PERSPECTIVES IN GENETIC COUNSELING

newsletter of the National Society of Genetic Counselors, Inc.

Vol 13, No. 1 **Spring 1991**

Member News

NEW MEMBERSHIP BENEFIT

The NSGC has developed a 3-fold, 8 1/2 x 11" public information brochure, *Genetic Counseling: Valuable Information for You and Your Family.* Two versions are available: one designed to enable you to personalize the brochure with your department's stamp and one for general, media or public relations needs. Leave this excellent resource in referring physicians' offices or stack them neatly in clinic education displays. Information includes:

- What is Genetic Counseling?
- Is Genetic Counseling Indicated in Your Family?
- When you Visit a Genetic Counselor
- Where to Find Genetic Counseling Services in Your Local Area (May be personalized with your stamp.)
- Facts & Myths

Members may request an order form and fee schedule by contacting the Executive Office.

on the inside...

The NSGC gratefully acknowledges Integrated Genetics' support of this issue of *Perspectives*

Part Two of a Two Part Series

REFERENCE LABS FOR DNA AND BIOCHEMICAL TESTING

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

This is the second article in a two-part series about genetic counselors assuming an active role in determining which reference laboratories are used for genetic testing. In the first article, issues concerning cytogenetics and alpha-fetoprotein testing were explored. This article will focus on DNA and biochemical testing.

GETTING STARTED

When I accepted the genetic counseling position in Savannah, I became the only person with graduate training in genetics in the area. Although Memorial Medical Center is the tertiary medical center for coastal Georgia, the closest medical geneticist is over 100 miles away.

Shortly after I arrived, I realized that a high percentage of my counseling would involve cases that could be evaluated by DNA or biochemical methods. Part of my job would involve determining the availability of testing, the predictability of the testing and the "best" laboratory to perform the testing. Although I have not created a formal questionnaire, I found myself asking the same questions.

FACING SOME REALITIES

Until recently, the majority of genetics-based DNA and biochemical testing was performed by research laboratories. For many of the recently discovered DNA probes, testing has been available in only a few research laboratories. Lately, commercial labs have begun to offer both DNA and biochemical testing.

Currently, there is no national group overseeing laboratory standards, inspections or proficiency testing for DNA-based testing. Some labs are inspected by the College of American Pathologists (CAP) and some research labs currently are not formally inspected by any external quality control system. This will change in the next few years as CLIA 88 is implemented. However, the current lack of standards is yet another reason for genetic counselors to evaluate each reference lab used for DNA and biochemical tests.

Regions within the Council of Regional Networks have begun assessing the issue of laboratory evaluations. The Southeastern Regional Genetics Group (SERGG) began a program of voluntary evaluation of regional labs to address this issue. This program has been accepted as the working model to develop a national certification program. The Pacific Southwest Regional Genetics Network (PSRGN) is in the process of creating quality assurance criteria for diagnostic molecular genetics. In addition, the American Society of Human Genetics and CAP have also begun discussions regarding the evaluation of DNA and biochemical labs.

KEYS TO ASSESSING LABS

Six areas emerged as I began evaluating DNA and biochemical labs.

- Definition of appropriate diagnostic tests for standard clinical care
- Qualifications of the lab director
- Quality control (QC) and quality assurance (QA)
- Policies, procedures and protocols as well as reporting of results
- Service
- Cost

• continued on page 6 •

FROM A DIFFERENT PERSPECTIVE...

Serving Patients within a Public Health System

In public health programs throughout the United States, there is an increasing need for administration, consultation and direct patient care services that can best be met by a person who is trained as a genetic counselor. This trend is particularly evident in the state of North Carolina, where public health genetic counselors are responding to these diverse needs.

Genetic services in North Carolina are administered through the Division of Maternal and Child Health of the North Carolina Department of Environment, Health and Natural Resources. These services are provided primarily through two programs. The Genetic Health Care Program provides newborn screening, genetic counseling, education and funding for services provided through state-sponsored outreach clinics and MSAFP screening programs. The Sickle Cell Program provides comprehensive counseling, education and care coordination.

In North Carolina, the public health genetic counselor is responsible for delivering genetic counseling services, expanding the awareness of genetic health care issues and improving the accessibility of genetic services to the citizens of the state. As part of the Genetic Health Care Program, public health genetic counselors provide a wide range of medical services which include: clinic coordination, education, referral and program consultation, as well as genetic counseling. Public health genetic counselors also coordinate the genetic outreach clinics for the statewide network of Developmental Evaluation Centers (DEC). Services at those clinics are provided to individuals and their families who have a known or suspected genetic condition or birth defect. Public health genetic counselors also provide services for women interested in prenatal diagnosis through DEC outreach clinics, although the majority of prenatal diagnostic care is delivered by maternity clinics at medical centers and county health departments.

Awareness of genetic health care issues is accomplished through education of public and private health care providers, schools and universities and community groups. Consultation and information and referrals are provided to public health programs, the private medical community and the general population.

Increased accessibility of genetic service occurs because of the established relationship as part of the public health system in North Carolina. By being part of the public health care system, genetic counselors are able to gain access to people who might not otherwise seek genetic health care services, and those patients are using the same system to gain access to genetic services. Instead of the traditional center-based delivery system, the public health genetic counselor can overcome transportation and financial barriers to better serve the citizens of North Carolina.

In recent years, as the medical genetics community created a heightened public awareness of genetic health care issues, direct services have developed rapidly in North Carolina. The awareness of the need for genetic services is coming not only from the public. The health care professionals who provide primary and preventive medical service are modifying their delivery systems to include genetic health care. North Carolina's public health genetic counselors, because of their diverse responsibilities, are well suited to provide a variety of services for a public with increased genetic health care needs. Furthermore, these counselors provide an important link between the public and other health care professionals that furnish genetic services. As the demand for genetic services in North Carolina grows, the need for more public health genetic counselors will surely increase.

by Kenneth Loud, Shane Palmer, and Kerry Crandall

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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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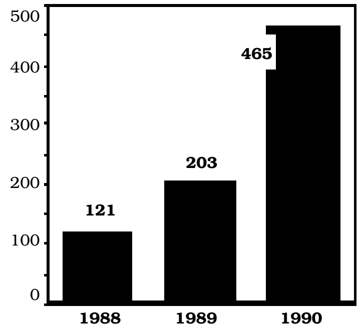
NSGC...ON THE GROW

REQUESTS FOR CAREER INFORMATION (COLLEGE/CAREER CHANGE LEVEL)



This graph represents career requests received at the Executive Office. High school level career information is not included.

Continuing Words

This issue marks a beginning and an ending for *PGC.* We begin volume 13, the 13th year that the newsletter has been the NSGC's primary means of membership communications. It also marks the end of *Perspectives* as the NSGC's only print communication. In early 1992, the *Journal of Genetic Counseling* will be introduced to accommodate our field's growing need for peer reviewed articles. I look forward to maintaining *PGC* as a high-quality and valued communications tool as this publications partnership evolves.

"From a Different Perspective," a column written by members in non-traditional roles, is one of the changes that will be instituted with this volume. We begin with a public health perspective of genetic services. It has been several years since our *ad hoc* Committee on Expanded Roles completed their work. How have we, as professionals, grown since then? What are the ways in which the training and skills of the genetic counselor fit into the changing health care system? Are you working in a unique setting? We want to know how you have expanded your boundaries.

I am especially pleased to present in this issue a special 4-page supplement. It is a comprehensive list of laboratories doing DNA-based genetic testing, collected from a survey conducted by CORN's DNA testing subcommittee, (QA committee), chaired by Dr. Patricia Murphy. We owe a special thank you to the subcommittee and the many laboratory directors who so promptly responded to our request for permission to publish their information. Feel free to duplicate this insert. Limited copies of the list are available from the NSGC Executive Office or CORN, 3008 N. 3rd, Ste 101, Phoenix, AZ 85012.

As we continue to develop our format and content, we are adding two members to our editorial board. Welcome to Andy Faucett and Kathy Steinhaus.

Please stay in touch.

