PERSPECTIVES
in genetic counseling

Volume 16:1 Spring 1994

Alternative Job Options: Will They Work for You?

Kathryn A. Steinhaus, MS, University of California Medical Center at Irvine, Orange CA

As the genetic counseling profession approaches it's third decade, greater numbers of counselors are choosing alternative work options to help them meet personal and professional goals. To support genetic counselors, some employers are implementing options such as flexible scheduling, job sharing and telecommuting for their employees. This win-win situation benefits the employers by allowing them to retain experienced counselors, and it benefits the counselors who report greater job satisfaction because it provides the flexibility necessary to balance family and personal needs.

Ninety-four percent of genetic counselors are women. The majority live in households in which both adult members work outside of the home. These demographics make issues regarding balancing family and career responsibilities especially relevant. This article will identify genetic counselors who have found successful ways to balance career goals, parenthood and leisure activities by choosing or creating alternative work schedules.

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Tough Decisions: Those Made by Patients

EXPANDED AFP SCREENING IN CALIFORNIA

Linda Foley, MS, Genetic Disease Branch, Berkeley CA

Scheduled for implementation in 1994, California is enlarging the scope of its original Maternal Serum Alpha-Fetoprotein Screening Program which began April 1986. All pregnant women in California will be offered the maternal serum Expanded AFP blood test, to be drawn when they are between 15 and 20 weeks of gestation.

By incorporating two additional biochemical markers, human chorionic gonadotropin (hCG) and unconjugated estriol (uE3), the program will identify approximately 60% of pregnant women of all ages at risk for a Down Syndrome (DS) pregnancy and also will allow screening for Trisomy 18. This detection rate is an improvement over the original AFP Screening Program which detected only 20% of the DS cases by MSAFP alone. The rates of detection for neural tube defects and abdominal wall defects will remain the same: 97% for anencephaly; 80-85% for open spina bifida and abdominal wall defects. In addition, the Expanded AFP result

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national society of genetic counselors, inc.

nsgc

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

ON THE INSIDE

NSGC acknowledges the following corporate friends for grants to support this newsletter.

Integrated Genetics, committed to providing quality DNA-based, cytogenetic and prenatal biochemistry testing, service and education and

Women's Health Care Services, Wichita KS, providers of late abortion care for fetal anomalies.

Liability Insurance: From Headache to Helpful Hints

Finally a professional and general liability insurance program is in place for NSGC Full members. Nearly 250 members have requested application forms.

In obtaining the commitment from a carrier to cover genetic counselors, the following four considerations were addressed: members' interest, documentation of genetic counselors' roles and responsibilities, cost comparisons and legal clearance. The final policy is both affordable and comprehensive.

What the Policy Covers

The coverage provides both professional *and* general liability insurance. *Professional coverage* offers payment for a claim arising "out of the rendering of or failure to render professional services" during the policy term. *General coverage* refers to the premises in which your services are provided.

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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.

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Deadline for Submissions: May 10

Presentation Obscures Content

Not surprisingly, some of you have experienced difficulty and confusion completing the application. In an attempt to provide a rapid response to the deluge of calls, the application was sent to interested members immediately upon receipt. The ensuing confusion has prompted this clarification to assist you in completing your form:

Page 1: General Information

- Issue or Quote: If you are seriously interested in coverage, check "issue." A quote will be issued with your policy, and coverage will not begin until you submit payment.
- Consider yourself an independent counselor. You do not need to attach an annual report, balance sheet or standards of hiring or screening. Where information is not being completed, simply write NA.
- Question #7: write "Genetic Counselor."
- Question #10, previous claims, answer "No Claims Made," assuming this is true. Consult with legal counsel if other circumstances exist.

Page 2: No Response Needed

Page 3: Section II - Liability Coverage

- The choices are either $1 million/$1 million aggregate *or* $1 million/$3 million aggregate. This translates to up to $1 million per case with up to $1 or $3 million per premium year. Each limit bears a different premium charge and depends on the geographic location of your services. Coverage will range from $275 to $450 per year.
- In the next section, only complete section (C) Out-patient services. List the number of clients you see per week, month or year. The remaining information is probably irrelevant. Write NA.

Description of Hazards

- Under the "Premises-Operations" section, you *must* indicate the estimated size of your *counseling office(s)* [ex: 10 x 12 or 120 sq ft]. Do not include the waiting room, elevator or other space.

Page 4: Supplemental Information

- Complete only if further explanation is needed.

Insurance as Member Benefit

Availability of insurance is dependent on member support. If you are currently holding a policy to cover your private practice, would like coverage in addition to that offered by your employer or anticipate needing coverage in the future, please consider this member benefit.

If you have been covered by the American Counseling Association (ACA), your savings are two-fold: NSGC's policy costs less, and you do not need to join ACA to qualify. Many counselors are also learning that their ACA coverage is being cancelled as of the next billing date.

This member benefit has come to fruition because of many hours of work by Donald Goode, the broker of record, Kate Fitzgerald, our lawyer, Luba Djurdjinovic, Beth Balkite and myself. I regret any confusion the application process has caused. Please call Donald Goode, 315-682-4101, or me if you need additional help completing your application. We're now well rehearsed in the process. ■

Bea Leopold, MA
Executive Director

COMMITTEES AT WORK:

OPPORTUNITIES GALORE IN PROFESSIONAL AND SOCIAL ISSUES

PROFESSIONAL ISSUES ACTIVITIES: OLD AND NEW

In addition to the established projects such as the Standardization of Family Pedigree Project, "Voices of Genetic Counselors" brochure and our bi-annual survey, the Professional Issues Committee members are involved in a variety of other exciting activities. Networking accurately describes some new projects of this committee.

- The Increased Networking Project, coordinated by Debra Lochner Doyle, focuses on national and international organizations which provide services to individuals and families with genetic conditions or birth defects.
- The Networking with Medical Subspecialities Project, coordinated by Kathy Keenan, is increasing awareness of genetic counseling services among subspecialities such as neurology, oncology, cardiology and ophthalmology.
- Networking among counselors with 10+ years experience, coordinated by Cindy Malin and Tillie Young, will feature a workshop at the 1994 Annual Educational Conference.

Other ongoing projects include:

- Providing job search guidelines whether you are a new graduate or veteran counselor, coordinated by Michelle Jenkins and Julie Berger.
- Providing guidelines to enhance our professional status (i.e., negotiating salaries, working with human resource departments), coordinated by Stacie Rosenthal and Diana Chambers.

Contact the coordinator if you are interested in working on any of these projects.

MEMBER RECOGNITION

We are excited to initiate two award programs for NSGC members who have excelled in the field of genetic counseling. The Natalie Paul Outstanding Volunteer Achievement Award and the Regional Leadership Recognition Certificates of Achievement are a direct result of implementing our strategic plan. These awards have been created to celebrate our diversity, support our colleagues, share our successes and acknowledge motivated members who have innovative ideas. If you know someone deserving of such recognition, please return the nomination form enclosed in the recent membership mailing by the April 15 deadline. ■

Ann Boldt, MS, Chair
Professional Issues Committee

NOTES FROM THE SOCIAL ISSUES COMMITTEE

The Social Issues Committee (SIC) generated enough ideas during the meeting in Atlanta to keep us busy for the next year and beyond! The following are highlights of some activities of these committee members since last October:

The Legislative subcommittee proposed amendments to two NSGC resolutions, reproductive freedom and access to care, which address potential changes in health insurance that may result from a national health care policy. These amendments are currently being prepared for Board review at the interim meeting.

