick himself. Mapping and probe information, defective gene products and clinical summaries are provided for each entry. Users can ask questions like "How many genetic disorders have cystic hygromata as a manifestation?", "Which disorders result from point mutations in which histidine is substituted for arginine?" or "How many documents refer to works by Elvis Presley?"

Your Will Need Patience

GDB/OMIM can be useful in select situations for most genetic counselors, and very useful for those working on publications or involved with DNA research on a daily basis. It takes time and patience to learn GDB/OMIM. We have received anecdotal reports of difficulties simply logging onto the system (we both also had the same problem). Once you manage to log on, the software is not particularly user friendly - some keys will boot you out of the system and many key combinations and commands are not intuitively obvious. There is no on-line help or IBM mouse support yet, and printed copy is not always easy to obtain. The William H. Welch Library offers a free training program at different locations around the country, a course we strongly recommend for anybody using the system even occasionally. New versions of the software are installed regularly and the OMIM/GDB staff is working toward improving the product. In addition, a help column appears in *Human Genome News*.

GDB/OMIM is free (that's right - free), as is connect time! Any computer with a 1200 or 2400 baud modem can access. For more information, contact User Support at the William H. Welch Library, 410-955-7058.



Note: Look for the Welch Medical Library in the exhibit area, Farallon Room, at the NSGC's 11th Annual Education Conference in San Francisco.

Legislative Briefs:

Arkansas Law Suit Dismissed

As a follow up to "Arkansas Genetics Program in Jeopardy," (PGC13:4), this article was prepared with assistance from the Office of General Council of the UAMS:

The lawsuit against Chancellor Harry Ward seeking to terminate the operation of the Arkansas Genetics Program (AGP) was dismissed in February when Judge Robin Mays granted the University's motion for partial summary judgment.

The court found that no abortions are performed at, through or by the AGP and that the testing performed by AGP and the information disseminated to a prospective mother and her family by AGP does not violate Amendment 68 to the Arkansas Constitution. The Court also found that following dissemination of information by AGP, any decision regarding termination or completion of a pregnancy is solely made by the patient and her family.

The plaintiff has appealed to the Arkansas Supreme Court. The University has filed to have the appeal dismissed since the order of partial summary judgment only dealt with one aspect of the plaintiff's complaint. The complaint also sought to prohibit abortions at UAMS, except those necessary to save the mother's life.

In June 1991, the court issued a preliminary injunction, which requires that, except in cases where it is necessary to save the life of the mother, UAMS must obtain payment for an abortion in advance or assurance that the procedure is covered by insurance or other third-party guarantee of payment.

Since the injunction was entered, five indigent patients with severe or lethal abnormalities have not been able to receive abortion services at University Hospital.

Becky Butler, MSSW
University of Arkansas for Medical Sciences, Little Rock, AR

Focus on Reproductive Freedom

Utah Problems Continue

As a follow-up to "News from the Region," (PGC 13:2), the struggle for reproductive freedom continues in the state of Utah:

In a special legislative session in 1991, some of the most restrictive and punitive provisions of the law were amended. Since that time, the case was heard by Judge J. Thomas Greene, who refused to hear any live testi-mony from plaintiffs or expert witnesses. Instead, he considered written testimony only, stating that there were no fact disputes in the case. Thus, the complete testimony of the plaintiffs was never considered. The judge dismissed all claims regarding religion, vagueness, involuntary servitude and equal protection.

He deferred ruling on the right to privacy claim until the Supreme Court ruled on the Pennsylvania case (Planned Parenthood vs. Casey). After Casey was decided, the State of Utah wrote a letter to Judge Greene suggesting that he not ignore its precedent. The State essentially conceded that the Utah law is unconstitutional, with the exception of spousal notification requirement, which they viewed as less restrictive than the Pennsylvania requirement. To date, Judge Greene has not issued a final ruling.

Since this law was enacted, there has been a chilling effect on the practice of perinatology and medical genetics in Utah, even though there is a temporary injunction against the law. It is not clear what the exception "to prevent the birth of a child that would be born with grave defects" means. Judge Greene threw out the claims of vagueness without listening to any live testimony. In practice, when physicians don't know whether a pregnancy termination fits this exception, the woman is denied an abortion, making it difficult to accurately counsel a family about their options.

