PERSPECTIVE S in genetic counseling

Volume 15:1 Spring 1993

Will We Be Reimbursed?

by Vickie Venne, MS with Andrew Faucett, MS, and Karen Copeland, MS

■ Most genetic counselors went to school anticipating that they would spend most of their clinical energies answering questions about genetics. So why do many counselors spend much of their time answering billing questions? Some of the answer lies in the unique nature of genetics, but the rest is contained in the global problems of our health care financial system. That system is changing. Can we become part of the solution, or will others make the decisions for us?

O ur US health care system is in trouble. While our money can buy some of the best medical technology in the world, the costs are rising. Approximately 36 million Americans, mostly employees and their families, have no coverage. As a result, some people neglect routine office visits, and end up in emergency rooms when their conditions become urgent. Despite all the money and continued on p. 8

ABGC Incorporates

The American Board of Genetic Counseling (ABGC) was officially incorporated in the State of New York on February 17, 1993. By-laws have been adopted by the ABGC Board of Directors and a document delineating terms of separation from the American Board of Medical Genetics (ABMG) is almost ready to be signed by representatives of both Boards. When the separation is final, current genetic counseling diplomates of ABMG will be sent a copy of the by-laws and invited to become charter members of ABGC. A nominating committee from the ABGC membership will then propose candidates for an election to fill a vacancy on the Board and replace the two founding Board members who rotate off at the end of 1993. The current ABGC Board and officers are: Ann Walker, President, Diane Baker, Vice-President, Ann CM Smith, Treasurer, Joan Scott, Secretary, Debra Collins, Ed Kloza and Beth Fine.

All applications received for the 1993 examination in Genetic Counseling, which was written by ABMG, are being reviewed by *it's* credentials committee. ABGC, however, will establish pass/fail criteria following the examination and will confer certification. Rules and regulations concerning eligibility for subsequent examinations and for accreditation of training sites and programs will be established by ABGC. In developing standards for accreditation, ABGC hopes to sponsor a conference to solicit input from a wide variety of individuals with interest in the training of genetic counselors or expertise in accreditation.

The Board appreciates your many letters and calls offering support or expressing concerns. Be assured that we will do our best to respond as soon as the immediate issues surrounding the Board's formation have been navigated.

national society of genetic counselors, inc.

nsgc

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

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NSGC gratefully acknowledges Integrated Genetics for a grant in support of this newsletter.

Committed to providing highest quality DNA-based, cytogenetic and prenatal biochemistry testing, service and education.

FAMILIAL ALS LINKED TO DEFECTS IN SUPEROXIDE DISMUTASE GENE

BACKGROUND

Amyotrophic lateral sclerosis (ALS) is a degenerative disorder of the motor neurons in the cortex, brainstem and spinal cord. The prevalence has been estimated to be approximately 1:16,000 with about 5000 new cases diagnosed annually.

The mean age of onset is about 50 years. The disease causes generalized and progressive wasting of the skeletal muscles and it is uniformly fatal, typically within five years. Confirmation of a diagnosis of ALS has depended on neurological examination, an electromyogram and a muscle biopsy. Currently, there is no treatment to prevent or alter its unremitting course.

GENETICS

About 10% of cases are inherited as an autosomal dominant trait with high penetrance after the sixth decade. In most instances, sporadic and autosomal dominant familial ALS (FALS) are clinically similar.

In approximately 2/3 of FALS pedigrees, the disease is linked to a genetic defect on chromosome 21q. The March 4 issue of *Nature* reports tight genetic linkage between FALS and a gene that encodes the enzyme superoxide dismutase (SOD 1), a cytosol enzyme that catalyzes the conversion of the toxic superoxide radicals to hydrogen peroxide plus dioxygen.

In a subset of FALS families, the studies identified 11 different SOD 1 missense mutations in 13 different FALS families, suggesting that SOD 1 is a candidate gene in FALS, but a causative role has not yet been proven.

GENETIC TESTING

Strictly on an experimental basis, DNA analysis of the

known mutations in SOD 1 can be offered to the following patients at this time:

- *affected* individuals with FALS
- *affected* individuals with sporadic ALS.

It is important to counsel patients on the limitations of the current analysis. Only screening for the known mutations in 2:5 exons of the gene are possible.

The aims of the research are to extend the analysis of SOD 1 mutations, to ascertain whether sporadic ALS and FALS are due to mutations in the same gene and to gain insight from the molecular studies on the pathenogenesis of ALS. Potential therapies are under investigation.

SPECIMEN HANDLING

Send 3-4 Acid-Dextrose
Citrate (ACD) tubes (20-30cc) at
room temperature by overnight
mail, along with a pedigree,
clinical diagnosis and informed
consent to: Diane McKennaYasek, Day Neuromuscular
Research Laboratory, Mass.
General Hospital, Rm 6627,
MGH-East, Bldg 149, 13th St,
Charleston MA 02129. Call
617-726-5750 for collection kits
or for inclusion on a mailing list
for ongoing research. ■

Donna Russo, MS Presbyterian Hospital New York City, NY

- Rosen, DR, et al. Mutations in Cu/Zn superoxide dismutase gene are associated with familial amyotrophic lateral sclerosis. *Nature* 362:59-62 (1993).
- 2. Siddique, T, et al. NEJM 324,1381-1384 (1991).

MEETING MANAGER

April 16 - 18 "Joining Together, Journeying Forward," Natl Tay-Sachs and Allied Diseases Association, New Orleans LA. Contact: NTSAD, 617-277-4463.



- April 18 20 "Human Teratogens," Harvard Medical School, Boston MA. Contact: Dept. Continuing Education, 617-432-1525.
- April 19 24 "Fifty Years of Bringing it All Together," Genetics Session, Thurs, Apr 22, American Cleft Palate-Craniofacial Association, Pittsburgh PA. Contact: N. Smythe, 412-481-1376.
- May 14 16 Genetics Board Review Course 1993. Houston TX. Contact: C Soroka, 713-798-6020.
- June 26 27 International Beckwith-Wiedemann Support Network Symposium for families and professionals. Keynote address by Dr. J. Bruce Beckwith, Ann Arbor MI. Contact: Susan Fettes, 313-973-0263.
- August 1 7 Short Course on Molecular Diagnostics, "Counseling and the Human Genome Project," sponsored by University of Michigan Human Genome Center Education Program, Ann Arbor MI. Contact: L. Hallett, 313-764-8050.

1992 Professional Status Survey, Part II Analysis of Trends in the Genetic Counseling Profession

by Wendy R. Uhlmann, MS, Professional Issues Chair

This article presents addi-I tional data from the statistical analysis of the 1992 National Society of Genetic Counselors' Professional Status Survey. The survey has been administered approximately every two years since 1980 to evaluate our professional roles and compensation. Of the 769 surveys mailed to full members of NSGC in February 1992, 537 (69.8%) were returned and 45 (8.4%) were excluded from the analysis. In the statistical analysis, the totals vary since some respondents did not answer all questions in the survey.

Detailed information regarding demographics, work setting, certification, faculty status, salaries, publications, teaching and professional activities of respondents was reported in *PGC* 14:2,7-10, Summer, 1992.