The Legislative subcommittee is developing a position statement to address DNA population screening in juvenile onset disorders, and the Genetic Research Issues Subcommittee is creating a position statement regarding pediatric and presymptomatic testing in adult onset disorders.

Alysia Bemus-Spear, with support from the NSGC Executive Committee, wrote a letter to President Clinton addressing the freedom to exercise the right to an abortion, urging him to sign the conference committee report on Senate Bill S1550 and House Bill HR796. These bills support stricter penalties for people who block access to abortion clinics. For copies of either the bills or the letter, contact Vivian Weinblatt.

The Genetic Research Issues Subcommittee is developing a framework for appropriate disclosure to patients involved in research projects.

The proposed SIC workshop for the 1994 Annual Education Conference is "Whose Choice is it Anyway? Impact of Litigation on Genetic Policies." It will explore ways public policy and litigation affect the options available to our patients. Tentatively, we plan to present two actual and two fictitious cases before a 'judge.' The workshop will be divided into two groups, each arguing one side of each case. Members interested in volunteering for this workshop are asked to contact Vivian Weinblatt. ■

Lori Williamson-Kruse, MS
Social Issues Committee

14th Annual Education Conference

'95 Conference Chairs Propose Innovations

Planning is already underway for the 1995 Annual Education Conference in Minneapolis MN. The tentative dates are October 21 - 24.

With the recent success of the Cancer Genetics Short Course in Atlanta, we want to explore whether the short course format should be considered to replace one day of the Annual Education Conference in place of offering a short course prior to the meeting.

If incorporated into the program, conference attendees would be given the option of attending one of at least four day-long "Short Courses" that would be offered simultaneously. These courses would replace one day of plenary speakers and workshops. The goal would be to promote a more in-depth exploration of topics directly pertaining to the practice of genetic counseling or professional development.

The Annual Education Committee, chaired by Barbara Bowles Biesecker, will be conducting a comprehensive survey later this year to obtain more global feedback on the format of future meetings. In the interim, your input on the enclosed card will help with our preliminary planning.

We welcome your feedback and involvement in the 1995 Annual Education Conference.

Complete the poll, and let us know what you think. ■

Carol Strom, MS
Wendy Uhlmann, MS
1995 Annual Education Conference Co-Chairs

13th Annual Education Conference

"Twenty Five Years of Genetic Counseling: Expanding Roles, Extending Horizons"

October 15 - 18, 1994

The 1994 Annual Education Conference will begin with an important focus on the history of genetic counseling; continue with an emphasis on current technology, trends and patient care issues; and conclude with a charge and vision for the future of genetic counseling.

Registration: If you have not received your copy of the Registration and Information brochure by April 1, call the Executive Office. Leave a message and a brochure will be mailed to your preferred address within one week. Plan ahead: The deadline for registration without penalty is *August 15.*

Program: Eight plenary sessions and 12 workshops will draw on national and international expertise. The program and workshop committees have planned a balance of science, counseling techniques and professional development to meet the educational needs of genetic counselors and related professionals in all career stages.

Receptions: Our Opening Reception will focus on the history of genetic counseling as we create an interactive Professional Timeline. Help trace our beginnings by adding your experiences. Our Social Event will be held at the Place desArt, Montreal's cultural arts center, located directly across from LeMeridien. Gather for a reception of hors d'oerves, drinks, exhibits and lively conversation. Dinner will be on your own.

Abstracts: Postmark Deadline: *Friday, April 15.* Please note the following changes (noted in italics) of Bob Resta's mailing address: 747 *Broadway*, Perinatal Medicine, Box 14999, Seattle WA *98114*-0999.

Ancillary Meetings: All meetings or receptions must be scheduled through the NSGC Executive Office. Request an Ancillary Meeting Reservation Form by phone or fax. Deadline: *July 15.*

Hotel: LeMeridien is the most convenient ASHG hotel to the Convention Centre. We have arranged for our registrants to maintain their rooms for the duration of both NSGC and ASHG meetings. Please make your reservations early. Crediting NSGC for the entire duration of your hotel stay reduces our meeting costs and keeps our registration fee low.

Slide Swap: Back by popular demand…The slide swap, a popular conference feature, is being revitalized. Step one is to collect slides. The better the selection, the better the swap. Anyone who has slides to share is urged to contact Cynthia Kane, 7 Olive Ave, Piedmont CA 94611 for further instructions.

NSGC Code of Ethics: Fostering Partnerships with Colleagues

■ *As we review the four sections of our Code of Ethics, this third part of our series reflects on that aspect which may be easiest for us …relationships with each other.*

Section III of the NSGC Code of Ethics focuses on genetic counselors' relationships with colleagues. Those relationships are many and varied. In addition to the daily relationships with counselors at their own institutions, most have professional relationships with colleagues at other facilities.

Many counselors have developed relationships with other genetic professionals by serving on committees of NSGC, ASHG, regional genetic groups and other professional societies. Genetic counselors also have relationships with other genetic and non genetic health care professionals with whom they work.

Additionally, genetic counselors have relationships with genetic counseling students and students in other health professions in whose training they participate.

Few Requests to Date

The Ethics Subcommittee receives few inquiries regarding ethical dilemmas in the area of professional relationships, suggesting that most genetic counselors are not experiencing difficulties in this area or, that when difficulties arise, genetic counselors have the skills necessary to successfully resolve the situation. The very skills used by genetic counselors in their relationships with clients serve them well in their collegial relationships. An excellent example of how a genetic counselor and a social worker worked together to resolve a conflict about role definitions was presented in an article by Lori Williamson-Kruse and Kimberly Harris in a previous issue of *PGC* (Vol. 15:2).

The second guideline in Section III, encouraging ethical behavior in colleagues, is perhaps the most challenging or has the potential for causing the most discomfort on a practical level. Nonetheless, many counselors follow this guideline in professional relationships by modeling ethical behavior and, drawing on their skills as counselors, by being willing to openly discuss difficult situations with their colleagues.

Proactive Support of Code

Following is a list of some of the activities that exemplify the guidelines set forth in Section III of the code. We suspect that many genetic counselors could easily add examples to this list.

- Responding to requests from students for information about the profession of genetic counseling.
- Providing inservice education about genetics and genetic counseling for other health professionals.
- Attending clinic conferences and discussing difficult cases with other genetic counselors and health care team members.
- Networking with colleagues to identify testing or support resources for clients.
- Mentoring students by teaching or providing supervision during clinical rotations or summer internships.
- Completing surveys for student research projects.
- Sharing opinions, ideas and research results by publication in *Perspectives, Journal of Genetic Counseling*, regional genetic newsletters and other publications.
- Actively participating in NSGC, state and regional genetic organizations and other professional groups by attending meetings, serving on committees and planning education programs.