As states pass laws restricting reproductive freedom, there is a grave danger to the professions of medical genetics and genetic counseling. The original 1991 Utah law provided penalties up to life imprisonment for aiding a woman when obtaining an abortion. The present law still allows the possibility of prosecution under Utah's general "criminal responsibility" law.

We await the ruling on the Utah law with hope that it will be struck soon. However, it is likely that another law enacting restrictions similar to Pennsylvania's law will be passed, which unfairly burdens families who are poor, rural and less capable of aggressive action on their own behalf. When the composition of the Supreme Court changes, the recent decisions which offered partial protection of reproductive freedom may again change. I urge individuals who are concerned about these developments to actively support the Freedom of Choice Act, which is currently being considered by the House of Representatives. The goal of this bill is to block state-by-state restrictions of women's reproductive freedom.

Bonnie Jeanne Baty, MS,
University of Utah Medical Center,
Salt Lake City, UT

Letters to the Editor

Power of the Pen

To the membership:

The NSGC enacted its right for choice by not going to New Orleans in 1993. At our recent NSGC regional meeting, we recognized the need for individuals to send a message of non-support to ASHG for their decision to go to New Orleans. We encourage our colleagues to direct correspondence to Walter Nance, MD, President ASHG, 9650 Rockville Pike, Bethesda, MD 20814-3998. State your opinion regarding the ASHG decision to meet in a state which has chosen to limit access to reproductive services. We particularly urge those who have chosen not to go to ASHG meetings in New Orleans in 1993 to voice their opinion.

Janice Cox Palumbos, M.S.
for Region Vmeeting attendees,
Steamboat Springs, CO

Finding Funding Support

To the Editor:

Assisting military couples who want abortions for fetal abnormalities has been one of the most frustrating aspects of my job. Federal employees' medical insurance does not provide coverage for elective abortion. Seemingly, this denial is due to an Executive Order issued by President Reagan.

Too often, I counsel a military couple with a confirmed fetal abnormality prior to 25 weeks. Most of these couples cannot afford an abortion. Military aid groups are not allowed to provide loans for abortions and, until recently, there was little help I could offer.

Recently, I identified a local woman willing to help these couples. With several friends, she has provided partial or complete funds for two recent abortions ($600 and $1900) for a military couple and a Medicaid patient. This group has volunteered to continue to help. I only know one of the women, and the group does not want recognition.

She states that there are probably similar individuals in every city. It is time for genetic counselors to take an active role in identifying this type of support. I would be glad to share my experience.

Andrew Faucett, M.S.
Memorial Medical Center,
Savannah Perinatology,
Savannah, GA

Legislative Liaison Position Still Available

The Legislative Liaison position to the *PGC* Board remains unfilled. For further information contact Vickie Venne, 800-642-4657x4310 or Trish Magyari, 301-588-5484x356.

November 3, 1992
Election Day USA
Know Your Issues
When You Choose

RESOURCES • RESOURCES • RESOURCES

• BOOKS •

The Genetic Revolution: Scientific Prospects and Public Perceptions
editor: Bernard D. Davis
publisher: The Johns Hopkins University Press, (Baltimore: 1992)
price: $45 hb; $15.95 pb
reviewed by: Kathi E. Hanna, M.S., Ph.D., Senior Analyst, Office of Technology Assessment, United States Congress

Coincidentally, I was asked to review this book at the same time that I waschoosing a textbook for "Biotechnology and Its Social Impact," a course I teach. I decided to use *The Genetic Revolution* because it provides a reasonably balanced perspective on the risks, benefits and attendant concerns surrounding the use of recombinant DNA techniques in medicine, agriculture and environment.

The book is a collection of essays written by a diverse group of individuals on matters such as molecular genetics, field testing of engineered microbes, neuroscience, transgenic animals, regulation and public policy. With the exception of the typically shrill voice of Henry Miller of the U.S. Food and Drug Administration, the insights provided by the authors are thoughtful and well developed. This is the best collection of essays I have seen to date. Most publications tend to be too technical, too fantastic, too policy-oriented or too naive.

Biotechnology is complicated because of its penetration into so many areas of research and development. Perhaps the only way to discuss the potential benefits and unseen harms is in a collection of essays. One drawback is that the technical level of the writing varies tremendously and poses a problem in the classroom where there are often varying levels of technical and scientific proficiency.

There are only three essays in the book directly relevant to clinical genetics: a background piece on molecular genetics by Bernard Davis, an article on molecular medicine by Theodore Friedmann and an impressive overview of molecular neuroscience by James Schwartz, although I'm not convinced it really belongs in this book.