Vickie Venne

TIPS OF THE TRADE

Heightened awareness of genetic services provides new opportunities to educate the public, dispel misconceptions and shape popular understanding of genetic counseling and clinical services. Unfortunately, the increased demand for public speakers, written materials and laboratory tours has been commensurate with a markedly increased caseload. Not only were we sorely pressed for time, but we found tour groups in particular interfered with the smooth operation of the lab and clinic and presented a potential for breach of patient confidentiality. How could we satisfy our desire to educate as well as our duty to provide appropriate, efficient clinical services?

Our solution was a videotaped walking tour of the Center for Human Genetics. Narrated by our director, the tape explains basic genetic concepts while illustrating lab techniques, clinical testing and counseling through a "case study." The viewers join a husband and wife who are referred for prenatal diagnosis following an abnormal MSAFP screen. "Mr. and Mrs. Hansen" (portrayed by staff members) visit with the counselor, have an ultrasound examination, and undergo amniocentesis. The cytotechnologists then process and analyze the specimen, the completed karyotype is reviewed by the cytogeneticist, and the local physician is notified of a normal result. During the narrative, additional services such as our statewide genetics clinics are mentioned. The closing images are of the couple and their new baby.

This depiction of typical prenatal clinical and cytogenetic services also affords glimpses of various career opportunities in human genetics. It gives short shrift to primary research, molecular genetics and postnatal clinical services, but satisfies the majority of our lay inquiries. The tape serves as a prelude to more specific discussions with selected visiting groups, and is frequently mailed to high schools along with other video productions addressing general genetics and birth defects.

The entire process of developing, scripting and filming took about three months, with a media department cost of $1250. Most importantly, our staff is freed from the necessity of frequent canned speeches and our media department no longer encounters the scheduling headaches attendant upon lab tours and live presenters.

Rebecca Anderson, M.S., J.D.,
Center for Human Genetics,
University of Nebraska Medical Center

NSGC...WHAT'S IN IT FOR ME

"ALTHOUGH I have only been working as a genetic counselor since this past summer, I have been a member of the National Society of Genetic Counselors for almost three years. As a student member, I was able to attend the annual meetings at a reduced rate and finally meet many of the genetic counselors that I had heard about in school. The job listings available through the Society also provided me with an efficient way to locate the right job. It even led to my current position. As the only genetic counselor in a large community hospital, I rely on being able to contact counselors here in Baltimore and across the country for updates on the most current information and services available. Therefore, I don't go far without my NSGC directory. *Perspectives* is also a quick and easy way to learn what other counselors are doing and what resources are available. Most importantly, I now have many friends in the NSGC!"

Jean Jirikowic, M.S.
Sinai Hospital of Baltimore

Point CounterPoint

Should the NSGC Encourage

In the last issue, we explored the concept of training individuals who may not have any formal genetics education to provide direct patient services in genetics. In this issue, Point CounterPoint probes into the potential development of a genetic counseling doctoral program. We examine an issue that impacts our membership as we evaluate our personal career ladders. Do I really want to go back to school? And if I do, what benefits will be derived?

And, as we look to the future, how will individuals trained at either of these extremes impact the development of genetic counseling?

by Janice G. Edwards, M.S., Assistant Director, Genetic Counseling Program, University of South Carolina, Columbia, SC

The debate surrounding the Ph.D. in Genetic Counseling has evolved from discussions in the hallways at NSGC meetings to the subject of a formal workshop at the 1989 Asilomar Conference[1] and is reflected in genetic counselors' attitudes in a recent study.[2] What it would mean to the future of our profession and how it would impact each practicing counselor creates many questions. Its consideration, in my own mind, has evolved slowly into the belief that the doctoral degree is a necessary, progressive step for our future.

The Shape of the Program

A two or three year doctoral in genetic counseling should be available to master's-trained, ABMG certified genetic counselors who have at least three to five years of experience in the field. The program should be small, with two or three candidates entering training per year and should be an extension of a master's level genetic counseling program. The coursework and dissertation topics should focus on the evaluation of the process of genetic counseling. The main purpose of this degree would be to create qualified academicians to teach and perform research and thereby, establish an academic leadership for our future direction.

The Ph.D in Genetic Counseling Would Not...

...replace the M.S. as the degree required for clinical practice. Indeed, skills developed in traditional training programs meet the clinical needs of our patients and employers and will continue to do so regardless of the development of a doctoral degree. Additionally, the total number of Ph.D. genetic counselors would represent a very small percentage of the profession.

...conflict with the role of the Ph.D. medical geneticist, who is usually trained in laboratory science. The research questions are different. The Ph.D. genetic counselor would fill a void by studying the genetic counseling process and its impact. This research is now only rarely analyzed, and then, usually from the sociologic, anthropologic or psychologic professional viewpoint.

...require a separate ABMG certification, since candidates would already be certified M.S. genetic counselors, well grounded in clinical experience prior to advanced study.

...offer monetary gains, as most practicing counselors make equivalent, if not better, salaries than entry level assistant professors in most academic institutions.

The Ph.D. in Genetic Counseling Would...

...allow a small percentage of interested, qualified counselors to specialize and deepen our knowledge of genetic counseling. As our field matures, and as the number of services increases with technologic advances, the research questions will continue to multiply.

...provide academic opportunities for research, teaching and grant funding usually not available to master's level professionals. Only 4% of current faculty appointments held by genetic counselors are tenure track positions.[3]

...create the opportunity for the Ph.D. genetic counselor to continue to practice genetic counseling, while teaching and performing much needed research. Academic standing at the Ph.D. level would also open the door for the doctorally prepared counselor to develop and direct M.S. training programs.

...expand the resources and depth of study in M.S. training programs that also offer a Ph.D. Experienced genetic counselors seeking the doctorate would interact with and potentially teach M.S. students. The research activity of doctoral candidates would offer the unique opportunity of early exposure to critical analysis of the field, not usually available to master's students.

As We Look Forward

As a new profession, genetic counseling has expended much of its energies during the first twenty years in establishing roles, creating positions and defining the tenets of its discipline. We have reached a level of maturity that requires academicians who understand genetic counseling to analyze the individual, societal and public impact of our work and importantly, to create a literature from within our profession. That debate over the Ph.D. in genetic counseling will continue. I have no doubt that the doctoral degree is ultimately part of our future.

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[1] Walker, AP, et al. Report of the 1989 Asilomar meeting on education in genetic counseling. *Am J Hum Genet,* 46: 1223-1230, 1990.

[2] Gaupman, KM, et al. The doctoral degree in genetic counseling: attitudes of genetic counselors. *Am J Hum Genet* (in press).

[3] Edwards, JG. Professional status survey results. *PGC,* 12(2), 7-10, 1990.

the Development of a Doctorate in Genetic Counseling?

by Jacqueline T. Hecht, M.S., Ph.D., Director, Genetic Counseling Program, University of Texas, Houston, TX

The NSGC should carefully consider the development of a doctoral degree in genetic counseling because it has important implications for the future growth of our profession. This vantage point restrains enthusiasm by considering some deleterious effects of the pursuit of an advanced degree in genetic counseling.

Doctoral degrees have classically been considered research degrees. Those seeking one generally perform independent research. For example, I obtained a Ph.D. in Epidemiology to pursue an independent research career. In the genetic counseling setting, a doctoral degree would be pursued primarily by those interested in research in genetic counseling or related topics. However, a doctoral degree in genetic counseling would be pursued by clinically-oriented individuals who have practiced genetic counseling for a period of time. Will these individuals be pursuing this degree because they are primarily interested in research or because they are primarily interested in clinical practice, but want an advanced degree? If the latter is true, these Ph.D. genetic counselors will assuredly have an important impact on the practice of genetic counseling.

COMPARATIVE FIELDS EXAMINED

It might be valuable to explore the impact of various degrees on two other fields that are similar to genetic counseling: psychology and social work.

Ph.D. psychologists are licensed to practice and bill independently. The Ph.D. is the terminal degree in psychology and the M.S. degree is not clinically valuable.

Clinical counseling in the United States at the master's level is provided by social workers, who are licensed or certified, depending on the particular state. They can bill for their services and do not, in general, have reimbursement problems. The M.S. degree in social work is usually the terminal degree. Individuals with a doctorate in social work generally work in administration, teaching, and, in particular, they direct training programs.