Support from NSGC

Just as individual genetic counselors strive to enhance their professional relationships with colleagues, NSGC, as our professional organization, has similar goals from which members can benefit.

The Annual Education Conference provides a forum for sharing knowledge and experience, presenting research results and networking with other genetic counselors and students. The recently established LGS/NSGC Speakers' Travel Fund will provide financial support for NSGC members to attend meetings of other professional organizations to provide education about genetics and genetic counseling. The Professional Issues Committee plans to develop a series of brochures describing the role of genetic counselors in relation to other medical specialties.

Active involvement in NSGC not only increases opportunities for developing relationships with colleagues, but also enhances our ability to meet our ethical obligations to self, clients and society. ■

Nancy Callanan, MS
U North Carolina - Chapel Hill
and Judith Benkendorf, MS
Georgetown University,
Washington DC

ALTERNATIVE WORK SCHEDULE: FLEXIBLE HOURS…

continued from p. 1

Flexible work hours are an option for counselors choosing to work full-time but wanting to add flexibility to respond to specific professional, family or personal needs. *Flextime* allows counselors to shift their work schedules by a fixed period. Another alternative, a *compressed work week*, permits counselors to complete their usual number of working hours in fewer days per week.

FLEXTIME IN PRACTICE

Steve Keiles and Monica Alvarado, both prenatal genetic counselors at Kaiser Permanente in Southern California, find flexible scheduling works for them. Steve has implemented a compressed work week of four 10 hour days. This 4/40 schedule allows him one full day to supplement his income by moonlighting. Monica works at Kaiser 80% time, three eight hour and two four hour days. She then spends two four hour days at other prenatal genetic offices.

Steve's long work day at Kaiser provides early and late appointment times, allowing greater patient access to the counseling service. His schedule allows him to commute the greater distance one less day per week. Both Monica and Steve say that they personally benefit from their arrangements due to their higher earning power. Both work enough hours at their primary setting to qualify for full benefits.

The variation in work setting is also a plus. According to Steve, "You're exposing yourself to more medical situations and work settings...you're not always doing it your way." As a consultant, Monica also likes the fact that away from Kaiser she is not responsible for patient follow-up… "you do it and it's over."

THE DOWN SIDE

Conversely, both Monica and Steve work many more than 40 hours per week.

Having more than one work setting can also make patient contact difficult. Both emphasize the importance of a good support staff who know where and when you can be reached.

The lack of job security for their private practices is also a disadvantage. According to Monica "if they want to hire someone full-time, you're out."

JOB SHARING AS AN OPTION

JoAnn Inserra at Norwalk Hospital in Connecticut has implemented *job sharing*. JoAnn and co-workers Lynn Duchan and Cindy Malin all work 20 - 24 hours per week. JoAnn receives full benefits, an important advantage, since her self-employed husband does not carry a benefit package. The majority of JoAnn's patients are prenatal, however all three cover a monthly pediatric clinic. According to JoAnn, "We all have personal commitments outside the office that we can tend to without feeling guilty."

To be successful in job sharing, JoAnn says you have to be flexible, willing to finish something someone else has started and able to compromise. Although they always try to follow their own prenatal patients from counseling to results, they're not always able to provide this continuity and sometimes need to rely on each other for patient follow-up.

JoAnn also believes that communication is key. "We need to be even more diligent with charting so we can cover for each other." To work smoothly, clarity around issues of division of labor and the concept of consensus is essential. Formal office protocols help minimize tensions and clarify expectations.

Job sharing has been successful for JoAnn, meeting her personal and professional

TIPS: HOW TO MAKE IT WORK

- INVEST in voice mail, a cellular phone and/or a beeper. Make it easy for co-workers and patients to reach you when you're out of the office.
- SPEND the time to find and train good support staff.
- STAY in close communication with your co-workers to make sure that your arrangement is working for them. An unhealthy work environment is created when co-workers are constantly burdened by your unfinished business.
- OFFER to cover for your co-workers, even if they are in the office full-time, to help equalize some of the job responsibilities.
- BE flexible with your schedule by being available when a co-worker is sick, on vacation or simply on overload.
- PLAN ahead for unusual cases. If you work in multiple settings, it helps to organize your references. Carrying information regarding some of the more common diseases is helpful.

…Help to Balance Professional and Personal Lives

goals. "I have the best of both worlds. I can be with my son, but still remain up to date in the field."

Working at Home

Telecommuting, another option, allows counselors to work at home. Genetic counselor (and new mom) Hilary Bachman Kershberg is currently embarking on this new alternative through her employer, Genetrix. Using a laptop computer, Hilary works at home one day per week. Via modem and fax, Hilary can obtain patient information, as well as results, from the office. She can then relay information by telephone and modem to the office, patients and physicians. For counselors working in an office that is not computerized, many can still be productive at home by simply using a telephone, pen and pad of paper.

Alternative Work Options

- **Flexible Scheduling**
  - **Flextime**
  - **Compressed Work Week**
- **Job Sharing**
- **Telecommuting**

Amy Cronister, at Integrated Genetics, also telecommutes. Amy, who lives 50 miles from the office, works 30 hours a week, including one day at home. Since Amy, as the Fragile X Product Manager, spends most of her time on the phone, her job adapts well to telecommuting.

Amy initially approached her employer about working part time to obtain hours to write and work on projects at home. Now, it also allows her to spend time with her new son. She says that not working 50+ hours per week means that some don't see her as serious about her profession. However, Amy says, "You can maintain the respect of others if you do your job well." Amy has also learned to be efficient and has made the hours in her office more productive.

It's Not for Everyone

In offices which contain both full and part time counselors, the division of labor may not be as clear. Many salaried full time counselors work more than 40 hours per week without additional compensation. If they are in an office with a part time counselor who, because of child care or other responsibilities, is rarely able to add hours when the work load increases, resentments may increase as well. On the other hand, if a part time counselor constantly works overtime to accomplish the scheduled tasks, any advantage to their alternative scheduling is lost.

Some counselors, due to their job description, may not find alternative scheduling or telecommuting an option. Counselors involved in supervision or other duties requiring a constant physical presence may not be able to change from an 8 to 5 schedule. Alternative job scheduling may also not be rewarding for counselors wanting more patient continuity. Counselors who work part time or moonlight are often not available to provide follow-up counseling to patients with abnormal test results or ongoing concerns. These counselors may find their jobs less satisfying, because they give up the in-depth psychosocial follow-up that many find so rewarding.

First Make a List

If you're interested in exploring one of these job options, one way to start would be to list all the advantages and disadvantages of the proposed arrangement to both you and to your employer.

- Do you have a realistic expectation of the number of hours necessary to get your job done?
- How should routine and unexpected job responsibilities be assigned?
- How would this arrangement affect your co-workers?

If you think the advantages make it worth pursuing, approach your employer. If you know of genetic counselors in similar work situations, ask permission to let your employer talk to their employer.