Although one would have hoped that Henry Miller of the FDA would have discussed how biotechnologically-developed drugs will be treated at his own agency, he chose to dwell on six myths that are preventing biotechnology from reaching rapid assimilation into American agriculture. In the meantime, serious questions remain about how DNA-based test kits will be approved, marketed and regulated in the United States.

Other than the essay by Theodore Friedmann, there is not much discussion of the policy and ethical issues involved in use of recombinant DNA techniques in human health. Other excellent sources for discussion of those issues, include *Proceed With Caution* by Tony Holtzman and several documents produced by the Congressional Office of Technology Assessment.

Many of the essays not specific to human health have relevance because they deal with the regulatory framework for biotechnology from applications far afield from the human genetics center. Talk to a layperson who has read *Jurassic Park* by Michael Crichton and see what they think of the capabilities of recombinant DNA techniques.

Because of its diverse approach both in content and view, *The Genetic Revolution* is appropriate reading for genetic counselors interested in the "other words" of biotechnology—applications in agriculture and environmental cleanup—and want to know more about the issues in those fields.

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In the Name of Eugenics
author: Daniel Kevles
publishers: hb: Alfred A. Knopf, (New York, 1985) 426 pp; pb: UC Berkeley (1986) 426 pp
price: $22.95 (hb); $13.95 (pb)
reviewed by: Christina Palmer, M.S., University of Wisconsin, Madison

In *The Name of Eugenics* provides an historical, comparative account of the evolution in knowledge of human heredity and genetics and the uses and abuses of the various applications of this knowledge over time. This account compares and contrasts the activities occurring primarily in the United States and Great Britain.

There are two major reasons why this book is recommended reading for a genetic counselor. First, it provides an excellent description of the development of the corpus of knowledge which we know of today as "genetics." From Francis Galton's coining of the term "eugenics" in 1883 to the mapping of the gene for Huntington's disease on chromosome 4 in 1983, the evolution of genetics is aptly depicted, although not absolutely current. It will leave the reader awed at the explosion of knowledge and technical capability in the relatively short period of time in which this field has actually been pursued in a scientific manner.

Second, this book explores the interactions between the scientific understanding of human heredity and genetics at particular points in time, the social climate of the day and the ideologies of the key players. Knowledge in the area of heredity and genetics fueled and attempted to answer fundamental questions such as who should [be allowed to] procreate, the amount of human behavior, intelligence and health that is determined by heredity as opposed to the environment and the optimal level of human genetic diversity.

RESOURCES • RESOURCES • RESOURCES

The actual level of genetic knowledge, coupled with the social climate and the ideologies of the key players, resulted in various socio-political phenomena, such as the enactment and subsequent repeal of restrictive immigration, compulsory sterilization and restrictive marriage laws based on race in the U.S. (e.g., non-Caucasians out-numbering Caucasians) and based on classe in Britain (e.g., lower socioeconomic class out-numbering higher socioeconomic class subjects); the use of intelligence tests to support inherent discriminatory patterns (again, between class in Britain, between race in the U.S.); the rise and fall of compulsory carrier testing in the U.S. (e.g., sickle cell testing); the rise in newborn screening for genetic diseases; and recognition of the need for ethical discussion in the application of genetics knowledge.

The underlying theme is that the focus of genetics-based research (and researchers) and its subsequent application are based on fundamental ideals regarding humanity and underlying ideologies of what constitutes societal and individual health. As communicators of genetics information, genetic counselors need to have an awareness of this perspective.

As a final note, since this book was published in 1985, the author does not provide the reader with current information on the status of genetics knowledge or its current or projected impact on society. Most strikingly, the Human Genome Project is not mentioned. However, the author provides the reader with an excellent foundation and multiple avenues from which to explore this topic.

Perhaps a genetic counselor could write the next chapter.

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Psychosocial Aspects of Genetic Counseling
editors: G Evers-Kiebooms, J Fryns, J Cassiman, and H Vandenberghe
publisher: Wiley-Liss (New York) 1992, 203 p.
price: $95.00
reviewed by: Ellen Simpson, Ph.D., M.S., IG, Signal Hill, CA

This volume is the proceedings of the conference, *Psychosocial Aspects of Genetic Counseling*, held in September of 1990 in Belgium. The reported research includes outcome studies and process research about several topics, including: genetic counseling, psychological aspects of prenatal diagnosis, the consequences of termination of pregnancy for fetal abnormalities and community knowledge and attitudes about genetics.