There is disagreement between the master's level social workers who think that a doctoral degree is superfluous and the Ph.D./D.S.W.s who think the degree is important for research and education.

POTENTIAL LOSS OF JOBS

Perhaps those advocating for a Ph.D. in genetic counseling have not thought about potential loss of jobs for M.S. individuals directing genetic counseling programs. Master's degree social work training programs are generally directed and taught by Ph.D. social workers, while field instruction is delegated to the M.S. level workers. Five genetic counseling programs are now directed by Ph.D. geneticists or psychologists.

In addition, genetic counselors with Ph.D.s may become the directors of genetic counseling centers now being administered by master's level genetic counselors. This will lead to a loss of jobs and prestige for the master's level genetic counselors.

NEW COMPETITION WITHIN FIELD

Will Ph.D. genetic counselors and Ph.D. medical geneticists compete for patients and usurp the interesting cases, leaving only the routine counseling for the master's level genetic counselors? If the Ph.D. becomes the terminal genetic counseling degree, does this set a scenario in which the M.S. level counselors become "second-rate" citizens? Who will decide salary increments, and how will the self-image of the M.S. genetic counselor be affected by yet another degree level supervising them? This could produce unnecessary tension in a field that is still growing and expanding into new areas of expertise.

THE ISSUE OF REIMBURSEMENT

An additional and important concern is reimbursement for genetic counseling services. There is currently no mechanism in place for M.S. genetic counselors to bill for their services without a co-signing licensed physician. This is also true for Ph.D. medical geneticists and will be true for any other Ph.D. in the genetic counseling field. There can be no true separate identity for service providing groups unless there is a mechanism for billing.

IN CONCLUSION

The question still remains: Is there a place for a Ph.D. in genetic counseling? Does one who achieves a Ph.D. become a Ph.D medical geneticist? The latter group generally pursues research and teaching and some are involved in providing clinical service, albeit usually minimally. However, some Ph.D. medical geneticists research genetic counseling issues. Perhaps we should consider that a Ph.D. in genetics already exists, and it may not be necessary to established a specialized Ph.D. genetic counseling degree. Alternatively, maybe we should add a stronger research component to our M.S. training programs to train genetic counselors to conduct research. This may involve extending or changing the programs, but will ultimately be extremely important to the future of the newly established *Journal of Genetic Counseling.*

DID YOU KNOW...

that 8.6%, 65 of 755, of the NSGC's current combined full and associate membership hold advanced degrees? Those degrees are:

1	**D.M.Sc**
1	**D.N.S.**
1	**D.P.H.**
1	**D.S.N.**
1	**D.S.W.**
2	**J.D.**
4	**M.D.**
2	**M.D., Ph.D.**
1	**M.D., M.P.H.**
50	**Ph.D.**
1	**Ph.N.**

CHOOSING DNA AND BIOCHEMICAL LABS from p. 1

Research vs. Clinical?

In such a rapidly advancing field, it is sometimes difficult to determine when testing moves from the research arena to a clinical service. Evaluations regarding the acceptability of the test as clinical service can be determined by speaking with colleagues in the genetics community and researching the literature.[1]

- What research literature is available to support this testing?
- Is another testing method available? If so, how does it compare?
- Does the lab follow-up on both normal and abnormal results?
- Has there ever been an error, and, if so, is there an explanation?
- Is the data used generated from this lab or another researcher? In the case of the latter, has the lab replicated the researcher's work?
- Is the laboratory licensed as a diagnostic laboratory and checked under some regulatory agency?

Checking the Credentials of Who's in Charge

- Does the lab director have a doctoral degree in medicine, genetics, biochemistry, molecular biology, or a related health science field?
- What is the lab director's level of post-doctoral practical experience?
- How many cases has the director *independently* and correctly studied?
- Is the director ABMG board certified or eligible in Clinical Molecular/Biochemical Genetics?
- If technicians are performing the test, what is their level of experience?

Considerations of Quality Control and Quality Assurance

- What precautions are taken to reduce sample mix-up, bad lots of chemicals, technician errors or equipment failures?
- Are guidelines in place to assure consistent digestion, banding, amplification and resolution?
- Are controls run on each assay?
- Are studies read or interpreted by more than one person?
- If PCR is used, what precautions are used to eliminate cross-contaminations of samples?
- Is the lab willing and able to bank patient DNA for prolonged periods, if necessary?
- Are confirmation samples requested and studied on abnormals?

Policies, Procedures, Protocols and Reports Need Careful Scrutiny

- Is there a complete, updated procedure manual?
- Is there written criteria to determine acceptability of specimens?
- Which technique is used for a given test? Is it compatible with the literature standard?
- If PCR is used, does the lab have an appropriate license?
- What is the usual time schedule for each phase of the study?
- Which tissue types is the lab experienced with for analysis? (amniotic fluid/culture, CVS direct/culture, peripheral blood)
- How are results reported? ... directly to the genetic counselor? Is a preliminary verbal report available?
- Are report forms easy to interpret?
- Will a partial study be run if all family members are not available?
- In linkage studies, does the report include an estimation of the risk? Is the risk calculation clearly explained? Is all relevant clinical information being considered?
- Are limitations of the testing clearly stated and explained?
- How long are records kept?

Service

- What are the lab hours?
- Is a genetic counselor on staff?
- Is the lab director readily accessible for technical questions?
- Is a medical geneticist available to discuss the appropriateness of tests?
- Who helps determine family members needed for linkage studies?
- What is the turnaround time? Can this be verified by more than one recent client?
- What is the set-up frequency?
- Does the lab provide supplies?
- Are there toll free numbers?
- Are patient and professional education materials available?
- Can results be phoned?...faxed?

Cost

- What is the cost for the test?
- Is the price per sample or family?
- Is there a mechanism available to subsidize indigent patients or patients with limited funds?
- Has the test been covered by insurance in the past and can the lab help with insurance filing?
- What costs are involved if additional family members decide later to cooperate with the study?
- Is there a volume discount?
- What are the costs to retest an uninformative family with new markers?

In Conclusion

When evaluating labs, all six components are essential ingredients in the equation. Genetic counselors will, however, choose laboratories based on their priorities and according to their patient population needs.

Two Resources Help Unlock Complicated Information

"Genetic Testing for Cystic Fibrosis: A Handbook for Professionals" was written by NSGC members as a result of a grant from Collaborative Research, Inc. The complexity of DNA testing is described for the health professional. The explanation supports the importance of genetic counselors in the system. Appendix A, a flow chart for carrier testing, is particularly helpful for individuals who only occasionally see CF patients. TIP: Appendix B, a checklist for laboratory arrangements, can easily be modified for use when ordering any DNA-based test.

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"Understanding DNA Testing: A Basic Guide for Families," was published in 1989 by the Southeastern Regional Genetics Group (SERGG), Genetic Counselor's Workshop. This booklet is designed for persons considering DNA testing in conjunction with genetic counseling. It thoroughly explains technology in a readable manner that, patients report, is easy to follow and helps them explain DNA testing to other family members, particularly those needed for family linkage analyses.

Copies of the booklet are available from: National Center for Education in Maternal and Child Health, 38th and R Street, NW, Washington, DC 20057.

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[1] Lebo, RV, et al. Defining DNA diagnostic tests appropriate for standard clinical care. *Am. J. Hum. Genet.* 47:583-590, 1990.

SUPPLEMENT TO PERSPECTIVES IN GENETIC COUNSELING

SURVEY OF CLINICAL DNA DIAGNOSTIC LABORATORIES

JANUARY, 1991

REPRINTED WITH PERMISSION BY
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COUNCIL OF REGIONAL NETWORKS OF GENETICS

This survey was conducted under the auspices of the Council of Regional Networks of Genetic Services (CORN). CORN makes no warranty and assumes no liability with respect to the information listed. There can be no assumptions made or implied that laboratories included are appropriately licensed (where required) or adhere to equivalent quality assurance standards. It is suggested that consumers contact the laboratories directly for further details.