Flexibility Increases Effectiveness and Efficiency

Alternative job options provide benefits to both employer and employee. Employers reduce the amount of employee absenteeism, since most counselors with flexible schedules report greater job satisfaction. Flexible scheduling also encourages personal business to be handled outside work hours, making counselors more productive when they are at the office. Genetic counselors benefit from scheduling alternatives which facilitate arrangements for child care, doctor's appointments and leisure activities. In addition, more efficient use of time at the office allows for the option of moonlighting or other activities which can increase income. ■

California to Implement...

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will continue to alert clinicians to other significant obstetrical conditions including multiple gestation, miscalculated gestational age and increased risk of fetal loss.

Women Under 35

Women who are <35 years at EDC will be given the booklet "The California Expanded AFP Screening Program - for Women under 35 years of age." Those wishing to participate will have their blood drawn between 15 - 20 weeks of gestation. The cost will be $115, which covers all authorized follow-up services at state approved Expanded AFP Prenatal Diagnosis Centers (PDCs).

Blood samples will be sent to one of eight state approved laboratories for analysis. Three screening protocols will issue interpretations based on these results. Any AFP MoM ≥2.5 will be screen positive for neural tube/abdominal wall defects. An algorithm using a likelihood ratio to modify the *a priori* age related risk of DS will be used to estimate the DS risk, and a different algorithm will be used for the Trisomy 18 risk.

If results for all three screening protocols (neural tube/abdominal wall defects, DS and Trisomy 18) are negative, a mailer listing relevant patient information, results and interpretation of the results will be sent to the clinician who is responsible for informing the patient.

Screen positive results will be assigned to one of the 14 regional Expanded AFP coordinators. The coordinator will phone the clinician to verify patient information and if there are no changes, the coordinator will give the clinician the names and locations of the state approved PDCs where the woman can be referred. Currently, there are 96 approved sites for AFP follow-up services in California.

At the PDC, women will be counseled by a Board Certified/Eligible genetic counselor, will receive an ultrasound scan and, if appropriate, an amniocentesis for analysis of amniotic fluid AFP, acetylcholinesterase and/or chromosomes. Follow-up of significant findings identified during the PDC visit(s) will be discussed with the referring clinician and the patient. After counseling and an appropriate option is chosen, follow-up care will be managed by the referring physician.

Women 35 and Older

If the woman is ≥35 years of age at EDC, she will be given the booklet "Prenatal Testing Choices for Women 35 Years and Older." After the prenatal care provider explains the choices, the woman will be offered a genetic counseling referral to one of the PDCs. At the PDC, appropriate options for prenatal detection of a fetus with DS (Expanded AFP screening, CVS or amniocentesis) will be discussed with a Board Certified/Board Eligible genetic counselor. For women who decline referral, the prenatal care provider will provide the information and obtain consent for participation.

The Genetic Disease Branch (GDB) strongly recommends that any woman who wants an invasive diagnostic procedure be referred to a PDC. Women who elect to have CVS or amniocentesis before 15 weeks will be offered Expanded AFP testing between 15 and 20 weeks to detect neural tube and abdominal wall defects. Only the risk for neural tube and abdominal wall defects will be provided and acted upon for authorization for further follow-up. The cost of this screening will be $57.

Additional Options for Women 35 and Older

Before the availability of the Expanded AFP screening, amniocentesis or CVS was considered the appropriate referral option for women age 35 and over. With the implementation of Expanded AFP Screening, these options still must be offered. However, the Expanded AFP blood test must also be offered as an option, since it may be a more acceptable alternative to some women. Once she is properly informed of the risks and benefits of the alternatives and if her choice is the Expanded AFP blood test, the protocols explained above for women under 35 will be followed.

Many women will continue to elect amniocentesis, since it will detect 100% of DS cases. It is expected that the Expanded AFP blood test will detect 80-90% of DS cases in women ≥35. However, in California only approximately 60% of the pregnant women over 35 currently choose to have amniocentesis, so the actual DS detection rate is *not* 100% in this age group. It is hoped that many of those who now decline amniocentesis will accept the Expanded AFP blood test, and therefore overall detection will improve.

An important point to remember is that a woman with a negative Expanded AFP

...Expanded APF Program

screen for DS (i.e., risk of a DS fetus is less than 1/250 at term) has a four to five times greater chance of having a procedure related loss of a normal fetus than she does of having a DS fetus. For that reason and the high cost per additional case detected, the State will not pay for amniocentesis for women who are screen negative.

ADMINISTRATION OF THE EXPANDED PROGRAM

The Expanded AFP Screening Program will be administered by the GDB of the California Department of Health Services. The GDB is divided into the Genetic Disease Laboratory (GDL) and five clinical and administrative sections. It is the joint responsibility of the Prenatal Screening Section and the GDL to administer, maintain and monitor the Expanded AFP Screening Program to assure quality and timeliness of result reporting and the delivery of services.

In addition to the overall improved detection of DS, the program is a cost effective alternative with a positive cost/benefit ratio. DS is the most expensive and most prevalent of the chromosomal abnormalities, but there are other defects such as Trisomy 13 and sex aneuploidies identified by amniocentesis that concern some women and practitioners. Expanded AFP will pick up about 40% of these defects and others will be found by positive AFP results and ultrasound.

The original California Maternal Serum AFP Program has a utilization rate of 60%. A goal of the Expanded AFP Program is to obtain participation of an even higher percentage of women than the current 60%. ■

Tough Decisions: Those Made by Professionals

DNA TESTING: RIGHT OR PRIVILEGE

■*Non-directive counseling…access to care…These are academic models that our profession holds as standards. However, practical application can sometimes be frustrating. This provocative article questions these ideals. It asks that we move beyond discussion to formulate practical policies.*

With advances in DNA technology, testing individuals who may be at risk for certain genetic conditions is becoming more common. However, costs of this testing can often be prohibitive to individuals and families. For those individuals using public assistance, the situation is even more complicated.

Currently, when an individual on public assistance has DNA testing arranged through a hospital clinic or department, the clinic or department is responsible for the finances.

Typically, the hospital is billed for the testing, covers the charge and then attempts to collect from the state. This becomes costly, especially as departments are being increasingly urged to become self supportive.

Various issues have been raised regarding this subject:

- How much costly testing are we obliged to provide to families on public assistance?
- Are we mandated to arrange the coverage of esoteric testing in all instances, especially if we know that financial arrangements may not be possible?
- Should the degree of recurrence risk or severity of the disorder influence our decision whether to offer DNA testing?
- For an autosomal recessive diagnosis, when no information is available about the paternal genotype, do we have an obligation to *insist* that the information be obtained prior to consideration of amniocentesis?
- Should the issue of termination ever become a component for deciding who will be offered DNA tests, especially if the family is clear that they would never consider this option?
- Should laboratories providing specialized DNA tests be mandated to accept public assistance payment? Currently, many labs require payment in advance or a hospital billing address for clients on public assistance.