As a genetic counseling student, I found this research to be a practical review of many psychological aspects of counseling pertinent to clinical experience. The wide range of nationalities of the conferees brought a cross-cultural perspective to the material and specific reports dealing with cross-cultural issues. For example, Diana Punales-Morejon and Victor Penchaszadeh delineated the dimensions of the cultural and ethnic diversity of the counselee population in the United States, identified major barriers to genetics services and outlined strategies to approach in practice.

The Frets' study of the strategies for supporting counselee decision-making includes a listing of possible influences in reproductive planning, a useful organizational tool.

The wealth of research reported here ideas and strategies for further studies in these areas. Criticisms are minor, including some awkward translations and editorial lapses such as misspellings. For a student, this volume is an introduction to interesting research in psychosocial aspects of genetic counseling and genetics education.

• SUPPORT GROUPS •

DUBOWITZ SYNDROME

Dubowitz syndrome is an autosomal recessive condition marked by an unusual facial appearance, infantile eczema, small stature and variable degrees of mental deficiency.

Several families are forming a nationwide support group network.

Families may contact: Patricia Graf, RR 1 Box 114, Downs, IL, 61736; 309-724-8407.

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JEUNE SYNDROME

A group of 12 families has formed an informal support group for families and individuals with Jeune syndrome (asphyxiating thoracic dystrophy). The group provides support and information, including a newsletter and reading list.

For more information contact: Kelly Bowron, 5636 Secor Rd., #11, Toledo, OH 43627; 419-475-9632.

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PALLISTER-KILLIAN SYNDROME

Pallister-Killian is characterized by postnatal growth retardation, mental retardation, seizures, hypotonia and deafness. Individuals have a distinct facies, abnormal scalp hair distribution and tetrasomy 12p.

A support group has been formed to identify and support families, publish a bi-annual newsletter and increase awareness.

For more information, contact Marianne Haven, 4255 5th Ave SW, Naples, FL 33999; 813-455-0400.

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AICARDI SYNDROME

Aicardi syndrome, an X-linked disorder affecting females only, is characterized by the absence of the corpus callosum, retinal lesions specific to the disorder, seizures and mental retardation.

A group has formed to provide support, information and referral.

Contact Denise Raynor, Aicardi Syndrome Newsletter, 5115 Troy Urbana Rd, Casstown, OH 45312; 513-339-6033.

BULLETIN BOARD

JOURNAL REQUESTS ARTICLES

SHHH, the journal of Self Help for Hard of Hearing People, has received readers' requests for articles related to genetics of hearing loss. Members with contributions are invited to request author's guidelines. Contact Barbara Harris, Editor, *SHHH Journal*, 7800 Wisconsin Ave, Bethesda, MD 20814; 301-657-2248.

QUILT COMMEMORATES AIDS VICTIMS

Members planning to attend the Display of Names Quilt Ceremonies, commemorating people who have died of AIDS, are invited to join an NSGC contingent, organized by June Peters. The event, which will include a candlelighting on Saturday evening, has been scheduled for October 9 - 11 in Washington, D.C.

Call June at 310-933-2907 (office) or 310-987-0396 (home).

GENETICS DATABASE SOUGHT

The counselors at Rockford Memorial Hospital are seeking a genetic database to track patient scheduling and demographics.

If anyone is already using a program or knows of access to one, please contact Christi Munn or Mary O'Connor, Dept Medical Genetics, Rockford Memorial Hospital, 2400 N. Rockton Ave, Rockford, IL 61103; 815-969-5069.

ANNUAL EDUCATION CONFERENCE...JUST WEEKS AWAY

HAVE YOU REGISTERED? HERE ARE SOME DEADLINE REMINDERS

- LATE REGISTRATION penalty for postmark after Friday, October 2 is $25.
- WALK-IN REGISTRATIONS (postmarked after October 31) will be assessed $35. If you cannot register by October 31, wait and register on-site.
- A CONFERENCE ATTENDANCE LIST will include only those participants whose registration is *received* by Saturday, October 24.

Note: These assessements and deadlines are less a penalty to you than a planning and time saver for the administration of the conference. Your cooperation and compliance are greatly appreciated.