FINDING EMPLOYMENT

Table 1 shows how respondents first learned about their current positions. Respondents primarily used networking/self-initiated contacts and recommendations by genetic counselors to obtain a position. Respondents with less than four years of experience were more likely to have used the NSGC national job board, PGC and mailings from employers, while respondents with six or more years of experience were more likely to have relied on networking/selfinitiated contacts, recommendations from MD/PhDs and selfcreated positions.

WORK SETTING

There were significant salary differences in different work settings, with respondents working in health maintenance organizations and diagnostic laboratories having the highest average salaries (Table 2). When salaries were compared between respondents working in prenatal genetics and pediatric genetics, there were also significant differences (p<0.05). Respondents working in prenatal genetics had a mean salary of \$38,123 (SD=\$8722), while the mean salary of respondents working in pediatric genetics was \$35,122 (SD= \$6,617). The mean salary of respondents with positions that combined prenatal and pediatric genetics (\$38,122, SD= \$7,319) was similar to the mean salary of respondents working solely in prenatal genetics. Respondents with only clinical roles had the lowest average salaries (Table 3).

SALARY RANGES

Respondents were asked to indicate the salary ranges of genetic counselors at their institutions (Table 4). There were significant positive correlations between salary and number of patients per year, years in the field and years at current job. The high end of the salary range had the highest correlation with salary (R=0.560,p<0.001), indicating that respondents were closer to the high end of their salary

TABLE 1: METHODS OF FINDING EMPLOYME	ENT	
(Total=479)		
	N	Percent
Networking/Self-initiated Contacts	148	30.9 %
Recommendation by genetic counselor	65	13.6 %
Self-created position	49	10.2 %
Recommendation by MD/PhD	44	9.2 %
Mailing from employer/job agency	34	7.1 %
Perspectives in Genetic Counseling	29	6.1 %
NSGC Job Hotline	26	5.4 %
NSGC national meeting job board	22	4.6 %
NSGC regional meeting job board	1	0.2 %
Other	61	12.7 %

TABLE 2: SALARY BY PRIMARY WORK SETTING						
(Total=443)						
Health Maintenance Org	N 26	Mean \$43,159	SD \$7,568			
Diagnostic Laboratory	21	\$41,336	\$7,378			
Federal/State/County Office	19	\$39,822	\$9,694			
Outreach/Satellite/Field Clinic	5	\$38,304	\$9,947			
Private Hospital/Medical Facility	125	\$38,279	\$8,836			
University Medical Center	228	\$36,989	\$6,789			
Private Practice	9	\$36,729	\$5,930			
Other	10	\$36,471	\$4,798			
(p<0.004)						

range than the low end. Respondents whose salaries were not grant dependent earned slightly more than respondents who were paid from grants (Table 5).

FACULTY STATUS

The analysis indicated that faculty status did not significantly affect salaries; respondents with faculty status had about the same average salary as non-faculty (Table 6). Job satisfaction for faculty and non-faculty respondents was similar (Table 7). Coordinators and directors were not more likely to have faculty status.

ABMG CERTIFICATION

The results indicated that although benefits from ABMG certification are improving over time, only a small proportion of respondents are receiving increased compensation or professional advancement following certification (Table 8). Of the 330 respondents who indicated that they are ABMG certified, 54 (16.4%) received a raise in salary, 18 (5.5%) received a promotion and 8 (2.4%) achieved faculty status.

GENDER DIFFERENCES

In an evaluation of salary by gender, male genetic counselors were found to earn slightly more than female respondents (Table 9). The interpretation of this data is limited since the salary information only reflects twenty-four male respondents. There was no significant difference in average years of experience between male and female respondents (p>0.30): females (6.6 years, SD=4.9); males (7.7 years, SD=5.6). The difference in salaries is most likely due to differences in job classifications. A higher

proportion of male respondents were classified as directors/ administrators/ coordinators; these positions have higher average salaries (Tables 10, 11). Job classifications correlated with years of experience (Table 12). To fully evaluate gender differences in salary, an analysis of male and female respondents by job classification and years of experience would need to be performed; however, the

sample size was too small to conduct this analysis.

Publications, Teaching, Professional Activities

Publications, teaching and professional activities were compared between faculty and non-faculty respondents, and ABMG certified versus ABMG eligible respondents (Table 13). A further breakdown of publications is presented in Table 14. Respondents with faculty status

TABLE 3: SALARY BY PRIMARY ROLE					
(Total=449)					
	N	Mean	SD		
Coordinator/Administration	25	\$44,237	\$12,151		
Teaching/Educational Activities	3	\$42,824	\$2,752		
Research	9	\$42,707	\$9,171		
Customer Liaison/Business/Mktg	5	\$41,877	\$5,754		
Clinical and Teaching	25	\$39,612	\$8,757		
Clinical and Coordination/Admin	114	\$39,326	\$6,754		
Clinical	257	\$36,527	\$7,521		
Other	11	\$38,629	\$7,014		
(p<0.0001)					

TABLE 4:	SALARY	RANGES	5		
	N	Mean	SD	Min	Max
Low End	259	\$30,437	\$4,637	\$18,000	\$45,000
High End	242	\$42,376	\$6,590	\$25,000	\$60,000

TABLE 5: SALARIES DEPENDENT ON GRANT SUPPORT				
(Total=448)				
	N	Mean		
Yes, completely	48	\$37,030		
Yes, partially	105	\$36,595		
No	288	\$38,860		
Other	7	\$38,756		
(p<0.06)				

TABLE 6: SALARY BY						
FACULTY S	FACULTY STATUS					
(Total=435)						
	N	Mean	SD			
Faculty	109	\$39,130	\$7,941			
Non-faculty 326 \$37,720 \$8,052 (p>0.10)						

Table 7: Job Satisfaction					
AND FACULTY	AND FACULTY STATUS				
Faculty Non-					
faculty					
Very satisfied	28%	21%			
Satisfied	61%	66%			
Dissatisfied	11%	13%			

were significantly more likely to have published and been involved with teaching/ clinical rotations than nonfaculty respondents. There was a marginally significant association between faculty status and guest lecturing and no association between faculty status and professional activities. Respondents with ABMG certification were significantly more likely to have published, given guest lectures and been involved in professional activities. The

TABLE 8: BENEFITS FROM ABMG CERTIFICATION (Total=330)					
		Year member	r became certifi	ed	
	81	84	87	90	
(N=70)	(N=66)	(N=100)	(N=94)	
Raise in salary	11%	12%	16%	23%	
Promotion	3%	5%	5%	9%	
Faculty Status	4%	0%	3%	2%	

Table 9: Salaries						
BY GENDER						
(Total=44	4)					
	N	Mean	SD			
Females	420	\$37,886	\$7,632			
Males	24	\$40,713	\$9,153			
(p<0.08)						

Table 10: Job					
CLASSIFICATION AND GENDER					
Males					
24%					
20%					
48%					

TABLE 11: SALARIES BY JOB CLASSIFICATION (Total=449)						
Job Classification	N	Mean	SD			
Director	29	\$46,359	\$12,308			
Genetic Counselor Coordinator	55	\$41,092	\$7,491			
Clinical Coordinator	10	\$34,480	\$3,969			
Genetic Counselor/ Genetic Associate	294	\$36,412	\$6,718			
Genetic Nurse Counselor/						
Nurse Geneticist	7	\$41,958	\$12,598			
Research Assistant/Associate	9	\$36,600	\$7,701			
Other (p<0.0001)	45	\$40,816	\$7,829			

TABLE 12: JOB CLASSIFICATIONS	AND YEARS OF	EXPERIENCE
(Total=388)		
	N	Mean
Director/Administrator	27	11.47 years
GC Coordinator	57	8.36 years
Clinical Coordinator	10	5.58 years
Genetic Counselor/Associates	294	5.47 years
		·

differences between certified and eligible respondents can be accounted for because the majority of the eligible respondents (55%) were recent graduates.