Although many of these issues have been discussed previously, the time and energy involved in coordinating DNA studies as well as capitation issues, require that they be readdressed. If laboratories will not accept the specimens without assured reimbursement or families will not alter medical management based on the information that is received, how do counselors provide consistent service to their clients? ■

Fiona Field, MS
University of Illinois at Chicago

✍✍✍ LETTERS TO THE EDITOR ✍✍✍

PUT IT TO REST!

TO THE EDITOR:

RE: "Restricted Patient Information" (*PGC* 15:4) . Debate and the marketplace of ideas should have no better home than *PGC*. I would strongly argue, however, that the topic of whether or not to withhold information from a patient is outdated, been dealt with by this newsletter before and is no longer worthy of newsletter space.

Apparently this needs to be rehashed one more time. As I have told students and audiences alike, we call our field not genetics, but genetic *counseling!* This is an important difference. One of the basic underpinnings of genetic counseling is the communication of information coupled with the ability to do so and to do so in a manner in which the client can understand, given his or her abilities. To not communicate fully with the client — to withhold information — is to misunderstand our *raison d'etre*, the history of our profession and to continue along a long historical path laid down by others of paternalism.

Specifically Ms. Simonsen writes "...we did not inform them ... because we did not have any evidence at that time that it would have any effect on his growth or development." I fail to see the moral, legal, ethical or practical reason to withhold this information. Also, to give partial information and hold back on some is at minimum disingenuous and perhaps deceitful.

Permit one hypothetical: If in the future it is determined that maternally derived UPD for chromosome 16 has clinical significance, will you, the clinician, be able to find these patients to recontact them?

I submit to my fellow genetic counselors that NSGC should formally declare: "The profession of genetic counseling is committed to full disclosure of information to our clients." ■

Seth Marcus, MS
Lutheran General Hospital
Park Ridge IL

SUGGEST YOU TELL ALL

TO THE EDITOR:

We read with interest the differing approaches to counseling patients with a newborn at risk for/with Trisomy 16 UPD. We believe the approach Ms. Simonsen takes, withholding information, does the patient a disservice. The following issues come to mind:

- Parental bloods were drawn for the disomy study. Can you justify doing so while simultaneously withholding the results?
- These particular studies are currently offered as research. Would it be different if charges were generated?
- Do you also withhold a report to the referring physician? If not, don't you put him or her in the position of either explaining a complex genetic situation or of also withholding information?
- Failing to provide available information now might put the family at a disadvantage later, perhaps leading to duplicate or unnecessary testing and expense.

Genetic counselors often handle ambiguous situations. Ambiguity does not excuse us from having to deal with families who specifically 'contract' with us to do just that. We think it sets a dangerous precedent to pick and choose what patients 'need' to know. ■

Susan Mundt, MPH
Genafacts
Patricia Mullinix Shires, MS
St Luke's Perinatal Center
Kansas City MO

Responses to these letters are on p. 14.

COMMON SENSE SHOULD PREVAIL

TO THE EDITOR:

RE: Code of Ethics: A Further Application (*PGC* 15:4). As the narrative unfolded, we expected that Ms. Schmerler would use the Code of Ethics as a justification for providing the hospital's security staff with the name and address of their client. We agree wholeheartedly that the substance of our interactions with a family are indeed subject of all of the principles involved in maintaining the patient's confidentiality. Nevertheless, identifying this woman as the possible perpetrator of a crime is an issue which we believe is outside of the NSGC Code of Ethics and one which we must address as members of a larger society. Each of us desires to live in a community which is characterized by order and general decency. To achieve this state, there are certain rules that all members of such a society must follow. One of those rules involves respecting the property of others. When we witness a violation of that rule, we have a responsibility to report that individual to the appropriate authority. Such an

action would not violate a patient's confidentiality.

We are disappointed that our Code of Ethics can be used to supersede what are intuitively understood commitments such as helping to identify individuals who violated the law.

Have we taken ourselves so seriously that we cannot see the absurdity in this situation? Our Code of Ethics is designed to help 'guide' us through the ethical and moral difficulties we encounter on a daily basis. But it is nothing more than a guide. It should not take precedence over what is just plain common sense. ■

Michael L. Begleiter, MS
Jill Cellars Rogers, MS
Childrens Mercy Hospital
Kansas City MO

Author's Response: You missed the point. By 'identifying this woman as the possible perpetrator of a crime,' we also identify her as a recipient of genetic services. This is a clear breach of confidentiality and could have serious repercussions. It may not only be damaging to the client (e.g., by stigmatizing her) but could prevent other people from seeking genetic counseling services. Confidentiality is more than a matter of 'common sense.' It is a moral principle that protects the privacy both of the client as an individual and the client-counselor relationship by creating a shield against the intrusion of what some may think of as society's greater interests. We use our Code as a guide when conflicts arise that are problematic, but a stronger reason than 'common sense' must exist to justify overruling the principle of confidentiality. ■

Susan Schmerler, MS
St. Joseph's Hospital
Paterson NJ

GeneBytes

Another Option for Pedigree Drawing

KINDRED, from Epicenter Software, can be evaluated with a demo disk, which permits creation of 20 pedigrees and contains enough of the features of the full program to allow the user to grasp KINDRED's strengths and weaknesses.

Individuals are added to a pedigree by moving the cursor to an existing individual and then adding parents, sibs or offspring. Information about individuals in the pedigree can be entered by editing within the database or while viewing the pedigree by placing the cursor on the individual. Standard information such as name, DOB, age and diagnosis can be maintained for each individual, and user-defined variables can be added. Individuals can be located in a large pedigree by ID number, name or a pattern rule such as "name and DOB<1930." A variety of fill symbols are available to show multiple phenotypes or disease codes. Pedigree data are stored in dBase files, and KINDRED can convert existing dBase files into KINDRED's format.

Viewing the pedigree is enhanced by several features. The information that is displayed under the symbols, such as name, age and diagnosis, can be easily changed. The disease symbols can be varied to display the individual symptoms or grouped as a syndrome. One can zoom in on any portion of a pedigree for easier viewing on-screen or for printing. This is especially important for large pedigrees, as the program can handle pedigrees of over 300 individuals. The program is partially menu-driven, but many commands must be remembered while working from the pedigree display, which takes away from it's ease of use.

Not Without Limitations

The demo disk was not without its problems. The installation instructions weren't quite right for our computer, and it took some finagling to get KINDRED up and running. An automatic tutorial ran too quickly on our 486 to permit viewing by human eyes. Using the written instructions and the onscreen help, it took several hours to figure out how to construct a pedigree. The directions, which are printed from the demo disk, are over 20 (unnumbered) pages and need to be followed carefully. As users who resort to instruction manuals only under dire circumstances, we found ourselves reviewing the directions often and closely.

Some of the program's limitations present particular difficulty for genetic counselors. There were no symbols for pregnancy, miscarriage, pregnancy termination, stillbirth or adoption. Sibs cannot be placed in descending age order, and the DOB display was in the difficult to read format "dd/yy/mm."