OPEN FORUM ON ABMG RESTRUCTURING AUGMENTS AGENDA

An open forum to address concerns related specifically to counselors regarding the pending ABMG bylaws vote will be held November 8 at 5:00pm in the Plaza Ballroom, Grand Hyatt.

VIDEO VIEW

Cynthia Kane, a UC Berkeley student, is conducting a search for videos related to the HGP. If you have a video to share, please contact her at 510-642-6328 and plan to bring it to the Media Resource Center, to be organized by counseling students.

MEETINGS OF NOTE

- All NSGC Committee meetings are open. New members are welcome. Most will be held during the lunch break on Sunday, November 8.
- NSGC has reserved two meeting rooms at the Moscone Convention Center for members' use throughout the ASHG meeting. An administrative office will be in Room 216. Room 218 will be set conference-style and be available by reservation.
- The ASHG TASK FORCE to develop strategies for increasing pubic awareness about pro-choice issues on Tuesday, November 10 at 6:00pm

Ginny Corson will represent NSGC on the panel.

CORPORATE AND ORGANIZATIONAL CONFERENCE SUPPORT

With thanks and acknowledgement to the new exhibitors and business friends joining our roster since the publication of our last newsletter:

Genelex	Genetics & IVF Institute	University of Chicago Press
Genetrix	MetPath	

MEETING MANAGER

NSGC REGIONAL CONFERENCES

REGION I: December 9. *Fragile X Carrier Genetics*, Durham, NH, Contact: Marsha Lanes, Prenatal Diagnostic Center, 80 Hayden Ave, Lexington, MA 02173; 617-862-1171.

REGION II: March 13-15. Topic: Genetic counseling for adult onset conditions, Alexandria, VA, in conjunction with MARHGN meeting. Contact: Jill Fonda Allen, Children's National Medical Center, Division Genetics, 111 Michigan Ave NW, Washington, DC 20010; 202-745-4166.

OTHER CONFERENCES THIS FALL

OCTOBER 9-10: *Fallen from the Tree*, Eighth National Perinatal Bereavement Conference, New Haven, Connecticut, for parents and families as well as health care professionals, funeral directors and clergy.

Contact: Office of Post Graduate and Continuing Medical Education, Yale University School of Medicine, 333 Cedar St, PO Box 3333, New Haven, CT 06510; 203-785-4578.

NOVEMBER 19-22: *Changes and Challenges in Perinatal Care*, National Perinatal Association's 1992 Clinical Conference and Exposition, Orlando, Florida.

Contact: National Perinatal Association, University Profession Center, Suite 525, 3500 E. Fletcher Ave, Tampa, FL 33613; 813-971-1008.

NOVEMBER 21-22: *The Empty Pocket Syndrome: How to Get Funds*, Alliance of Genetic Support Groups, Tempe, Arizona. Held in conjunction with the Alliance's annual meeting.

Contact: Alliance of Genetic Support Groups, 35 Wisconsin Circle, Suite 440, Chevy Chase, MD 20815; 800-336-GENE.

• CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED •

The classified listings printed in this issue represent the most recent additions to the NSGC JobConnection service. Members and students interested in complete or regional information may receive a computerized printout, at no charge, by contacting the Executive Office. Printouts are mailed on the first and third Monday of each month. This service is strictly confidential.

ORANGE, CA: Immediate opening for BC/BE Genetic Counselor in rapidly growing genetics services facility; fluency in Spanish helpful, but not required.
RESPONSIBILITIES: All aspects of prenatal & general GC (CVS, amnio, PUBS, MSAFP, teratogens, etc); participate in twice weekly general genetics clinic, specialty clinics; coordinate support groups; opportunity for public education & professional development; contribute to publication of newsletter.
CONTACT: Jon Haverstick, MS, Genetics Center, 1000 W. LaVeta, #9, Orange CA 92668; 714-667-0878. EOE/AA

SACRAMENTO, CA: Immediate opening for 2 BC/BE Genetic Counselors. Salary commensurate with experience, starting at $39,000.
RESPONSIBILITIES: All aspects of pediatric & general GC and case management: amnio, CVS, teratogens, MSAFP & hemoglobinopathy screening.
CONTACT: Mark Lipson, MD, Kaiser Permanente Medical Center, Genetics Dept, 2025 Morse Ave, Sacramento, CA 95825; 916-978-1402. EOE/AA