JOB SATISFACTION

Respondents with more years of experience were significantly more likely to be satisfied with their jobs (Table 15). There was no significant correlation between years of experience and the decision to leave the field of genetic counseling (p<0.10). Respondents who considered leaving the field of genetic counseling were more likely to be dissatisfied with their jobs (Table 16).

SALARY SATISFACTION

Approximately 40% of respondents indicated that they were dissatisfied with their salaries. Approximately 70% of respondents were dissatisfied with their opportunities for advancement and earning potential. For those respondents who indicated that they are considering leaving the field of genetic counseling, these two areas of dissatisfaction were the prime reasons cited. In response to a question regarding whether any attempts had been made to increase salaries, 148 (30.9%) respondents had not made any attempts. Of the 331 (69.1%) respondents who made attempts to increase their salaries, 136 (41.1%) were successful, 131 (39.6%) were partially successful and 64 (19.3%) were unsuccessful. The data suggests that for those genetic counselors who asked for a salary increase, 80% of the time they were either successful or partially successful. In order to effect salary changes on a national level, as individual genetic counselors, we need to take the first step.

5

SURVEY COSTS AND FUTURE DIRECTIONS

The cost of the 1992 NSGC Professional Status Survey was approximately \$3000: data entry and analysis, \$2100; copying and postage, \$893. The data entry and analysis took 190 hours and was performed by Sharon Reilly, PhD and Diana DeVries, MA.

Many hours were also spent

by the Professional Issues Committee in developing and writing the survey. While conducting the Professional Status Survey involves a significant time and financial commitment of NSGC, the information gained from this survey is instrumental for tracking our professional roles and compensation. The survey results also have been utilized by genetic counselors in job negotiations. 230 (47%) respondents indicated that information from previous surveys has been used to negotiate salary increases.

Other respondents indicated that the information has been used to obtain faculty status and coverage of fees for the ABMG certification exam. The NSGC Professional Status Survey will next be administered in 1994. Steps are being taken to develop a survey that can be used long-term and to establish a computer database for longitudinal analysis.

Please contact the Chair of the Professional Issues Committee if you have questions to suggest for future surveys, computer skills or energy to lend to this endeavor.

TABLE 13: PUBLICATIONS, TEACHING AND PROFESSIONAL ACTIVITIES

	Faculty	Non-	ABMG	ABMG
	•	faculty	Certified	Eligible
Publications	82 %	60 %	71%	55%
Teaching/rotations	94 %	80 %	83%	80%
Guest lectures	83 %	74 %	81%	63%
Professional activities	90 %	85 %	90%	76%

TABLE 14: PUBLICATIONS AND FACULTY STATUS

	Percent Publishing	
Publications	Faculty	Non-faculty
Abstracts or articles on case reports	42%	24%
Abstracts or articles on original research	36%	20%
Platform presentation/poster/workshop	42%	25%
Brochures/Pamphlets/Videos	34%	25%
Chapters in books	19%	4%
Books	3%	1%

Table 15: Job Satisfaction and Years of Experience (Total=442)

(1otal=442)		
	Percent	Avg length exp
Very Satisfied	23 %	7.8 years
Satisfied	64 %	6.5 years
Dissatisfied	13 %	5.9 years
(p < 0.05)		

TABLE 16: JOB SATISFACTION AND CONSIDERATION OF LEAVING THE FIELD OF GENETIC COUNSELING

	Considering Leaving the Field		
	Yes	No	Undecided
Job Satisfaction	<u>(64)</u>	(323)	<u>(91)</u>
Very Satisfied	16%	27%	13%
Satisfied	51%	66%	62%
Dissatisfied	33%	7%	25%

ACKNOWLEDGEMENTS

I would like to acknowledge the comprehensive statistical analysis that was performed by Diana DeVries, MA and Sharon Reilly, PhD. I would also like to acknowledge the work of the Professional Issues Committee in preparing the survey: Beth Balkite, Robin Bennett, Janice Berliner, Kathy Boland, Ann Boldt, Barbara Briscoe, Stephanie Brown, Lisa Carpenter, Diana Chambers, Leslie Ciarleglio, Debra Doyle, Janice Edwards, Mary-Frances Garber, Robin Gold, Cheryl Harper, Priscilla Harris, Jacqueline Hecht, Valerie Jansen, Golnaz Kavianian, Kathy Keenan, Lucinda Malin, Diana Punales-Morejon, Robin Schwartz, Elaine Sugarman. Diane Baker, Barbara Bowles Biesecker, Debra Collins, Beth Fine, Betsy Gettig, Ed Kloza, Bea Leopold, Linda Lustig, Linda Nicholson, Joan Scott and Vickie Venne reviewed the survey and provided helpful comments. ■

NATIONAL ON-LINE DATABASE FOR GENETIC EDUCATIONAL MATERIALS

■ The concept of an on-line easy-to-access database of genetic materials for patients (support groups, newsletters, brochures, fact sheets) may seem like an unobtainable dream. However, this task is being actively pursued on a national level, and NSGC is involved in making this database a reality.

The Patient Literature Subcommittee of the Education Committee was formed initially to investigate the feasibility of developing a patient materials database within NSGC. After we realized the enormity of that task, we turned to the possibility of collaboration and learned that the CORN Education Committee was working on a similar project.

FACT FINDING CONFERENCE

CORN sponsored a one-day working conference last fall in Maryland to explore establishing a genetic materials database. Representatives from 17 organizations attended. Subcommitee Co-chair Jannell Sloan represented NSGC.

Virginia Proud, MD, CORN Education Committee, chaired the meeting and is spearheading the effort to obtain funds for the database project.

The conference goal was to consider ideas for implementing a national, collaborative, bibliographic database of genetic education resources. Issues raised were:

- The breadth of the database for not only genetic disease related information, but for basic human genetic information, will target a large, diverse population.
- The need to identify existing regional databases of genetic materials; these databases may choose to be included within a national database which could be easily accessed by professionals and consumers.
- Appropriate review of genetic materials for quality will involve educator and provider organizations.

LOOK TO THE FUTURE

Patient Literature Subcommittee future goals include:

- Identifying and selecting appropriate tools for reviewing genetic materials,
- Identifying genetic materials currently used by NSGC members and reviewing them for content, quality and

readability, and

• Identifying underserved areas for which new materials might be developed.

LOOK IN YOUR DATABASE

NSGC's current role in this project is to identify all existing databases of materials being used by genetic counselors. This project could ultimately result in an efficient, userfriendly, up-to-date and comprehensive collection of patient materials.