KINDRED is a DOS based program that doesn't use Windows or a mouse. The system requirements include an IBM compatible computer with 640K memory, and up to 1.2Mb of expanded memory for high resolution printer output. The demonstration disk or full version is available from Epicenter Software, PO Box 90073, Pasadena CA 91109, 818-304-9487. ■

Karen Wcislo, MS
and Robert Resta, MS

■ RESOURCES ■

■ BOOKS ■

This reviewer comments on a series of children's books about genetics. To our knowledge, few such resources exist. We also received a review on this series from Cynthia Kane. Although the reviewers perceived different strengths and weaknesses, both agreed that students would need adult guidance when using these books. — *Susan Jones, MS*

Cells are Us; DNA is Here to Stay; Amazing Schemes Within our Genes

Author: Fran Balkwill
Publisher: Cold Spring Harbor Laboratory Press, 1990 - 1993
Price: $8.95 ea., 32 pp ea.
Reviewer: Judy Capra, MA, Middle School Life Science Project, Golden CO

While these slim, colorful paperbacks look inviting, use them cautiously. Balkwill assumes that short sentences, bright graphics and few pages can make difficult concepts comprehensible to young readers. She also falls into the traps of introducing too much technical vocabulary, underestimating the difficulty of the subject and presenting misconceptions in the process of trying to simplify the material.

What follows are a few examples of these problems from each of the three books. Incorporated in each of the reviews are comments from students, ages 9, 13, 14 and 15.

Cells Are Us is recommended for children ages 5 to 8 years. However, it would take a motivated youngster to sit through this story. It has a fairly heavy vocabulary load, including terms such as neutrophils, bacteria and melanin. By reading the book aloud to the 9 year old, the words could be redefined as needed and additional information supplied. All of the students thought the book was best used with students aged 8 to 13.

DNA is Here to Stay is intended for ages 9 to 15. None of the four students thought that it was totally clear. The 14 year old commented that without the illustrations he would have had a difficult time with most of the material. This is not surprising, considering the number of concepts, including DNA structure, cell division, protein synthesis and human variability, addressed in a mere 32 pages. There is simply too much in this book. Instead of mentioning some of the many details (such as the incorporation of uracil instead of thymine into 'copy strands'), it would have been better to clarify the significance of important genetic concepts.

Considering that *Amazing Schemes Within Your Genes* is recommended for ages 15 and up, the tone is startlingly juvenile. The text begins, "Think of all the people you know and see every day. Your family, your friends, people who live on your street or work near you - even people on the radio and television." The oversimplified explanations then become problematic. For example, we learn that, "DNA makes genes" and "You have about 50,000 genes inside you." Both of these explanations are fuzzy, creating misconceptions instead of lending clarity.

The British origins of the books were noted by all of the students. Some found the spelling (colour, centre) and word choices (queue, nappies, wildlife park) more distracting than others. Children liked the pictures, but when questioned, they did not know what they represented. Without a knowledgeable adult as guide, students will not learn much from these books.

Behavior and Development in Fragile X Syndrome, Vol 28. Developmental Clinical Psychology and Psychiatry

Author: Elisabeth Dykens, Robert Hodapp, James Leckman
Publisher: Sage Publications, 1994
Reviewer: Amy Cronister, MS, Integrated Genetics, Santa Fe NM

Discovery of the FMR-1 gene increased the public's awareness of fragile X syndrome. Health care professionals, special education teachers and therapists are eager to gain a better understanding of this complex genetic condition. Parents grappling with the implications of this diagnosis for their child generally have little available information. For these reasons, it is exciting to see these authors tackle the specific topics of behavior and development of individuals with fragile X syndrome.

Although this book was written for families as well as professionals, it is quite sophisticated and technical. The chapter on genetics contains information which is too broad and too complicated for most families. Unfortunately, as a result, information which may have practical relevance to

■ RESOURCES ■

families is left out or not explained clearly.

Nevertheless, the chapters on cognitive functioning, speech and language and adaptive functioning are excellent reviews of the research conducted in these areas to date. The questionable association between fragile X and autism is comprehensively and objectively addressed in a chapter entitled, "Psychopathology and Maladaptive Behavior." However, seizures, sleep apnea and Klinefelter syndrome were inappropriate for discussion in this chapter.

This book should be read by special education teachers and therapists, since it may impact educational or therapeutic intervention strategies. The book may be appropriate for families willing to struggle with difficult and complicated concepts. Most families, however, will turn to genetic counselors, eager to have information beyond inheritance, recurrence risks and reproductive options.

As genetic counselors provide emotional support and assist families when addressing the underlying psychosocial issues, they cannot neglect parents' concerns about the developmental future of their children. The book provides insight into past and present research regarding development and behavior in people with fragile X syndrome and is a valuable resource to professionals who wish to incorporate this information into their counseling sessions. ■

MEETING MANAGER

Apr 8	*Chinese Culture and Genetics: Implications for Service Delivery.* Beth Israel Medical Ctr, New York NY. Contact: M. Louie, 212-420-4179.
Apr 15	*Designs on Life: Choice, Control and Responsibility in Genetic Manipulation.* International Bioethics Institute and School of Public Health at UC Berkeley, San Francisco CA. Contact: Deborah Kamradt, 415-435-4900.
Apr 18 - 20	*7th Annual OTIS (Organization of Teratology Information Services) Meeting.* Woods Hole MA. Contact: Susan Rosenwasser, 617-787-4957.
Apr 25 - 27	*Gene Therapy: New Technologies & Applications.* Bethesda MD. Contact: CHI, 617-487-7989.
Apr 27 - 29	*Workshop on Hereditary Breast, Ovarian and Colon Cancer.* Washington DC. Contact: Lisa Needleman, 301-650-7472 or Andrea Brooks, 301-650-7471.
Apr 29	*Genetics, Health and Culture: Latino Perspectives.* Beth Israel Medical Center, New York NY. Contact: Raquel Rivera, 212-420-4179.
May 5-6	*Ethical Implications of New Genetics.* Boston MA. Contact: Danielle Demko, 617-423-4112.
June 12-15	*Genomic Information: Ethical Implications.* Seattle WA. Contact: B. Brownfield, 206-543-5447.
July 31 - Aug 6	*Short Course on Molecular Diagnostics, Counseling, and the Human Genome Project.* Ann Arbor MI. Contact: Louise Hallett, 313-764-8050.

RESEARCH NETWORK

Francis DiMario, MD, a pediatric neurologist at University of Connecticut Health Center, is working on a project related to the genetics of breathholding spells. He is seeking information on whether and how genetic counselors verify pedigree information and history taking in genetic counseling sessions. Specifically, he would like answers to the following questions:

- What do genetic counselors do to verify family history information given by families in sessions when diagnostic documentation is not presented?
- Is there a standardized format for obtaining genetic information that assures accuracy?
- Is there any published research regarding the verification of accuracy of an obtained family history?

Members with procedures, suggestions or related discussions are invited to contact Dr. DiMario at UCHC, Dept Pediatrics, 263 Farmington Ave, Farmington CT 06030; 203-679-3631; FAX# 203-679-1220; E-mail-dimario@brcu.conn.edu ■

LEGISLATIVE BRIEFS

Health Care Reform - Showdown on Capitol Hill

With Congress set to begin debate on the health care plan submitted by President Clinton, numerous alternative proposals have been introduced. Most attention is being paid to a plan proposed by Congressman Jim Cooper, dubbed 'Clinton lite.'