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HEMA, HEMB

KEY TO DISEASE SYMBOLS FOR GENETIC DISORDERS
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MAYO
Stephen Thibodeau, Ph.D., Dept. Laboratory Medicine,
370 Hilton Bldg., Rochester, MN 55905; 507-284-9185;
FAX: 507-284-0043
AT, APK, BCR, BM, B, CF, DMD, FAM, FRAX, L, MEN 2a, PKU, T, Y, OTHER

OHIO STATE UNIVERSITY HOSPITAL
Thomas Prior, Ph.D., Arthur Burghes, Ph.D., North 305
Doan Hall, 410 W. 10th Avenue, Columbia, OH 43210
614-293-3987
DMD/BMD

THE UNIVERSITY OF CHICAGO
Carole Ober, Ph.D., Dept. Obstetrics & Gynecology, 5841
Maryland Avenue, Chicago, IL 60637; 312-702-0826
CF, SC

THE UNIVERSITY OF CHICAGO
Tim McKeithan, M.D., Ph.D., Dept. Pathology, 5841
Maryland Avenue, Chicago, IL 60637; 312-702-0937
B, BCR, BM, L, T

UNIVERSITY OF MINNESOTA
Harry Orr, Ph.D., Box 206, UMHC, Minneapolis, MN
55455; 612-625-3647; FAX: 612-626-7031
BM, CAH, CF, HD, NFI, Y

GPGSN

GREAT PLAINS GENETIC SERVICE NETWORK

CHILDREN'S MEDICAL CENTER
Nancy Carpenter, Ph.D., Fred Schaefer, Ph.D., Chapman
Institute of Medical Genetics, 5300 E. Skelly Drive, Tulsa,
OK 74135; 918-628-6363; FAX: 918-628-6322
APK, BANK, CF, DMD/BMD, FRAX, HD, HEMA, HEMB, MD, NFI, SC

WASHINGTON UNIVERSITY SCHOOL OF MEDICINE
Berengere de Martinville, M.D., Dept. Pediatrics,
Div. Medical Genetics, 400 S. Kingshighway, St. Louis,
MO 63110; 314-454-6093
CF, DMD/BMD

UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES
Gary Bannon, Ph.D., Genetic Services - Slot 512,
4301 West Markham, Little Rock, AR 72205-7199;
501-320-2966
CF, PAT, SC

MARHGN

MID ATLANTIC REGIONAL HUMAN GENETICS NETWORK

A.I. DUPONT INSTITUTE
Vicky Funanage, Ph.D., Musculoskeletal Inherited
Disease Research Department, P.O. Box 269,
Wilmington, DE 19899; 302-651-6814
BANK, DMD/BMD, MD

ALBERT EINSTEIN MEDICAL CENTER
Ellen Pfender, Ph.D., Molecular Genetics Laboratory,
313 Korman, York & Tabor Roads, Philadelphia, PA
19141; 215-456-6127
B, BANK, BCR, CF, DMD/BMD, FRAX, HEMA, HEMB, L, T, Y, OTHER

GENETICS AND IVF INSTITUTE
Anne Maddalena, Ph.D., 3020 Javier Rd., Fairfax, VA
22031; 703-698-7355
CF, FRAX, HEMA, HEMB, OTC, SC, OTHER

GEORGETOWN UNIVERSITY MEDICAL CENTER
Jan Blancato, Ph.D., Dept. OB/GYN, Div. Genetics,
3800 Reservoir Rd., NW, Washington, D.C. 20007;
202-687-8810
BM, PAT

HOSPITAL OF UNIVERSITY OF PENNSYLVANIA
Jeffrey Kant, M.D., Ph.D., Dept. Pathology and
Laboratory Medicine, 3400 Spruce Street, 7E-Gates,
Philadelphia, PA 19104; 215-662-6583 or 6121
CF, DMD, MD, NFI, OTHER

JOHNS HOPKINS HOSPITAL
Haig Kazazian, Jr., M.D., CMSC 10-110, 600 N. Wolfe
St., Baltimore, MD 21205; 301-955-0483;
FAX: 301-955-0484
AT, BT, CF, DMD/BMD, HD, HEMA, NFI, PKU, SC

MEDICAL CENTER OF DELAWARE
Digamber S. Borgaonkar, Ph.D., Cytogenetics Lab,
P.O. Box 6001, Newark, DE 19718; 302-733-3530;
FAX: 302-733-1365
BANK, BCR, BM, MD, OTHER

ROCHE DIAGNOSTIC GENETICS
Inder K. Gadi, Ph.D., Raj R. Bharathur, Ph.D., 69 First
Avenue , Raritan, NJ 08869; 1-800-631-5250, X2300
BCR, ONCO

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Mountain States
Mountain States Regional Genetics Services Network

Genetrix, Inc.
Avery A. Sandberg, M.D., D.Sc., 6401 East Thomas Rd., Scottsdale, AZ 85251; 602-945-4363; 800-333-4363
AAT, B, BANK, BCR, CF, DMD/BMD, ONCO, PAT, SC, T

The Children's Hospital
Vincent L. Wilson, Ph.D., Annette K. Taylor, Ph.D., Molecular Genetics/Oncology Laboratory, 1056 E. 19th Avenue, Denver, CO 80218-1088; 303-861-6440; 837-2725; 861-6340; FAX: 303-831-4112
BCR, FRAX, ONCO, RB

University of Colorado School of Medicine
William K. Seltzer, Ph.D., Dept. Pediatrics, UCHSC DNA Diagnostic Lab, C-233, 4200 East Ninth Avenue, Denver, CO 80262; 303-270-8415; FAX: 303-270-8080
CF, DMD/BMD, MD, SC

University of Utah
Kenneth Ward, M.D., DNA Diagnostic Laboratory, 517 Wintrobe Bldg., University of Utah Medical Center, Salt Lake City, UT 84132; 801-581-8334; FAX: 801-581-7199
APC, CAH, CF, HEMA, HEMB, MD, NFI, PAT, RB, TS, OTHER

Vivigen, Inc.
Kirk Aleck, M.D., Gail Kaplan, Ph.D., 2000 Vivigen Way, Santa Fe, NM 87505; 1-800-848-4436;
FAX: 505-438-1111
BANK, CF, SC, TS, OTHER

NERGG
New England Regional Genetics Group

Boston University School of Medicine
Jean Amos, Ph.D., Center for Human Genetics, NEB-605
80 East Concord Street, Boston, MA 02118;
617-638-7083; FAX: 617-638-7092
APK, CF, DMD/BMD, FAM, FRDA, HEMA, MD, MEN1, NFI, OTC, PAT, SC, XLPD, OTHER

The Children's Hospital
Bruce R. Korf, M.D., Ph.D., Clinical Genetics Laboratory
300 Longwood Avenue, Boston, MA 02115;
617-735-7582; FAX: 617-735-7588
DMD/BMD

Collaborative Research, Inc.
Jeffrey Sklar, M.D., Ph.D., Diagnostic Services Division, 1365 Main Street, Waltham, MA 02154; 617-894-5807; 800-356-4566; FAX: 617-891-5062
APK, B, BANK, BCR, BM, CF, L, PAT, T, Y

Dartmouth-Hitchcock Medical Center
Walter Noll, M.D., Dept. Pathology, Hanover, NH 03756; 603-646-7171
B, BCR, CF, DMD/BMD, L, MEN 2a, T

Integrated Genetics
Barbara Handelin, Ph.D., Genetic Reference Laboratory, One Mountain Road, Framingham, MA 01701; 800-255-7357, 508-872-8400 x2215
APK, AT, BT, CF, DMD, HD, HEMA, HEMB, PAT, SC, OTHER

Yale University
Allen Bale, M.D., Dept. Human Genetics, DNA Diagnostic Laboratory, WWW 318, New Haven, CT 06518; 203-785-5749
APK, DMD/BMD, HEMA, MEN 1, MEN 2a, OTC

PacNORG
Pacific Northwest Regional Genetics Network

University of Washington
Jonathan Tait, M.D., Ph.D., Genetics Laboratory, Dept. Laboratory Medicine, SB-10, Seattle, WA 98195; 206-543-7911; FAX: 206-548-6189
AT, CF, SC, HD

PSRGN
Pacific Southwest Regional Genetics Network

Cedars Sinai Medical Center
Julie Korenberg, M.D., Ph.D., Molecular Diagnostics Lab, Medical Genetics, Steven Spielberg Building, 8723 Alden Drive, Los Angeles, CA 90048;
213-855-6451 (office); 213-855-4984 (lab);
FAX: 213-967-0112
BCR, OTHER