In the future, we will be polling the membership to identify "experts" in specific diseases who would be willing to review materials. ■

by Barbara Pettersen, MS and Jannell Sloan, MS, Co-chairs, Patient Literature Subcommittee

YOU CAN HELP!

Please complete the enclosed postcard so we may report a list of databases which is as complete as possible.

HGP UPDATE

NEW NCHGR APPOINTMENT

Francis Collins, MD, PhD, has been asked to head the Human Genome Project. Once he has accepted, he plans to relocate his research laboratory to National Institutes of Health in Bethesda.

Dr. Collins is currently a professor of internal medicine and human genetics at University of Michigan in Ann Arbor. In addition, Dr. Collins is a Howard Hughes Medical Institute Investigator. He has been instrumental in molecular research in the breakthrough research in finding both the cystic fibrosis and neurofibromatosis genes.

In his new position, Dr. Collins will coordinate the research of the various genome centers and hopes to add the component of an intramural program to the project. Given Dr. Collins' proven track record of support for genetic counselors, we can anticipate additional involvement of the genetic counseling profession in the Human Genome Project. ■

JoAnn Inserra, MS

LEGISLATIVE BRIEFS

The US Supreme Court has refused to hear arguments on both Louisiana's and Guam's restrictive abortion legislation. This suggests that the Court is willing to allow states to *limit* access but not outlaw abortion. In other action, Attorney General Janet Reno has requested legistation to protect women entering abortion clinics. Both the Senate and House have responded with bills making it a federal crime to attack medical personnel or property, thus allowing the US to bring civil suits to obtain injunctions against such conduct. ■

COMMITTEES AT WORK

SOCIAL ISSUES: THE COMMITTEE OF VOICE, OPINION AND ACTION

The Social Issues Committee is primarily responsible for advocating for our patients' needs, identifying issues that affect our patients, defining resolutions and position statements and communicating information to the membership. Currently, a resolution regarding cystic fibrosis screening is being drafted and will be put before the Full membership for a vote.

NEW SUBCOMMITTEE TO FOCUS ON GENETIC RESEARCH

We are also involved in promoting responsibility in genetic

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc. Editorial Staff:

- Editor-in-Chief
 Vickie Venne, Nichols Institute, 33608 Ortega, San Juan Capistrano CA 92690; 800-642-4657; FAX# 714-728-4979
- Karen Copeland, Central Texas Genetics, Austin TX
- Richard Dineen, Univ Illinois School Medicine, Peoria IL
- Andrew Faucett, Memorial Medical Center, Savannah GA
- Susan Jones, Childrens Hospital of Philadelphia, Philadelphia PA
- Seth Marcus, Lutheran General Hospital, Park Ridge IL
- Kathryn Steinhaus, Univ California Irvine Medical Center, Orange CA
- Executive Director
 Bea Leopold
 NSGC Executive Office, 233 Canterbury Drive, Wallingford PA 19086;
 215-872-7608; FAX# 215-872-1192

Send articles, reviews, correspondence to the Editor-in-Chief; address changes, subscription inquiries, advertisements and classifieds to the Executive Director. Contact any member of the Editorial Board with ideas or suggestions.

Publication Date, Next Issue: June 15 Deadline for Submissions: May 10

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

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A special thank you to Liz Stierman whose creativity provided the new look of PGC.

research. Dorene Markel chairs the Genetic Research Issues subcommittee. Her subcommittee will generate policy statements regarding our patients' right to informed consent and ethical use of data. Specifically, this subcommittee is engaged in developing recommendations for the use and availability of prenatal and presymptomatic testing in adult onset disorders. In addition, they plan to develop a database collected by genetic counselors to provide information about chromosome translocation carriers, since many disease genes are localized using those individuals.

AEC FEATURES WORKSHOP

The Committee sponsors a workshop at each annual education conference. In concert with this year's theme, "The Technology Paradox: Facing the Challenges," the 1993 workshop will address difficult DNA diagnoses, a discussion of the implications of partially or non-informative cases.

PUBLIC POLICY INFLUENCE

The work of the Social Issues Committee allows us to influence public policy at the legislative or judicial level to ultimately benefit our patients. Laura Wozencraft, National Eye Institute, NIH, is our new legislative liaison, replacing the fine job of Trish Magyari.

Participation in this group requires a commitment to define your opinion, a voice to articulate it and the energy to support it. We must never assume that change is easy.

Vivian Weinblatt, MS, Chair, Social Issues Committee

Managed Care...

from p. 1

technology, the US now ranks 21st in infant mortality.

CURRENT FINANCES

Most employees obtain health insurance from their employers. Traditionally, people see the physician of their choice, and bills go to an insurance company or government program. Employers typically pay the bulk of the premiums, but employees are being asked to pay for a greater share, as well as deductibles and copayments. Increasingly, health plans limit the choice of physicians and are being more selective in what they do cover.

Under the current system, the most common reason for payment denial is ineligibility. Ineligibility occurs when a procedure is not approved, considered experimental or when a patient is not covered. Other reasons that payment is not rendered include having a test ordered by someone other than a physician, ordering a test deemed unnecessary, ordering a procedure at odds with the diagnosis and testing for a preexisting condition.

CURRENT MANAGED CARE

Health Maintenance Organizations (HMO) and Preferred Provider Organizations (PPO) are managed care arrangements under which discounted fees with networks of health care providers are negotiated in return for a certain volume and guaranteed payment. Managed care health plans currently in existence have common key features. They:

 arrange with selected providers to furnish a comprehensive set of health care services to members.

...What will be Your Role as a Genetic Counselor?

- set explicit standards for selecting health care providers.
- conduct formal programs for on-going quality assurance and utilization review.
- offer significant financial incentives for members to use providers and procedures associated with the plan.

These features will be important aspects of any future economic health plan.

PROPOSED MODEL

The term that is being used these days for the future of our health care is "managed competition," an economic plan conceived by Alain Enthoven of Stanford University. It is complex, involving governmental controls, competing health networks of hospitals and physicians and use of tax money to ensure that everyone has

minimum health insurance. The proposal calls for the formation of regional health plans composed of doctors, hospitals, other health services and insurers, functioning as HMOs. There might be several networks of providers in a region, or stronger governmental controls in a rural area which may only have limited providers. Each health plan would be required to offer an identical core package of services, competing on price and quality. Many discussions also include the extensive use of "health care assistants," non-physician health care providers who are traditionally less expensive.

IMPLICATIONS FOR GCS

The key to genetic counseling involvement in a new health care system would be to

define genetics as part of basic health care. This goal is probably achievable in obstetrics, where our role in conjunction with MSAFP screening and prenatal testing has become standard of care. Inclusion of pediatric and adult genetic services will require demonstration of direct patient benefits.

When managed care is promoted on the basis of cost control, the quality of care will emerge as a basis of competition. Currently, factors involved in establishing fees are quantifiable, such as admissions or lab test volume. The cognitive component of health care is more difficult to measure. Therefore, although it is an important part of selling the comprehensive package, it is often negotiated away, such that revenues for direct counseling are not realized. If benefits are standardized, genetic counseling could be excluded from basic health care.

It is essential to know costs not just time spent with the patient, but also time spent on telephone consults, pre and post research and writing.