President Clinton's Health Security plan has been introduced in the House by Majority Leader Richard Gephardt and in the Senate by Majority Leader George Mitchell.

Much of the debate will occur in the Finance, Labor and Human Resources, Ways and Means and Energy and Commerce Committees.

Health care reform does not involve creating one insurance program, but will probably offer several plans, each with the same minimum coverage. The Clinton and Cooper plans have several similarities. Both require insurance reform and promote 'co-ops' to allow small businesses to pool funds, creating better purchasing clout. The President's plan promises universal health care, requiring all employers to pay benefits for their employees. Cooper's plan allows employers with fewer than 100 employees to offer but not pay for health care.

In Clinton's plan, the Feds are the regulators; critics assert that since government regulation is too burdensome and bureaucratic, it is doomed to failure. The government does not control prices in the Cooper plan, but promotes 'smarter consumers' to reduce costs and make health care more competitive.

As both aim to control costs, preventive medicine may finally be recognized as true primary care. However, some analysts feel that as preventive medicine becomes more high tech, it may price itself out of the market. Hopefully, as technology improves, it will become more cost effective and thus earn a permanent role in health care for everyone. ■

Lee Fallon, MS
Legislative Liaison

Counseling as a Process: Follow-Up to the UPD Stories

Even as we went to press with the previous issue of this newsletter, both authors of the uniparental disomy (UPD) cases (*PGC* 15:4) were expressing a desire to share subsequent information. In addition, we received two letters to the editor (See p. 10). The ideas expressed by those authors are valid in that counselors *should* provide patients with complete available information.

However, the original articles dealt with a different issue, that of providing information which is still considered by some to be in the research arena. For many, the concept of research defines that *no* results will be given to patients. UPD currently falls between research and clinical service. The descriptions of patient care presented two methods of dealing with this difficult issue. As new findings are revealed, genetic counselors will have to decide when information moves from research to clinical utility.

In addition, since the time in which the articles were first submitted for consideration (September 1993), changes in the cases and additional conversations have reinforced that genetic counseling is a communication *process.*

Following is a brief update from both authors. Both have subsequently reconsidered their approach and agree that they might respond differently in a future case. ■

A. Faucett, MS

Mrs. S. delivered at 36 weeks due to pre-eclampsia. The baby was growth retarded (4 lbs 13 oz) but otherwise healthy and is developing normally. Parental bloods were obtained at the time of delivery and studies showed that the baby had normal biparental inheritance of chromosome 16. I admit that I felt some relief that I did not have to tell the parents their daughter has UPD for chromosome 16. Perhaps I will have more information to give to the next couple with a similar result.

K. Leonard

In April 1993, the couple appeared to be under a great deal of stress, and I felt that the information would generate unnecessary anxiety. In November 1993, I met with them at the time of their son's hypospadius surgery to request a tissue sample for research. I informed them that the results might be uninterpretable or ambiguous. They appeared to understand and indicated their interest in the results. In February 1994, I informed the husband of the UPD finding and offered genetic counseling.

D. Simonsen

■ EMPLOYMENT OPPORTUNITIES ■

■ *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.*

OAKLAND CA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Join staff of 10 GCs & 2 MD geneticists; full range of PN & ped genetics in HMO setting.
CONTACT: Logan Karns, MS, Kaiser Permanente, 280 W. MacArthur, Oakland CA 94611; 510-596-6304. EOE/AA.

SACRAMENTO CA: Immediate opening for BC/BE Genetic Counselor. Experience pref. Salary range: $38,000 - 52,000 depending on qualifications & experience.
RESPONSIBILITIES: PN coun & independence in developing research & educ programs; some admin duties.
CONTACT: Douglas Hershey, MD, 1315 Alhambra Blvd, Suite 210, Sacramento CA 95816; 916-736-6888. EOE/AA.

SACRAMENTO CA: July 1 opening for full time BC/BE Genetic Counselor. (Earlier start may be part time.)
RESPONSIBILITIES: All aspects of ped & genrl GC & case mgmt: CVS, amnio, teratogens, MSAFP, hemoglobinopathy scrng.
CONTACT: Mark Lipson, MD, Kaiser Permanente Medical Center, Genetics Dept, 2345 Fair Oaks Blvd, Sacramento CA 95825; 916-978-1402. EOE/AA.

WASHINGTON DC: May 1 opening for 2 BC/BE Genetic Counselors. Sr. position (Asst Prof) req 8+ yrs exp in perinatal genetics; Instructor position, exp pref, not req.
RESPONSIBILITIES: Join site of new NICHD Perinatal Research Branch. Active role in all aspects of perinatal dx prog, interact w/ PRB, Fetal Dx and Therapy Team; CVS, amnio, PUBS, AFP+, fetal anom, genetic risks based on family hx & terat. Diverse pt population. Oppty for rsrch & prof development.
CONTACT: Judith Benkendorf, MS, Georgetown Univ Medical Ctr, Dept OB/GYN, Div Genetics, 3800 Reservoir Rd, NW, Washington DC 20007; 202-687-8810. EOE/AA.

AUGUSTA GA: June 1 opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Work with 2 clinical ped geneticists in tertiary care childrens hosp; coun pts & families on wide variety of genetic conditions; partic in specialty clinics for CF, NF, hemophilia, CL/CP; coord newborn scrng follow-up.
CONTACT: David Flannery, MD, Medical College of Georgia, Pediatric Genetics, BG-121, Augusta GA 30912; 706-721-2809. EOE/AA.

ATLANTA GA: Immediate opening for BC/BE Genetic Counselor/ Division Manager. Min 3 yrs clinical exp and excellent commun skills, strong admin & supervisory skills. Must be willing to manage satellite facility w/ GC, logistics, client svc components.
RESPONSIBILITIES: Unique oppty to provide coun suppt while exercising admin skills needed to supervise daily operations of satellite office.
CONTACT: Markey Burke, Human Resources Dept, Integrated Genetics, One Mountain Rd, Framingham MA 01701; 508-872-8400 x 2266. EOE/AA.

LEXINGTON MA: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Clin position includes pt coun & case mgmt for PN dx & genrl GC; partic in maternal serum scrng prog & supt groups.
CONTACT: Barbara Thayer, MS or Christine E. Ford, Human Resource Administrator, Prenatal Diagnostic Center, 80 Hayden Ave, Lexington MA 02173; 617-862-1171. EOE/AA.

DEARBORN MI: April 1 opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Coord new high-risk OB genetics clinic in full svc acute teaching hosp: provide GC for genrl & repro genetics, amnio, CVS, abnorm U/S, AFP+, teratogens; prof educ to staff & residents.
CONTACT: Diane Burt, Staffing Coordinator, Human Resources, Oakwood Hospital, 23400 Michigan Ave, Suite 111, Dearborn MI 48124; 313-278-8153. EOE/AA.