Cedars Sinai Medical Center
Daniel H. Cohn, Ph.D., Div. Medical Genetics, Steven Spielberg Building, Room 364, 8723 Alden Drive, Los Angeles, CA 90048; 213-855-4986 (lab);
213-855-6451 (office); FAX: 213-967-0112
EDS, OI

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Cedars Sinai Medical Center
Nathan Fischel-Ghodsian, M.D., Dept. Pediatrics, 8700 Beverly Blvd., Los Angeles, CA 90048;
213-855-2732 (lab); 213-855-4423 (office)
AT, BT, SC

Children's Hospital/Los Angeles
Karen Jain, Ph.D., Dept. Medical Genetics, 4650 Sunset Blvd., Los Angeles, CA 90027; 213-660-2450 x2011;
FAX 213-666-0489
B, BCR, CF, DMD/BMD, L, NFI, PKU, T, Y, OTHER

Children's Hospital/Oakland
John P. Johnson, M.D., Elaine Louie, Ph.D., Div. Medical Genetics, Molecular Genetics Laboratory, 747 52nd Street, Oakland, CA 94609; 415-428-3550; FAX: 415-428-3608
CF, SC

Children's Hospital/San Diego
Bradley Popovich, Ph.D., Dept. Molecular Genetics, 8001 Frost Street, San Diego, CA 92123; 619-495-4911/4912
CF, DMD/BMD, PAT

Hawaii Thalassemia Testing Laboratory
Y. Edward Hsai, M.D., Medical Genetic Services, University Hawaii, Kapiolani Medical Center for Women and Children, 1319 Punahou Street, Honolulu, HI 96826;
808-956-6834; FAX: 808-956-6872
AT, BT

Nichols Institute
Frank Fujimura, Ph.D., 32961 Calle Perfecto, San Juan Capistrano, CA 92675; 800-642-4657 x269;
FAX:714-240-5381
AAT, B, BCR, CF, DMD, ONCO, SC, T, OTHER

UC Davis Diagnostic Laboratory
Raymond L. Teplitz, M.D., James Carlson, Ph.D., UCDMC, Dept. Pathology, 1621 Alhambra Plaza, Suite 2500, Sacramento, CA 95816; 916-734-3655 (office);
916-734-6609 (lab); FAX: 916-734-6666
BT, CF, SC

UC San Diego
Theodore Friedmann, M.D., Oliver W. Jones, M.D., Molecular Diagnostic Laboratory, Depts. Medicine and Pediatrics, Div. Medical Genetics, M-039, La Jolla, CA 92093-0639; 619-534-4307/1417; FAX: 619-534-7929
AT, CF, DMD, SC

UC San Francisco Medical Center
Roger V. Lebo, Ph.D., 533 Parnassus, U-255, San Francisco, CA 94143; 415-476-5481
AT, BT, DMD/BMD, HEMA, ND, SC, Y

UCLA Medical Center/School of Medicine
Wayne Grody, M.D., Ph,D., Richard A. Gatti, M.D., Diagnostic Molecular Pathology Lab, Divs. Medical Genetics and Molecular Pathology, AL-332B, Los Angeles, CA 90024; 213-206-5294(lab); 213-825-5648(office);
FAX: 213-206-5061
B, BCR, BM, CF, L, PAT, T, Y, OTHER

SERGG

Southeastern Regional Genetics Group

Greenwood Genetics Center
Jack Tarleton, Ph.D., Diagnostic DNA Laboratory,
1 Gregor Mendel Circle, Greenwood, SC 02646;
803-223-9411; FAX: 803-227-1614
DMD, FRAX, OTHER

University of Miami
Mark Rabin, Ph.D., School of Medicine, Dept. Pediatrics, Box 01682D, Miami, FL 33101; 305-548-4620
CF, OTHER

University of South Florida
O. Thomas Mueller, Ph.D., Dept. Pediatrics, 12901 Bruce B. Downs Blvd., Tampa, FL 33612; 813-974-2456;
974-3310; FAX: 813-974-4985
CAH, CF, DMD, FRAX, HD, HEMA, MD, RB, OTHER

University of Tennessee
Karla Matteson, Ph.D., Medical Center at Knoxville, Developmental and Genetic Center, 1924 Alcoa Highway, Knoxville, TN 37920; 615-544-9449; FAX: 615-544-8888
CF, DMD, FRAX, HEMA, HEMB

Vanderbilt University
Cindy L. Unencak-Jones, Ph.D., Div. Genetics, T2404 Medical Center North, Nashville, TN 37322; 615-322-7601
APK, CAH, CF, HEMA, HEMB, OTHER

TEXGENE

Texas Genetic Network

GeneScreen, Inc.
Sue Richards, Ph.D., Robert Giles, Ph.D., 2600 Stemmons Freeway, Suite 133, Dallas, TX 75207; 214-631-8152;
800-DNA-TEST; FAX: 214-634-3322
AAT, B, BANK, BCR, CF, DMD/BMD, FOR, L, PAT, SC, T, OTHER

Kleberg DNA Diagnostic Laboratory
Raymond Fenwick, Ph.D., Institute for Molecular Genetics, Baylor College of Medicine, One Baylor Plaza, Houston, TX 77030; 713-798-6536; FAX: 713-798-6584
AAT, APK, BM, CAH, CF, DMD/BMD, FOR, HEMA, HPRT, MD, ND, OTC, PAT, PKU, RB, SC, OTHER

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LEGISLATIVE BRIEFS

NEW PROGRAM TARGETS INFANT MORTALITY

A new initiative designed to reduce the U.S. infant mortality rate was recently announced by the Federal Department of Health and Human Services. The "Healthy Start" program would allocate $171 million in fiscal year 1992 for programs in 10 urban areas whose infant mortality rate is more than 50 per cent over the national average. In 1989, the national infant mortality rate was 9.7 per 1,000 live births. Funds will be awarded to communities that propose innovative approaches to reducing infant mortality (including access to early prenatal care, detering teenage pregnancy and increasing access to drug and alcohol treatment programs).

Although the goals of the Healthy Start initiative are universally praised, there has been substantial controversy over the proposed funding mechanism. Specifically, the Healthy Start program is slated to take $66 million from the Maternal and Child Block Grants and the Community and Migrant Health Centers. For genetic counselors, this means that while Healthy Start may increase access to genetic services in the 10 areas chosen for funding, it stands to limit services in unfunded areas, especially smaller and rural communities. Given the lack of priority genetic services have been given in the administration of the MCH Block grants, this could mean big cuts in genetic programs funded by Block grant monies.

What can you do? Due to the public outcry related to the funding of Healthy Start, the funding matter may be taken to Congress for vote. Therefore, if you live in an area that stands to lose dollars, let your Congressman know that while you are supportive of the goals of Healthy Start, you are unhappy with the funding scheme. This would be a good opportunity to point out how genetic services can reduce the infant mortality rate.

MEDICAID FAMILY CARE ACT REINTRODUCED

The Medicaid Family Care Act, initially introduced last summer (*PGC* V.12:3, p. 12) has been reintroduced into this session of Congress. This act would allow Medicaid dollars to pay for residential treatment of drug and alcohol dependent pregnant women, and women and their children for up to one year post-partum.

Currently, these services are excluded under Medicaid regulations. The bills call for a wide range of medical, social service and ancillary services to be provided to women and children served under this new initiative. If passed, the Act would provide for the first time, a stable funding base for recovery services targeted at pregnant and post-partum women and their children. In addition, this would be a real step forward in the prevention of alcohol and other drug related birth defects. Please write to your senator to support S.0029, introduced by Sen. Moynihan as the Medicaid Family Care Act of 1991. This Act calls for states to have the option to provide these services.

On the House of Representatives side, Rep. Durbin has introduced the Medicaid Substance Abuse Treatment Act of 1991 (H.R. 1189) which is stronger than the Senate version in that it calls for these services to be mandated to the states (states would be required to provide them instead of having an option). The NSGC has recently been asked by Rep. Durbin's office to support this bill. Contact your Congressman at the address below.