The creation of quality assurance protocols will proactively position genetic counselors to offer consistent care in a cost efficient manner. Genetic counselors are beginning to evaluate quality assurance, and this will become important when requesting participation in managed care programs.

Change will happen. If we are prepared — with active participation to establish high quality guidelines — our profession stands a better chance of becoming a vital force in the new system. ■

Delivering Care: Have You Thought About...

Traditionally, screening for Down syndrome involved offering amniocentesis to women 35 years of age or older. Using that parameter, the prenatal detection rate of Down syndrome is 20%. Recently, Down syndrome screening has expanded to include those women with abnormal serum markers, such as AFP, HCG or uE3, with detection rates approaching 50%. As the detection rate for these markers improves, screening protocols may change such that no woman, regardless of age, receives an amniocentesis unless her screen is positive.

For those in the pediatric world, consider the initial genetic visit of a child with unusual features, mental retardation or growth delay. Laboratory testing often includes chromosome and metabolic studies. Even if testing has been previously performed, repeat tests are sometimes ordered rather than request or accept the previous studies. Are these studies ordered in the interest of the patient, the laboratory or the physician's finances? Could health care dollars be saved by a sequential testing protocol rather than a shotgun approach? The counselors may not be responsible for ordering, but what is their role as a team member?

Since genetic counselors may be responsible for communication of new protocols, space in PGC will be reserved for counselors to voice their thoughts about these topics. Please briefly write your thoughts, both pro and con, to be published in a future issue based on space availability. ■

HELIX: A NEW DIRECTORY

1 e have all acted out this scene. A patient seeks testing for Hemophilia A or perhaps a less common disorder like Wiskott-Aldrich. You vaguely remember reading or hearing that DNA markers are available ...but what labs run the test? Is the test available in more than one lab? How can labs be compared? Usually, word of mouth or departmental tradition determines where samples are sent. No doubt, somebody needs to computerize this information.

Finally, Dr. Bonnie Pagon of Seattle's Children's Hospital and Medical Center has spearheaded the development of Helix: A Directory of DNA Diagnostic Laboratories.

Funded by the NIH (through the National Library of Medicine's National Center for Biotechnology Information), Helix should be available in the next few months.

Maxine Covington is responsible for the day-to-day management of Helix at Seattle Children's Hospital.

Programmers from
the National Library of
Medicine have developed an
application (using FoxPro)
specifically for Helix. For now,
Maxine will obtain the requested information from the
database, and either fax or mail
the information to the users.
Plans call for the eventual addition of modem dial-ups so endusers can extract the information.

Laboratory participation is voluntary, and labs will be asked for updates at least every six months. For now, the listing will include lab name, address and phone number, contact person, list of DNA tests offered, CLIA and state licen-

sure numbers, information regarding enrollment in the Medicaid (Title XIX) program, and whether testing is available on a research

or clinical basis. There are currently no plans for laboratory evaluation. Initially, Helix will not contain biochemical or chromosomal testing information.

And the best news: Helix will be available at no charge to registered labs and users. Registration is open to anyone.

To register, contact Maxine Covington, c/o Helix, CH-94, Children's Hospital and Medical Center, PO Box 5371, Seattle WA 98105-0371; 206-528-2689; or FAX: 206-528-2687. ■

by Robert Resta, MS and Karen Wcislo, MS

STUDENT CORNER

A s president-elect, Betsy Gettig surveyed students to determine if NSGC could serve them better. One overwhelming response was an interest in being included in our newsletter.

Here is the new student column. Like many of the columns in our newsletter, it will have the flexibility to change and grow with time. However, we envision this new column will create several opportunities for both students and professionals.

We expect this column will list between six and ten students' theses or project topics per issue, as follows:

Name: Sandra Yang
Program: Howard University
Thesis: Factors involved in

Factors involved in participation in MSAFP Screening: Influence of knowledge of neural

tubal defects and Down syndrome

Phone: 301-460-8793 (pm)

Name: Laura Arabian
Program: UC, Irvine
Thesis: Segregation

distortion in retinoblastoma

Phone: 714-456-5838 (day) The column might also:

• Encourage immediate or fu-

ture contacts using this information as a resource for our profession. Since most counselors save *PGC*, they could refer to it several years later to identify a colleague who had worked on a particular topic.

- Spark ideas for other students or professionals to pursue.
- Make public current student research in genetic counseling, possibly attracting new individuals to our field.

We welcome your comments related to this new column. ■

Richard Dineen, MS Bonnie Hatten, MS

THE TECHNOLOGY PARADOX: FACING THE CHALLENGES

■ The plans are complete; the stage is set. All we need is YOU!

REGISTRATION INFORMATION:

Copies of the Information and Registration Brochures will be mailed on or about April 1 along with information about NSGC's first short course, "The ABCs of Cancer Genetics." *Plan ahead:* The deadline for registration without penalty is *August 1*.

PLENARY SESSIONS & WORKSHOPS:

Seven plenary sessions as well as nine workshops in three time slots have been scheduled to offer variety and flexibility to meet your professional educational needs. You can help by contributing the following:

- "When DNA Results aren't Simple," a workshop co-facilitated by Pat Ward and Vivian Weinblatt, and sponsored by the Social Issues Committee, is seeking summaries of cases with either partially informative, uninformative or ambiguous DNA results for consideration in small group discussions. Send cases to Vivian Weinblatt, Division of Genetics, Thomas Jefferson University Hospital, 1100 Walnut St, 400MOB, Philadelphia PA 19107.
- Jan C. Heller, whose address, "Information Overload and the 'New' Genetics," is seeking interesting ethical dilemmas for discussion. Cases or questions from the membership can cover the Human Genome Project, public policy issues, insurance denial or reimbursement problems. Send cases, questions or suggestions to Gail Goldberg, Mountain States Genetic Services, 4545 E. 9th Ave, #010, Denver CO 80220.

SPECIAL EVENT:

Snackin' Around Atlanta on the New Georgia Railroad promises to be an exciting experience for our annual evening out together. We'll journey on the New Georgia Railroad on an 18-mile loop around North Metro Atlanta while enjoying southern hospitality, delectible snacks and the company of our colleagues. Then, you can indulge yourself at the shops of the Under-Ground Atlanta and the sights of the new World of Coca-Cola Pavilion. Bus service to and from the Railroad will be provided.

ABSTRACTS:

Reminder: Deadline for receipt of abstracts is Thursday, April 15. Send to Daniel Riconda, c/o Fetal Diagnostic Center, Arnold Palmer Hospital, 92 W. Miller, Orlando FL 32806-2036. Fax copies will not be accepted.

VISIONING THE FUTURE



MEET JANET UNGER

The development of a vision and mission began our strategic planning process. To effect the next phase, NSGC has contracted the services of a consultant, Janet Unger, to conduct an indepth analysis of the strengths, weaknesses and opportunities facing NSGC and the profession into the 21st century. The purpose is to enable our Society to objectively set future goals and strategies. The process includes:

- Collecting information and opinions from the leadership and membership, using a membership survey, a conference call focus group and individual interviews with Board members and administrators of related genetics associations.
- Identifying and analyzing trends in the field of genetics.
- Addressing critical issues and strategic choices that may affect NSGC and the profession as we move toward our goals.