NEW BRUNSWICK NJ: May 1994 opening for Pediaric Nurse Coordinator; GC exp highly desirable. CV + 3 ltrs rec required.
RESPONSIBILITIES: Join team w/ 3 GCs, OB nurse, PhD cytogeneticist, MD/ PhD clin geneticist/molec biologist in rapidly growing comprehensive genetics ctr; multifaceted position w/ prim respon for coord ped genetic clin & all ped & neonatal pts.
CONTACT: Debra-Lynn Day-Salvatore, MD, PhD, Acting Chief, Div Clinical Genetics, Dept OB/GYN, Repro Sciences, MOB 4410, UMDNJ-Robert Wood Johnson Medical School & St. Peter's Medical Center, New Brunswick NJ 08903; 908-745-6678. EOE/AA.

FLUSHING NY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of PN coun, recurrent preg loss, peds. Great oppty for practice in estab growing genetic svc.
CONTACT: Gloria Harris, Genetrix, 158-13 72nd Ave, Flushing NY 11365; 718-380-7733x209. EOE/AA.

NEW YORK NY: Immediate opening for BC/BE Genetic Counselor. Exp pref, but not required.
RESPONSIBILITIES: All aspects of PN coun, case mgmt; some peds; diverse pt populations in clin & private sector; great oppty for indiv desiring balance of teamwork & independence.
CONTACT: Lisa B. Stevens, MS, St Lukes/Roosevelt Hospital, 425 West 59th St #4B, New York NY 10019; 212-523-3454. EOE/AA.

STATEN ISLAND NY: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: Diverse PN/ped coun: amnio, AFP, terat, malformations, etc; dysmorphology, fraX, CF & CL/CP clinics; cytogen in dev disab clin; inpt/NICU consults; partic in lay & prof educ, newsltr, advisory council, family supt grps.
CONTACT: Personnel Department, Ref#762, New York State Institute for Basic Research in Developmental Disabilities, 1050 Forest Hill Road, Staten Island NY 10314; 718-494-5221. EOE/AA.

RALEIGH NC: November 1 opening for BC/BE Community Outreach Genetic Counselor. Exp preferred.
RESPONSIBILITIES: Interact w/ public

national society
of genetic
counselors, inc.

nsgc

233 Canterbury Drive
Wallingford, PA 19086-6617

Employment Opportunities

health & med genetics ctr staff in public health setting: coord satellite clin system; coun ped & PN pts; educ prof & lay grps; partic in overall planning & implementation.
CONTACT: Elizabeth G. Moore, MSW, Div MCH, Genetic Health Care Unit, Box 27687, Raleigh NC 27611-7687; 919-715-3420. EOE/AA.

CLEVELAND OH: Immediate opening for BC/BE Genetic Counselor.
RESPONSIBILITIES: All aspects of PN coun in univ setting: CVS, amnio, PUBS, fetal abn, MSAFP, terat, prof & public ed, oppty for rsrch.
CONTACT: Brian A. Clark, PhD, MD, MetroHealth Medical Center, Dept OB/GYN, Div Repro Genetics, 2500 MetroHealth Dr , Cleveland OH 44109-1998; 216-459-5896. EOE/AA.

PORTLAND OR: Immediate opening for BC/BE Genetic Counselor/State Coordinator. Public health or educ exp desired.
RESPONSIBILITIES: Serve as state genetics coordinator with educ & admin respon. Part time ped & adult GC on multidisc team; joint appt in dept molec/med gen & CDRC.
CONTACT: Karen Kovak, MS, Oregon Health Sciences University, CDRC, PO Box 574, Portland OR 97207; 503-494-5606. EOE/AA.

PITTSBURGH PA: June 1 opening for BC/BE Genetic Counselor. Exp pref.
RESPONSIBILITIES: Coord clin & tchg activities of pediatric genetics prog, incl case mgmt.
CONTACT: Mark W. Steele, MD, Div Medical Genetics, Childrens Hospital of Pittsburgh, 3705 Fifth Ave, Pittsburgh PA 15213; 412-692-5070. EOE/AA.

FORT WORTH TX: Immediate opening for BC/BE Genetic Counselor; fluency in Spanish helpful.
RESPONSIBILITIES: Join multidisc team to provide comprehnsv gen svc to busy, hi-risk priv prac w/ growing ped caseload; partic in med resident tchg; involv exposure to wide range of gen dis in various settings; often req independ coun & case mgmt.
CONTACT: Martine Gould, MS or Kim McMillen, OB/GYN Consultants of the SW, PA, 1325 Pennsylvania Ave Ste 450, Fort Worth TX 76104; 817-878-5298. EOE/AA.

HOUSTON TX: April 1 opening for 2 BC/BE Genetic Counselors.
RESPONSIBILITIES: Join active team: coun & follow-up for amnio, CVS, AFP+, PUBS, DNA, biochem test, terat, U/S anom, hi-risk preg, fam hx concerns; One GC will serve as liaison/coordinator of AFP lab; educ & rsrch oppty avail.
CONTACT: Joy Redman, MS, Coordinator, Baylor College of Medicine, Prenatal Genetics Center, 6550 Fannin, Suite 921, Houston TX 77030; 713-798-4363. EOE/AA.

HOUSTON TX: Immediate opening BC/BE Genetic Counselor; fluency in Spanish helpful, but not required.
RESPONSIBILITIES: All aspects of PN coun & case mgmt: amnio, PUBS, AFP, abnorm U/S, terat; coord inpt ped consult svc & monthly ped genetics clin; oppty for clin rsrch & commun educ.
CONTACT: Jude P. Crino, MD, Lyndon B. Johnson General Hospital, Dept OB/GYN, 5656 Kelley St, Houston TX 77026; 713-636-5926. EOE/AA.

HOUSTON TX: Immediate opening BC/BE Genetic Counselor; fluency in Spanish helpful.
RESPONSIBILITIES: Partic in genetic outpt clins, s'vision of GC grad students, med house staff & med students on electives, mgmt of in-hosp consults, commun educ.
CONTACT: Gisele A. Greenhaw, MD, Univ Texas Medical School, P.O. Box 20708, Dept Pediatrics, Houston TX 77030; 713-792-5330x3060. EOE/AA.

NORFOLK VA: Summer 94 opening for BC/BE Genetic Counselor. Faculty position, dept ob/gyn, optional.
RESPONSIBILITIES: All aspects of GC/case mgmt in PNDx & repro med, MFM div: CVS, amnio, U/S, fetal dysmorph, fetal dx & therapy, AFP+, teratogens, multiple loss/repro wastage. Presence within Jones Inst for Repro Med involves assisting in expansion of preimplant prog infertility pts eval. Longitudinal case mgmt and follow-up, fetal & neonatal rx, psychosocial supt & grief coun; prof educ.
CONTACT: R. Nathan Slotnick, MD, PhD, Eastern Virginia Medical School, Div Maternal Fetal Medicine, 825 Fairfax Ave, Norfolk VA 23507; 804-446-7900. EOE/AA.