SAN JOSE, CA: Immediate opening for BC/BE Genetic Counselor to join 2 medical geneticists and 6 GCs.
RESPONSIBILITIES: All aspects of counseling & case management for pediatric/general genetics: amnio, CVS, teratogens, MSAFP, U/S, hemoglobinopathy screening; inservice, patient education; research publications & projects.
CONTACT: Karen Wcislo, MS, Kaiser Permanente Medical Center, 260 International Cr, San Jose, CA 95119; 408-972-3300. EOE/AA

FARMINGTON, CT: Immediate opening for BC/BE GC or related professional with 2 years experience in comparable setting. Academic appointment available.
RESPONSIBILITIES: General & consultation GC in human genetics division: case management; seminars; journal club; teaching; conferences.
CONTACT: Robert M. Greenstein, MD, University of Connecticut Health Center, Div. Human Genetics, MC6310, Farmington, CT 06030; 203-679-1500. EOE/AA

CHICAGO, IL: Immediate opening for 2 BC/BE Genetic Counselors; clinical experience preferred but not required.
CONTACT: Coordinate services & GC for (1) newly-established pediatric ophthalmology, genetics & birth defects clinic and (2) general prenatal & pediatric service for newly established Chicago Board of Health Clinics. Education, outreach & research opportunity.
CONTACT: Barbara K. Burton, MD, Humana Hospital Center for Medical & Reproductive Genetics, 2929 S. Ellis Ave, Chicago, IL 60616-3390; 312-567-7340. EOE/AA

KANSAS CITY, KS: Immediate opening for BC/BE Genetic Counselor (fulltime or parttime).
RESPONSIBILITIES: Pediatric & medical genetics clinics: CF, MD, SB, NF specialty clinics; science teacher education projects; opportunity for research & professional development.
CONTACT: Debra Collins, MS, University Kansas Medical Center, 3901 Rainbow Blvd, 4023-C, Kansas City, KS 66160; 913-588-6260. EOE/AA

LEXINGTON, KY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Promote & organize 35-40 state regional genetics clinics/year; provide genetic education services to local health programs & supporting agencies; participate in clinical genetics team in regional & university-based clinics; hospital consults.
CONTACT: Ron Cadle, MS or Bryan D. Hall, MD, University Kentucky College Medicine, Dept Pediatrics, Lexington, KY 40536-0084; 606-233-5558. EOE/AA

BOSTON, MA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join 2 GCs & multidisciplinary team at Harvard-affiliated teaching hospital: GC for amnio (early & 16 wk), PUBS, MSAFP triple panel, abnormal U/S, high risk OB service, teratogens. Also: perinatal consults, support groups, GC student supervision, cytogenetics; opportunity for teaching, research, professional interests.
CONTACT: Mary-Frances Garber, MS or Janice Stryker, MS, Brigham & Women's Hospital, 75 Francis St, Antenatal Diagnosis Center / Amb. 1+3, Boston, MA 02115; 617-732-4208. EOE/AA

SCARBOROUGH, ME: Immediate opening for BC/BE Genetic Counselor; Experience preferred.
RESPONSIBILITIES: Comprehensive prenatal & general genetics (Southern ME Genetics Services); large MSAFP (triple markers) program; pregnancy loss evaluation & treatment program with Dept OB (ME Medical Ctr). Ongoing research & education projects; genetics education program for OB & pediatrics residents.
CONTACT: Richard Doherty, MD, Genetics & Reproductive Immunology Program, Foundation for Blood Research, PO Box 190, Scarborough, ME 04070-0190; 207-883-4131. EOE/AA

DETROIT, MI: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join large genetics center with variety of counseling opportunities: pediatrics, adult & prenatal. Opportunity for teaching & publishing available.
CONTACT: Michelle Theobald, MS or Lester Weiss, MD, Henry Ford Hospital, Med Genetics CFP-4, 2799 W Grand Blvd, Detroit, MI 48202; 313-876-3188. EOE/AA

CHARLOTTE, NC: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join active & growing medical genetics center with broad range of counseling: prenatal, general pediatric, DNA, AFP & multidisciplinary satellite clinics; research & GC student teaching; other medical professional & public education projects available.
CONTACT: Pam Buennemeyer, Health Recruiter, Carolinas Medical Center, PO Box 32861, Charlotte, NC 28232-2861; 704-355-2101 or 800-942-6898. EOE/AA