Ms. Unger has 14 years experience in not-for-profit board governance, strategic planning, chapter relations and volunteer development. She has published articles and taught professional courses at universities. Her familiarity with genetic counseling is quite ingrained...her sister is Genetic Counselor Rachel Unger Rando, formerly of Georgetown University Department of Pediatrics, who has recently relocated to Texas.

Look for a summary of Ms. Unger's findings in a future issue of *PGC*. ■

BULLETIN BOARD BULLETIN

CALL FOR MANUSCRIPTS

Coincidence or a result of the recent ABMG restructure? Either way, all of the AMA's family of journals will dedicate all or most of one of their fall '93 issues to genetics. A call for manuscripts has been issued with a deadline of May 1, 1993.

Many counselors have expressed concern regarding our role in the medical genetics health care team given the restructuring. This is our golden opportunity to accept a challenge and follow our vision of being the leading voice for the genetic counseling profession. See American Journal of Diseases in Children (*AJDC*), Vol. 147, Jan. 1993, page 12 for details.

CORRECTIONS

Chantelle Wolpert, who authored *Risk Management Considerations for Genetic Counselors, (PGC* 14:4), is from University Hospital of *Brooklyn,* not Buffalo. I apologize for the confusion and promise to take a geography lesson soon.

Vickie Venne

Several addresses on page 11 of "Now That You've Been Told...Your Baby has Down Syndrome" are incorrect. The resources should read: The ARC, 500 E. Border St, #S-300, Arlington TX 76010; National Down Syndrome Congress, 1800 Dempster St, Park Ridge, IL 60068; and National Down Syndrome Society, 666 Broadway, New York NY 10012. March of Dimes is correct.

Beverly Tenenholz

BOARD CHANGES

Linda Lustig, NSGC treasurer, has requested that beginning immediately all mail be forwarded to her home: 2223 McGee Avenue, Berkeley CA 94703-1631. As of April 12, she will assume a position at California Pacific Medical Center. Members needing to reach her on or after April 12, may contact her by phone at home, 510-548-5113, work 415-923-3046, or by FAX 415-923-3049.

Please revise your NSGC directory information to facilitate communication.

The Board of Directors is pleased to announce that Iill Stopfer, Albert Einstein Medical Center, Philadelphia, will become Region II Representative, effective April 1. Jill will replace Ann Boldt, who is moving to Indianapolis to assume a position in the Dept Medical and Molecular Genetics, Indiana University Medical School with Dr. David Weaver. In addition to assuming counseling responsibilities, she will also work with students in the Indiana University Genetic Counseling Program.

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New Publications

The Genetics of Alcoholism

Publisher: National Institute on Alcohol Abuse and Alcoholism (NIAAA)

Topic & Audience: Summary of research findings for health care professionals.

Contact: CSR, Inc., 1400 Eye St, NW, Suite 600, Washington DC 20005. No charge. (Indicate you are a genetic counselor and you learned about the publication in *PGC*.)

Health Insurance Resource Guide

Publisher: Alliance of Genetic Support Groups

Topic & Audience: Handbook providing basic understanding of US health insurance system for professionals and consumers. Fee: \$10.

Contact: March of Dimes, c/o Supply Dept, March of Dimes, 1275 Mammaroneck Ave, White Plains NY 10605.

Directory of National Genetic Voluntary Organizations and Related Resources

Publisher: Alliance of Genetic Support Groups

Topic & Audience: Links service providers and consumers with appropriate support organizations and agencies. Fee: \$10.

Contact: Alliance of Genetic Support Groups, 35 Wisconsin Cr, #400, Chevy Chase MD 20815-7015.

MARHGN Comprehensive Directory of Genetic Services Publisher: MARHGN

Topic & Audience: 150-page directory includes myriad of information about genetic services and genetic service providers in the 7-state MARHGN region. Fee: \$15.

Contact: MARHGN, B-29 Korman, Albert Einstein Medical Center, 5501 Old York Rd, Philadelphia, PA 19141-3098.

Annual Education Conference Manual: A Handbook for Planners

Publisher: NSGC along with Annual Education Conference Subcommittee

Topic & Audience: Planners of National and Regional NSGC Conferences. No Charge. Contact: Executive Office.

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Book

Anna: A Daughter's Life
Author: William Loizeaux
Publisher: Arcade Publishing,
New York, 1993
Price: \$19.95, 213 pp.
Reviewer: Judith L. Benkendorf,
MS, Georgetown Univ,
Washington DC

Anna Loizeaux, a loved and longed-for child, was born on January 21, 1989. She died unexpectedly on July 4th, at 5 months and 13 days. Anna had VATER syndrome. Although prior to Anna's arrival, her parents were aware of some of the challenges they would face, no professional nor their own collective life experience could prepare the Loizeauxs for the depth of their loss.

Anna's father, William Loizeaux, is a writer. Hence, in the emptiness after Anna's death, he drew upon the craft which comes most naturally to

Resources •

him to express and explore the depths of his grief.

Anna is his journal, a deeply moving and beautiful literary portrait of the year after his daughter's death. Loizeaux takes the reader through the darkness of sorrow, the moments of existential reflection so common to parents after the loss of a child and the dayto-day drudgery of simply carrying on, seen in measuring each word on the autopsy report and listing his number of dependents on IRS forms.

All of this is offset by memories of love, laughter and all that was so normal to Anna's short childhood. Walking through grief in a father's footsteps and seeing Anna's mother through his eyes adds an interesting element to the success of the book and may help other fathers touch their own pain.

As their genetic counselor, the book gave me insight into those dimensions of a family's



biography not revealed in our brief and focused encounters.

Anna is not a book about a genetic disease, living with VATER syndrome or perinatal bereavement. Rather, Anna provides a map of events in the early years of her parent's marriage, describes the house in which they all lived together and allows the reader to experience with the Loizeauxs all that happened from the time the door closed and Anna's Georgetown Hospital family stayed behind, to the time they returned to Anna's caregivers for a subsequent pregnancy. These visits to Anna's second home would later become an important birthday ritual for the couple which continues to ease their pain.

For genetic counselors in practice and training, Loizeaux has opened a window into the invisible world parents bring with them when seeking our services.

BOOKLETS

■ Miscarriage: Surviving
Pregnancy Loss (1992)
Fold-out brochure addresses
the grief and healing process:
affirms the validity of emotions,
offers suggestions for coping
and deals with issues of the
future pregnancies. Audience:
adults who have had a miscarriage. No cost. Contact: Ferre
Institute, 258 Genesee, Ste 302,
Utica NY 13502, 315-724-4348.

■ What You Should Know About Genetic Testing and Pregnancy (1992) Recently translated into Russian to help emigres from the former Soviet Union understand the importance of genetic testing for a variety of conditions during pregnancy. Audience: adults with average reading ability. No cost. Contact: Penny Steiner-Grossman, MPH, Public Health Educator, 121 DeKalb Ave, Brooklyn NY 11201; 718-403-8000.

■ For Adults with Cystic Fibrosis: Facts on Reproduction ,Amy Lemke, MS (1993) Discusses reproductive issues and options, reviews genetics of CF, testing and genetic counseling. Audience is adults with CF, parents of children with CF. No cost. Contact: Louise Elbaum, GLaRGG Coordinator, University of Wisconsin - Madison, #328, 1500 Highland Avenue, Madison WI 53705-2280, 608-265-2907.