HOW TO CONTACT YOUR CONGRESSMAN

Rep ________________, c/o U.S.
House of Prepresentatives,
Washington, DC 20515.

HOW TO CONTACT YOUR SENATOR

Sen ________________, c/o
U.S. Senate, Washington, D.C.
20510.

NSGC AGAIN SUPPORTS AMICUS BRIEF

The ACLU has asked the NSGC to sign on to the Tennessee Supreme Court of Stowe v. Davis (*PGC* V. 12:4, p. 5). This case relates to the legal ownership of frozen embryos. Previous arguments for the case have involved the issue of whether "life begins at conception" and therefore raises issues related to reproductive freedom. The NSGC will be signing on in continuing support of reproductive freedom.

PHYSICIAN-BASED GENETICS COLLEGE TO BE FORMED

An *ad hoc* committee of the American Society of Human Genetics has recently concluded that there is a need for a new physician organization to advocate for clinical genetics services. Currently, medical (clinical) genetics is not a recognized medical subspecialty and, therefore, the field has not had representation among the established medical professional organizations, namely, the American Medical Association (AMA) and the American Board of Medical Specialties (ABMS). Both of these organizations require that delegate organizations are composed of physicians only.

In a recent mailing to the ASHG membership, the *ad hoc* committee expressed their unanimous decision to go ahead with the new College while acknowledging "support for a multidisciplinary approach to clinical genetics."

NSGC members who are also ASHG members are encouraged to respond to the call for a vote on this issue. As reported at the Fall membership meeting, the NSGC Board supports our physician colleagues as they go forward in this endeavor. Historically, allied health professionals have benefitted from the formation of professional organizations to represent physicians doing related work. The NSGC Board will be addressing our developing relationship to the new College. Please contact your regional representative or Ann C.M. Smith, the NSGC representative to the ASHG *ad hoc* committee, to express your opinion. **Trish Magyari**

BULLETIN BOARD

The Bottom Line: Billing by Phone for Genetic Services

Physicians may currently bill for telephone consultations by using CPT codes 98920 or 98921. Since many genetic counselors consult by telephone, particularly for teratogen questions, it may be beneficial for our membership to disseminate information about billing for telephone consultations. If you have successfully (or unsuccessfully) billed for telephone consultations, please contact me with the details c/o Genetic Counseling, Dept. Gynecology and Obstetrics, Stanford University Medical Center, Stanford, CA 94305; 415-723-5198.

Cindy Soliday

MoD Conference Announced

The 23rd Annual March of Dimes Clinical Genetics Conference, “Developmental and Genetic Disorders of the Central Nervous System,” has been scheduled for July 7 - 10 at the University of British Columbia, Vancouver, B.C.

For information about the submission of abstracts, due by April 15, or about registration, contact the March of Dimes, 1275 Mamaroneck Avenue, White Plains, NY 10605; 914-428-7100.

Carol Blagowidow
Project Coordinator

Regional Conferences Planned

Region IV in April: Region IV will hold its bi-annual education conference on April 3 - 4 in St. Louis, immediately preceding the GLaRGG conference. A partial list of topics includes: Ultrasound screening for chromosome abnormalities; Huntington disease presymptomatic testing; Genetic studies of major psychiatric disorders; Current issues in genetics training; Update on reproductive rights; and Paternity testing issues.

For more information, contact Regional Representative to Region IV, Laura Turlington, 314-454-7700.

Region III in July: Region III will convene on July 10. Information about the program and registration can be obtained by contacting Region III Representative, Stephanie Smith, 601-984-1900.

Lost and Found

We have lost touch with the following members in recent months.

name	last known address
Misha Angrist	Durham, NC
Catherine Biddle	Calgary, Can.
Beth Gazzola	Ontario, Can.
Sharon Pusso	Bethel Park, PA
Sheryl Schwabe	Ann Arbor, MI

Please call the Executive Office if you can help us find them.

Two Opportunities for Teratogen Education

- The Teratogen Information Services (TIS) conference will be held April 18 - 20 at the Holiday Inn at Chicago City Centre. Topics to be covered will include Reproductive hazards of occupational exposures and Mechanisms of teratogenicity.

For more information, contact Maureen Smith-Deichmann, c/o Illinois Teratogen Information Service, 312-908-7441 or Beth Conover, c/o Nebraska Teratogen Project, 402-559-5071.

- “Human Teratogens, Environmental Factors Which Cause Birth Defects” sponsored by the Massachusetts General Hospital, has been scheduled for April 29 - May 1 in Boston. For information and a program, call 617-432-1525.

I’d Rather Be Sailing...

Certification examinations offered by the American Board of Medical Genetics (ABMG) have been scheduled for June 1993. The deadline for applications is December 31, 1992. Information and application forms can be obtained by writing to ABMG, c/o 9650 Rockville Pike, Bethesda, MD 20814.

APHA to Convene in Atlanta

The American Public Health Association will hold its annual conference November 10 - 14 in Atlanta. The theme, “Public Health and a National Health Program,” will include: Public health issues and genetics; Manpower and reimbursement issues; Psychosocial issues, Birth defects registries/genetic epidemiology; Bioethics and The Human Genome Project; and Quality assurance and laboratory issues.

Karen Greendale
Genetic Services
Program Administrator

Code of Ethics Update

The Code of Ethics Committee has considered the responses to the draft that was disseminated to the entire membership last summer. The Code of Ethics document, now in the final revision stage, will be distributed to the full membership for a vote this summer. The final Code and a document reviewing adoption and implementation procedures will be included.

Judith Benkendorf

Human Genome Project Forum

A public forum on the Human Genome Project will be held on Monday, April 8 in Boston. This is the first of many public forums to be held around the country in which sponsors of the Project are seeking public comment on its implications. Topics to be covered are: a historical review of the Project; potential commercial and economic opportunities resulting from the research; the impact on genetic and medical counseling; and social, legal and ethical implications.

Robin J. R. Blatt,
Education Coordinator
Mass Genetics Program, DPH

To Do List: ICHG Registration

Be sure to not let your registration for the International Congress of Human Genetics slip to the bottom of your “To Do” list. Some important NSGC-related notes:

- Official hotel . . RamadaTechWorld
- Business dinner . . . . . Mon, Oct 7
- Board and committee meetings . . . . .Sun, Oct 6

The brochure marked “Third Announcement” is the only mailing for registration you will receive. Misplaced your copy? Call 301-530-7079.

And look for information about NSGC’s specially designed Genetic Counseling T-shirts in the next issue of *PGC.*

• BOOKLET •

Fragile X Syndrome: A Handbook for Families and Educators
Author: Brenda Finucane, M.S., Elwyn, Inc.
Reviewed by: Amy Cronister-Silverman, M.S., Fragile X Project, Denver, CO

As a resource person for the National Fragile X Foundation, I speak with families around the country who seek information which is easy to understand. There are several good booklets now available, but families frequently comment that they find the "Elwyn booklet" the most helpful.

Their reviews are appropriate. The book is well organized. Families are not overloaded with genetic terms and medical jargon. Instead, the booklet begins with three common scenarios: a son is newly diagnosed, a daughter with learning problems is found to have fragile X syndrome and a woman learns she is a carrier. With this introduction, families are given a frame of reference and are ready to tackle the facts.

In describing the fragile X syndrome, the booklet points out how normal looking fragile X individuals appear. This is nicely complemented by great photographs throughout the booklet. One improvement could be more pictures of younger children (parents have made similar comments), but the ones shown capture the social nature and personable side of these patients.

Mental impairment, macroorchidism, macrocephaly and the facial features are mentioned as part of the clinical characteristics of fragile X syndrome. In our clinic's experience, macrocephaly is not helpful in describing fragile X children, and this finding remains controversial among other researchers. Other features of fragile X individuals are well presented in a table format. A more detailed description of the behavioral characteristics would have been helpful, since these are often the only obvious clinical finding in the prepubertal child and since many parents view the behavioral aspects of the condition as one of the more important issues they face in dealing with their child's management.

The section on genetics is succinct and gives families the information they need. Importantly, families who have not yet met with a genetic counselor have found this section easy to comprehend. The illustrations are particularly helpful in guiding families through this section. For completeness, the topic of prenatal diagnosis, which was mentioned in the glossary, might have been added, since this is a common concern among families.