GREENVILLE, NC: Immediate opening for BC/BE Genetic Counselor. Faculty position available.
RESPONSIBILITIES: Wide range of responsibilities: prenatal genetic & specialty clinics; participate in satellite clinics.
CONTACT: Nancy Leggett, Administrator, East Carolina University School Medicine, Brody Building, Room 3E140, Greenville, NC 27858-4354; 919-551-2525. EOE/AA

CAMDEN, NJ: Immediate opening for BC/BE Genetic Counselor (parttime with potential for fulltime).
RESPONSIBILITIES: Prenatal counseling: CVS, amnio, PUBS, Level II U/S, fetal

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NATIONAL SOCIETY OF
GENETIC COUNSELORS, INC.
EXECUTIVE OFFICE
233 CANTERBURY DRIVE
WALLINGFORD, PA 19086

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loss, participation in satellite clinics with perinatologist. Potential for expansion into pediatric genetics.
CONTACT: Cheryl Reid, MD or Juliann Stevens, MS, Cooper Hospital, Dept Pediatrics, E&R Bldg, 3rd floor, 401 Haddon Ave, Camden, NJ 08103; 609-757-9797. EOE/AA

BUFFALO, NY: Immediate opening for BC/BE Genetic Counselor with faculty appointment on active service.
RESPONSIBILITIES: GC in pediatric, adult & OB patients; clinic coordination; sickle cell center activities; community & professional education.
CONTACT: Kathleen R. Verdaasdonk, MS or Richard W. Erbe, MD, Childrens Hospital, Div. Genetics, 936 Delaware Ave, Buffalo, NY 14209; KRV: 716-878-7545 or RWE: 716-878-7411. EOE/AA

VALHALLA, NY: Immediate opening for Genetic Counselor seeking scientific challenge in research, admininstration & new program development. Experience preferred.
RESPONSIBILITIES: Research & counseling with members of research families nationwide; work closely with Principal Investigator to develop new programs to provide lab-based counseling in genetics of common disorders (i.e., cancer, mental illness, diabetes mellitus).
CONTACT: Michael Swift, MD, New York Medical College, Div Molecular Genetics, Valhalla, NY 10595; 914-347-2592. EOE/AA

PORTLAND, OR: October '92 opening for PacNoRGG Project Coordinator. Masters or doctorate in GC, nursing, social work, health ed, public health and 5 yrs exp required.
RESPONSIBILITIES: Facilitate Steering & Standing committee projects; liaison with regional genetics networks & CORN; edit newsletter; prepare & monitor grant progress, reports, budgets; supervise administrative assistant.
CONTACT: Jonathan Zonana, MD, Project Director, Oregon Health Sciences University, CDRC, PO Box 574, Portland OR 97207; 503-494-8342. EOE/AA

NASHVILLE, TN: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join university-based genetics team: prenatal (CVS, amnio, PUBS), subspecialty & outreach clinics; in-house consultations; participate in public & professional education; work closely with molecular genetics lab. Participation in clinical research encouraged.
CONTACT: Vickie Hannig, MS or John Phillips, III, MD, Vanderbilt University Medical Center, Div Genetics, DD-2205/MCN, Nashville, TN 37232-2578; 615-322-7601. EOE/AA

GALVESTON, TX: Immediate opening for Genetic Counselor.
RESPONSIBILITIES: Obtain, analyze, counsel, educate & follow-up individuals & families at risk for genetic disease & birth defects; refer patients to various clinics & community resources; coordinate referrals from outreach perinatal clinics.
CONTACT: Lillian H. Lockhart, MD, University of Texas Medical Branch, Dept Pediatrics, Div Genetics, Galveston, TX 77555-0359; 409-772-3466. EOE/AA

SAN ANTONIO, TX: Immediate opening for BC/BE Genetic Counselor with minimum 3 years experience.
RESPONSIBILITIES: Work in fetal diagnosis unit, Maternal Fetal Medicine (OB/GYN): intake to follow-up for analysis, reports, scientific publications.
CONTACT: Carol Aubrey, Office of Human Resources, University of Texas Health Science Center, 7703 Floyd Curl Dr, San Antonio, TX 78284-7972; 512-567-2600. EOE/AA.

Erratum: We regret a typographical error in the last issue's classified section. Please note that the phone number for St. Joseph's Hospital and Medical Center in Paterson, NJ is 201-977-2429. The contact person is Victor Vena, Sr Recruiter; the job remains available at presstime.