■ Sotos Syndrome: A Handbook for Families (1992)

A 55-page spiral bound booklet with photographs which addresses medical, developmental, behavioral and genetic aspects. Reviews the medical specialists seen by and procedures performed on patients with Sotos syndrome. Audience is parents, educators and health care providers. Cost: \$8.00. Contact: Meyer Rehabilitation Institute, c/o Media, UNMC, 600 S. 42nd St, Omaha NE 68198-5430; 402-559-6497.

LETTERS TO THE EDITOR LE LE LE

PROFESSIONAL ROLES VS. PERSONAL BELIEFS

Re: Ms. FitzGerald's and Ms. Baty's letters addressing the role of genetic counselors in the pro-choice debate. I acknowledge Ms. FitzGerald's concern that aligning ourselves with a pro-choice stance might prejudice legislators against us and jeopardize our ability to provide comprehensive genetic services. However, as Social Issues Chair, I agree with Ms. Baty that we must publicly align our professional selves with this volatile issue, regardless of our personal beliefs.

NSGC has a policy statement supporting reproductive choice that was ratified by a majority of our membership. The purpose of creating the policy was specifically to grant our professional organization the authority to participate in legislative and judicial actions regarding this issue. Ms. FitzGerald is concerned that a pro-choice stance might be misconstrued as a pro-abortion stance. Maybe. But I do not believe that it is in our patients' best interests to hide from this controversy. Instead, we must use our skills as communicators to educate the public regarding the significance behind the words.

Instead of assuming that our personal feelings and professional responsibilities regarding this issue are identical, I suggest we separate these two parts of ourselves. One of our primary responsibilities is to respect and support our patients' decisions, independent of public or personal biases. As individuals, we have the luxury of making decisions based on our own moral,

ethical, religious and personal value systems. As professionals, we must allow our patients the same luxury. This means that we must continue to lobby for our patients' rights to all options. When state legislators limit availability of abortion, we are less able to provide a full range of options to our patients.

As Ms. Baty suggested, when medical geneticists and genetic counselors are made party to these restrictions, our patients' rights to decision-making suffers, and our autonomy as professionals is undermined. If this stance jeopardizes the provision of genetic services, then that must be our next lobbying effort. Anything less is shirking our ethical responsibility as patient advocates.

Vivian J. Weinblatt, MS Social Issues Committee, Chair

WHO WE ARE; WHAT WE DO

■ *NSGC President Betsy Gettig* wrote a letter to Hillary Rodham Clinton regarding the potential role of our Society (excerpted below). Since it has taken over 200 years for our health care system to become established, it will probably just take time for many of the changes to occur. There will be many public discussions regarding the plan. Each of us has both an individual and a professional responsibility to participate in the discussions. Feedback from all members with suggestions regarding our Society's role are welcome.

Dear Mrs. Clinton:

In my role as a local elected official (Borough Council) as well as a genetic counselor, I am keenly aware that your task of formulating a health care stra-

tegy is a monumental assignment and our Society would be happy to assist in any way.

Genetic counselors are actively involved with the provision of high risk prenatal and pediatric care. The role of the genetic counselor has been extended to substance abuse, teratogen exposures including occupational risk and early intervention. Furthermore, cutting edge genetic research will provide a role for genetic counselors in regard to predispositions to cancer, diabetes, heart disease and possibly AIDS. Genetic counselors are the professionals who will be responsible for translating complex information and issues related to risk assessment to patients and the public at large.

With the ongoing work of the Human Genome Project, the role of genetics will increasingly become a public health issue. Our Society wishes to have a proactive, thoughtful role regarding the impact of genetic screening and diagnosis on the public.

Betsy Gettig, MS President

EDITORIAL POLICY

The purpose of this newsletter is to promote dialogue about topics that impact the manner in which genetic counselors deliver care. To that end, Letters to the Editor and Membership are invited and encouraged.

All letters must be signed and include an address and day-time telephone number. The decision to publish letters will depend on space availability, timeliness of the issue and the relevance to the readership.

Classified Classified Classified

- These classified listings 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.
- San Jose CA: June 1 opening for two BC/BE Genetic Counselors. Ability to counsel in Spanish strongly preferred for one of the positions. Responsibilities: Join active team providing comprehensive genetics svcs in large HMO: all aspects of ped & adult general GC, PNDx (amnio, CVS, U/S anomalies, MSAFP) teratogens, insvc educ & research oppty. Contact: Karen Wcislo, MS, Kaiser Permanente, 260 International Cr, Genetics Dept, San Jose CA 95119; 408-972-3306. EOE/AA.
- WALNUT CREEK CA: Immediate opening for part-time BC/BE Genetic Counselor. Flexible hours. Responsibilities: Join growing private practice: coun for CVS, amnio 2-3 days/week. Contact: Carole Gurgone, East Bay Perinatal Medical Associates, 240 La Casa Via, #200, Walnut Creek CA 94598; 510-935-6491. EOE/AA.
- Denver CO: Immediate opening for BC/BE Genetic Counselor/Case Manager. Related degree w/GC exp considered.

 Responsibilities: Linkage analyses calculations, carrier risk determinations and molecular genetic testing in Molecular Genetics Dept.

 Contact: Bev Bjugan, Human

 Resources Dept, The Childrens

 Hospital, 1056 E 19th Ave, Denver

 CO 80218; 303-773-0111. EOE/AA
- TAMPA/ORLANDO FL: Immediate opening for BC/BE Genetic Counselor w/ minimum 3 yrs clinical exp. Must be willing to travel, possess excellent commun skills; and be independent, self starter personality. Responsibilities: All aspects of GC: case mgmt, coord of svcs in central FL. Unique oppty to work autonomously in satellite location while providing professional input into clinical program.

 Contact: Cliff Myers, Human Resources, Integrated Genetics, 7315
- ORLANDO FL: Immediate opening for BC/BE Genetic Counselor. Exp

SW 87th Ave, Miami FL 33173;

305-596-0126. EOE/AA.

- pref, not required. Independent, autonomous personality desired. RESPONSIBILITIES: Wide variety of responsibilities in active, growing PNDx practice in hosp-based tertiary care ctr encompassing large referral area: CVS, amnio, PUBS, fetal echo; Peds cases & clinical research oppty exists. Contact: Mark Cullen, MD, Florida Hospital, 601 E Rollins, Div Maternal Fetal Medicine, Orlando FL 32803; 407-895-7692. EOE/AA.
- AUGUSTA GA: July 1 opening for BC/BE Genetic Counselor.
 RESPONSIBILITIES: Coordinate and participate in preconceptual & PN GC; oppty to participate in clinical & research activities.
 CONTACT: Paul G. McDonough, MD,
- Medical College of Georgia, Human Genetics Institute, CK159, Augusta GA 30912-3360;706-721-2828. EOE/AA.
- HONOLULU HI: Immediate opening for BC/BE Genetic Counselor.
 RESPONSIBILITIES: Join rapidly expanding multidisciplinary genetics team in Level III tertiary care ctr: PN coun; some peds; wide range of oppty for prog development, clinical research, training, outreach.
 CONTACT: Annie Anno, Human Resources, Kapiolani Medical Center for Women & Children, 1500 S. Beretania St, #100, Honolulu HI 96826; 808-973-8207 (collect). EOE/AA.
- IOWA CITY IA: Immediate opening for BC/BE Program Associate/
 Genetic Counselor. Experience and leadership in supervisory position in Regional GC Services Program pref. RESPONSIBILITIES: Supervise 5 GCs & coordinate univ & state-wide regional programs.
 CONTACT: Jeffrey C. Murray, MD, University of Iowa Hospitals, Div Medical Genetics, Iowa City IA 52242-1083; 319-356-3508. EOE/AA.
- CAMBRIDGE, MA: July opening for Part-time BC/BE Genetic Counselor. RESPONSIBILITIES: Conduct detailed medical hx interviews w/ males applying for anonymous donor prog; assist pts, couples, med prof re donor screening process. CONTACT: Marilyn Ray, MPH,