A highlight of this booklet is the sensitive discussion of the emotional impact of the diagnosis. Following this section are quotes from family members who describe their personal experiences. This is an excellent means of providing comfort to families who may feel isolated or wonder whether anyone truly understands their emotions.

Most of my comments have been directed toward the use of this booklet for families, since it is targeted to them. However, I do not wish to overlook the booklet's value to educators and health care professionals, since it provides concise and accurate information. My only concern is that the booklet lacks information about available treatment and intervention. Medical management, educational intervention and occupational and speech/language therapy are critical issues that professionals working with fragile X children need to understand.

In general, this is an excellent booklet. It is also available in Spanish! I would strongly recommend that you have this booklet available if you are counseling a fragile X family.

A complementary copy of *Fragile X Syndrome: A Handbook for Families and Educators* is available from Brenda Finucane, M.S., Genetic Services, Elwyn, Inc, Elwyn, PA 19063.

• AUDIO-VISUAL •

Diagnosis: The Emotional Impact
Produced by: Universal Health Associates, Inc. 1990
Length: 15 minutes
Cost: $95.00
Reviewed by: Kathleen Valverde, M.S., Cystic Fibrosis Center, St. Vincent's Hospital and Medical Center of New York

This videotape addresses the emotional impact of a diagnosis of a serious disorder on the family, using cystic fibrosis (CF) as the disease model. The narrator raises ten points to which health care providers must be sensitive when delivering bad news to a family. He reinforces each of these points by having different families and health care providers relay their experiences. This tape nicely depicts the variability of cystic fibrosis by contrasting the experience of a woman in her late thirties who was recently diagnosed with that of a young couple whose newborn baby was born with meconium illeus.

One of the best aspects of this videotape is the recognition of how an inherited disease affects both the individual who is diagnosed and the extended family. It emphasizes that the extended family can be included in the diagnostic process. The last few minutes of the videotape are devoted to interviews with members of the CF team. The physician stressed that at the time of diagnosis, families need reassurance and attentive health care providers who can answer their questions. Lastly, the importance of continually reinforcing all presented material was emphasized.

Although the videotape has the positive points discussed above, this resource had some deficiencies which do not permit it to stand alone. Although cystic fibrosis is used as the disease model, minimal information about this disease is presented. Viewers who are unfamiliar with cystic fibrosis would benefit from reviewing the literature.

continued on next page

Since CF is an inherited disease, some discussion about the availability of genetic counseling services for family members would have been a welcome addition. As an instructional tool, this videotape would be most useful when used in conjunction with a group discussion to illustrate how families react to bad news.

Genetic counselors, who are often called upon to deliver bad news, gain practical reinforcement but no new insights from this tape. This presentation would be extremely useful as an instructional tool for other health care providers who do not regularly deal with these issues.

• BOOK BAG •

The Fragile X Syndrome

Editor: Kay Davies
Publisher: Oxford U Press, 1989
(Walton St, Oxford, England
OX2 6DP)
Price: $27.50 pbk, 138 pp
Reviewed by: Brenda Finucane,
M.S., Elwyn, Inc., Elwyn, PA

The Fragile X Syndrome provides a current and comprehensive reference on this complex syndrome about which knowledge is still evolving. The book is divided into five chapters, each authored by a leading expert in the field. Jean-Pierre Fryns' section on X-linked mental retardation (XLMR) is extraordinarily comprehensive in its coverage of the fragile X phenotype and presents the disorder in the context of the other XLMR syndromes. This chapter is complemented by one on behavior and treatment, written by Randi Hagerman. Tessa Webb's chapter on epidemiology makes for difficult reading, but offers a useful and complete review of the myriad (and often conflicting) studies in prevalence and institutional screening. The final two chapters, by W. Ted Brown and Niels Tommerup respectively, are devoted to DNA studies and cytogenetics. Both of these sections also describe various hypotheses proposed to explain the unique inheritance pattern of the Fragile X syndrome.

All the chapters are well written in their own right. However, the authors' differing literary styles read more as a collection of unrelated papers than a truly unified text.

There is also some redundancy, and in a few instances, discrepancy among the authors. For example, Webb states that a third of XLMR is due to the fragile syndrome, while Fryns touts a 40 to 50% figure.

The main shortcoming of the book is its lack of cohesiveness, making it difficult to pinpoint a suitable audience. Most families and non-medical professionals will be hampered by the highly technical language and concepts throughout the book; one exception is Hagerman's very readable chapter on behavior and treatment. Clinicians will find the sections by Fryns and Hagerman valuable, but few non-geneticists require the depth of information detailed in the sections on DNA studies and cytogenetics. These chapters, and indeed the book itself, appear to be of most value to those genetic professionals actively involved in the diagnosis and genetic counseling of families with Fragile X syndrome.

• CROSS-CULTURAL • REFERENCE

Prenatal Tests

Published by: New England
Regional Genetics Group
(NERGG), P.O. Box 682
Gorham, Maine 05038-0682
Available in: English, Chinese,
French, Khmer (Cambodian),
Laotian, Portuguese, Spanish, and
Vietnamese
Reviewed by: Sylvia Mann, M.S.
Medical Genetic Services, Hawaii

Developing a patient booklet is one of the most difficult jobs for health care professionals. The information presented must overcome education and language barriers in order to be successful. That is why I was pleasantly surprised to receive copies of this patient booklet in seven languages in addition to English. I gave the copies to nurses and lay people for review.

Overall, the booklets met with approval. Everyone found the booklet easy to read and understand. However, the nurses responded that the information was too general and thought that it would be more beneficial when used in conjunction with a genetic consultation. The lay people thought that the information was easily understood, but many wanted more detailed information from a health care professional after reading the booklet.

The translated versions were well accepted. However, translation of prenatal genetic testing terminology was not always faithful. This is most likely due to the difficulty of translating words that are not found in some languages. However, the reviewers found that the general idea was still kept intact even if some terms were not quite accurate.

This is a good resource for couples who need basic information about prenatal genetic testing. The translated versions will definitely be a great help for those who work with speakers of other languages.

• ORGANIZATION •

EHLERS-DANLOS NATIONAL FOUNDATION

This organization was first created in 1985 to help provide support, information and medical referrals for patients who have Ehlers-Danlos Syndrome and their families. Current information is available through a quarterly newsletter, *Loose Connections.* The Foundation holds an annual education conference. A physician referral program is available to affected individuals through the Foundation's medical database.

For additional information or to be added as a patient referral source, contact: Nancy A. Rogowski, Executive Director, Ehlers-Danlos National Foundation, P.O. Box 1212, Southgate, MI 48195 (313) 282-0180.

• CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED • CLASSIFIED •

SACRAMENTO, CA: June 1 opening for BC/BE Genetic Counselor.
Responsibilities: Join active team serving large & diverse population; prog offers full array of PN & genrl genetic services. Active amnio/CVS program.
Contact: Mark Lipson, MD, Kaiser Permanente, 2025 Morse Ave, Sacramento, CA 95825; 916-978-1405. EOE/AA.

SAN DIEGO, CA: Immediate opening for BC/BE Genetic Counselor. Working knowledge of Spanish preferred.
Responsibilities: Oppty for independence in interdisciplinary setting with consults from UCSD & Childrens; counsel & coordinate PN svc; professional & community outreach/education; coordinate dysmorphology clinics; liaison to genetic clinics.
Contact: Barbara Dixson, RN, MN, Prevention Coordinator, San Diego Regional Center for Developmentally Disabled, 4355 Ruffin Rd, San Diego, CA 92123; 619-576-2961. EOE/AA.

SAN FRANCISCO, CA: July '91 opening for BC/BE Program Coordinator. Min 2 yrs experience, ability to work independently required; (multiethnic/ supervisory/ grant writing experience preferred).
Responsibilities: Supervise federally-funded Perinatal Genetics Program: outreach to multiethnic populations; oversee grant progress reports/proposals; implement behavioral studies; develop materials; teaching.
Contact: Ilana Mittman, MS, San Francisco General Hospital, 1001 Potrero Ave, Room 6D-23, San Francisco, CA 94110; 415-821-3133. EOE/AA.