- California Cryobank, 1015 Gayley Ave, PO Box 439, Los Angeles CA 90024; 310-443-5244. EOE/AA.
- WALTHAM MA: Immediate opening for BC/BE Genetic Counselor. Start-up position.
 RESPONSIBILITIES: Assist in multidisciplinary reproductive treatment team: interview, select & counsel pts, manage genetic svc team in development & coordination of preimplantation embryo service.
 CONTACT: Lee Hoffman, Executive Director, IVF American Program-Boston, c/o WalthamWeston
 Hospital & Medical Ctr, Waltham MA 02254; 617-647-6762. EOE/AA.
- CHARLOTTE NC: Immediate opening for BC/BE Genetic Counselor.

RESPONSIBILITIES: Join active & growing medical genetics ctr w/broad range of counseling: PNDx, general peds, DNA, AFP & multidisciplinary satellite clinics; resident & 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.

■ FAYETTEVILLE & WINSTON-SALEM

- NC: Immediate opening for 2 BC/BE Genetic Counselors. Exp pref.
 RESPONSIBILITIES: Interact w/ public health & medical genetic ctr staff in public health setting: coordinate satellite clinic system; coun ped & PN pts; educate professional & lay groups; participate in overall prog planning & implementation.
 CONTACT: Elizabeth G. Moore, MSW, Div MCH, Genetic Health Care Unit, Box 27687, Raleigh NC 27611-7687; 919-733-0385. EOE/AA.
- CAMDEN NJ: Immediate opening for 2 BC/BE Gen etic Counselors.

 RESPONSIBILITIES: PN coun: CVS, amnio, PUBS, Level II U/S, fetal loss, participate in satellite clinics w/perinatologist; Pediatrics: general genetics & several specialty clinics.

national society of genetic counselors, inc.

nsgc

233 Canterbury Drive Wallingford, PA 19086-6617

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CONTACT: Cheryl Reid, MD or Ellen Schlenker, MS, Cooper Hospital, 401 Haddon Ave, E&R Bldg, Dept Pediatrics, 3rd fl, Camden NJ 08103; 609-757-9797. EOE/AA.

- Albany NY: Spring 1993 opening for BC/BE Genetic Counselor.
 RESPONSIBILITIES: Join 2 GCs on multidisciplinary team in teaching hosp: PN, ped & adult specialty (SB, Hemophilia, NF, CL/P) and satellite clinics; Oppty for teaching & research.
 CONTACT: Lenore Palladino, RN, MS, Albany Medical Center, 47 New Scotland Ave, Pediatrics A-88, Albany, NY 12208; 518-262-5120. EOE/AA.
- MANHASSET NY: Immediate opening for BC/BE Genetic Counselor. RESPONSIBILITIES: All aspects of PN & ped GC: amnio, CVS, teratogens, U/S abnorm; ped & adult evaluations. CONTACT: Gittel Silverberg, MS, North Shore University Hospital, 300 Community Dr, Human Genetics, Manhasset, NY 11030; 516-365-3996. EOE/AA.
- NEW YORK NY: Immediate opening for BC/BE Genetic Counselor. Exp pref; familiarity w/ molecular technology a plus.

 RESPONSIBILITIES: All aspects of coun/case mgmt for family history of cancer; coordinate molecular testing; participate in research protocols in genetic epidemiology; some admin; oppty for teaching & research, develop multidisc strategies for cancer risk assessment; atmosphere

- conducive to prof development. Contact: Karen Brown, MS, Program Coordinator, Memorial Sloan-Kettering Cancer Ctr, 1275 York Ave, Box 559, Clinical Genetics, New York NY 10021; 212-639-6760. EOE/AA.
- New York NY: June 1 opening for Part-time BC/BE Genetic Counselor. RESPONSIBILITIES: GC & testing in Div Pediatric Hematology in thalassemia & hemophilia clins; 2 days outreach GC in PN & clinical genetics. CONTACT: Jessica Davis, MD or Nancy Zellers, MS, Cornell Univ Medical Ctr, Div Human Genetics, Dept Peds, Rm HT150, 525 E 68th St, New York, NY 10021; 212-746-1496. EOE/AA.
- OKLAHOMA CITY OK: Immediate opening for BC Genetic Counselor. 5 yrs exp as genetics consultant in public health setting. RESPONSIBILITIES: Join active MCH Program: provide technical assistance & consultation in Congenital Disorders Section & other MCH programs; case consultations & professional insvc education; Potential for direct clinical service at genetic ctr; participate in research projects; Program Director role, if interested or exp in administration. CONTACT: Mary Ann Coffman, MS, Congenital Disorders Section, OSDH, 1000 NE 10th St, Oklahoma City OK 73117-1299; 405-271-6617. EOE/AA.
- PORTLAND OR: Immediate opening for BC/BE Genetic Counselor.
 RESPONSIBILITIES: Work in interdisc

- setting in general genetics clinic and DNA Diagnostic Laboratory: coun, coord svcs, participate in clinical & laboratory activities.

 CONTACT: Jonathan Zonana, MD or Bradley Popovich, PhD, Oregon Health Sciences University, 3181 SW Sam Jackson Park Rd, Molecular & Medical Genetics, L103, Portland OR 97201; JZ: 503-494-4448; BP: 503-494-7193. EOE/AA.
- DALLAS TX: Immediate opening for BC/BE Genetic Counselor.
 RESPONSIBILITIES: Diverse, flexible responsibilities in tertiary care ped teaching hosp: general genetics, metababolic & Down syndrome clinics, inpt consultations. Oppty for support groups, teaching, continuing education & research.
 CONTACT: Gail Brookshire, MS, Childrens Medical Ctr, 1935 Motor St, Dallas TX 75235; 214-640-2357. EOE/AA.
- MADISON, WI: Immediate opening for BC/BE Genetic Counselor. RESPONSIBILITIES: Join large, active team in established, comprehensive, expanding prog: PN, teratogens coun, dysmorphology, peds, stillbirth, metabolic, bone dysplasia, Down syndrome, others; cyto & molecular lab support; Oppty for professional education; flexible responsibilities depending on interests. CONTACT: Richard M. Pauli, MD, PhD or Catherine A. Reiser, MS, Wisconsin Clinical Genetics Center, UW-Madison, 1500 Highland Ave, Madison WI 537056-2280; 608-262-9722. EOE/AA.