TORRANCE, CA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Comprehensive program in academic setting: full range of PN services serving diverse ethnic/socioeconomic populations; oppty for participation in pediatric genetic clinic, hemoglobinopathy screening, inpatient consults; professional/community education.
Contact: Linda R. Burney, MA or Adam J. Jonas, MD, Harbor UCLA Medical Center, 1124 W. Carson St, Bldg E-4, Medical Genetics, Torrance, CA 90502; 213-533-3759. EOE/AA.

COLORADO SPRINGS, CO: Immediate opening for BC/BE Genetic Counselor. Experience preferred.
Responsibilities: PN dx; newborn, ped & adult genetic evals; MSAFP, community education; outreach.
Contact: Jane Congleton, MS, RN, Southern Colorado Perinatal Genetics Center, Memorial Hosp, 1400 E. Boulder St, Colorado Springs, CO 80909; 719-475-5960; EOE/AA

BOYNTON BEACH, FL: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join team in community hosp setting: amnio; CVS; teratogen counseling; general/post level II U'snd; oppty for ped counseling.
Contact: Lisa D'Augelli, MS, Bethesda Memorial Hosp, 2800 S. Seacrest Blvd, #104A, Boynton Beach, FL 33435; 407-738-0448. EOE/AA.

CHICAGO, IL: July 1 opening for BC/BE Genetic Counselor with PN experience.
Responsibilities: Join clinical research-oriented team in academic community; CVS, amnio coun; coordinate recurrent miscarriage clinic; assist in genetic diversity in CF pts study; outreach to patients & professionals.
Contact: Marion S. Verp, MD, University of Chicago, Dept. OB/GYN, 5841 S. Maryland, Box 446, Chicago, IL 60637; 312-702-6621. EOE/AA.

LEXINGTON, KY: Immediate opening for BC/BE Genetic Counselor. Potential for Faculty Position.
Responsibilities: Join active, expanding program: preconceptual & PN coun for MSAFP, amnio, teratology, malformation; prof/community outrch; some teaching.
Contact: Anjana Pettigrew, MD, University of Kentucky Medical School, Dept. Pathology, Lexington, KY 40536-0093; 606-257-4089. EOE/AA.

BOSTON, MA: Immediate opening for BC/BE Genetic Associate.
Responsibilities: Counsel for sickle cell and other hemoglobinopathies.
Contact: Mrs. Priscilla Blount, Executive Administrator, Boston Sickle Cell Center, 818 Harrison, FGH-2, Boston, MA 02118; 617-424-5727. EOE/AA.

WALTHAM, MA: Immediate opening for BC/BE Genetic Counselor. Full or part time negotiable.
Responsibilities: Join team in well-established PN & metabolic program affiliated with Harvard Medical School; oppty to establish community outreach/ education programs &/or genetic clinics.
Contact: Marvin Natowicz, MD, PhD, c/o Personnel Dept, Eunice Kennedy Shriver Center for Mental Retardation, Inc., 200 Trapelo Road, Waltham, MA 02254; 617-642-0175. EOE/AA.

ANN ARBOR, MI: Immediate opening for BC/BE Genetic Counselor with desire to bridge clinical & research in genetics.
Responsibilities: Join new Univ-based Human Genome Center (Dr. Francis Collins, P.I.) in Family Collection Core: identify, collect & counsel families critical to genome research.
Contact: Dorene Markel, MS, MHSA, U Michigan Human Genome Ctr, 2570A/ MSRBII, Ann Arbor, MI 48109-0674; 313-764-8056. EOE/AA.

DETROIT, MI: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Ped & PN coun: amnio, CVS, dx U'snd; opportunity for newborn scrng, outreach & education.
Contact: Lester Weiss, MD, Henry Ford Hosp, Medical Genetics & Birth Defects Ctr, 2799 West Grand Blvd, CFP-4, Detroit, MI 48202; 313-876-3188. EOE/AA.

EAST LANSING, MI: May 1991 opening for BC/BE Genetic Counselor. Large MSAFP scrng program experience desired.
Responsibilities: Coord & coun in large PN program: interface between physicians & PN program; coordinate public education & outreach; organize production of prof/pt materials; coord research projects; assist with grantwriting.
Contact: Janice Bach, MS, Michigan State University, B240 Life Sciences Bldg, Pediatrics, East Lansing, MI 48824; 517-355-3352. EOE/AA.

PROVIDENCE, RI: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join team in position offering wide range of respon: assist in coordination of MSAFP, birth defects, dysmorph, teratogen, pre/post amnio coun; prof/community education.
Contact: Krista Sauvageau, Employment Manager, Women & Infants Hospital , 101 Dudley St, Providence, RI 02905; 401-274-1100. EOE/AA.

FAIRFAX, VA: Immediate opening for BC/BE Genetic Counselor.
Responsibilities: Join estab PN genetics program offering amnio, CVS, growing ped/adult genetics referrals: counsel PN & pediatric patients; implement genetic svcs in public health setting; professional and community education; partic in clinical research.
Contact: Shirley L. Jones, RN, MS, Genetics & IVF Institute, 3020 Javier Rd, Fairfax, VA 22031; 703-698-7355.

RICHMOND, VA: Immediate opening for BC/BE Genetic Counselor/Fetal Anomalies Coordinator. Experience required.
Responsibilities: Join large, comprehensive team to coordinate overall PN mgmt: fetal dx/therapeutic svcs; prof /commun education; research; assist in devel protocols for practitioner/ pt concerns; coordinate conferences.
Contact: Dr. Joann Bodurtha, Dept. Human Genetics, Medical College of VA, VA Commonwealth University, Box 33, MCV Station, Richmond, VA 23298-0033; 804-786-9632; EOE/AA.

National Society of
Genetic Counselors, Inc.
Executive Office
233 Canterbury Drive
Wallingford, PA 19086

ORGANIZATION MEETS SPECIAL NEEDS FOR NURSES

Many counselors are members of teams that also include nurses. Please share this page (or issue) to encourage their involvement in a national organization which will enhance the genetic component of their practice.

The International Society of Nurses in Genetics (ISONG) provides nurses practicing in genetics with a forum to foster scientific and professional growth. The major goal of the Society is to promote the professional interests of nurses in genetics and to facilitate communication among colleagues. To that end, specific goals include:

- providing a forum for the integration of the nursing process into genetic services
- encouraging faculties to incorporate human genetics curricula into nursing education at all levels
- promoting the development of standards for clinical nurse practice in genetics
- advancing nursing research in genetics and genetic counseling
- providing a mechanism for continuing education
- providing a structure for networking among nurses and their colleagues in the genetics and nursing communities.

ISONG began as discussion groups among nurses who were providing genetic services and counseling as part of their clinical practice. At the annual March of Dimes Birth Defects meetings and American Society of Human Genetics meetings, we began to meet each other and recognized our growing numbers. We shared our experiences, frustrations, needs and goals and recognized the uniqueness of our group. Under the guidance and efforts of such members as Elizabeth Thompson, Janet Williams, Lynette Wright and Shirley Jones, the “Genetics Nurse Network” was developed.

With growing interest among supporters of the Network, a task force was charged to formalize the group’s activities. Inclusion of the work “International” reflected the diverse and potential global makeup of the group as it became the International Society of Nurses in Genetics in 1988.

ISONG now has 70 paid members, a diverse group of nurses who practice in a variety of settings. Of those members responding to the recent ISONG membership survey (N=48), over 40% had been in the field of genetics 10 or more years. More than 50% stated that their practice was focused specifically in genetics, with the majority practicing in either hospitals or clinical settings. Over half have completed certification in either genetics (AMBG certified) or other nursing specialities, or both.

Members have the opportunity to network through the ISONG newsletter which is published twice a year. Additionally, ISONG sponsors an annual educational meeting, usually held in conjunction with the National Society of Genetic Counselors and the American Society of Human Genetics meeting in the fall. We have interacted with our NSGC colleagues in joint platform sessions and poster presentations during the educational meetings. We are planning to hold our annual 1991 meeting on October 5 and 6, just prior to the International Congress of Human Genetics.

Anne L. Matthews, R.N., Ph.D.
President,
ISONG