PERSPECTIVES
in Genetic Counseling

newsletter of the National Society of Genetic Counselors, Inc.

Vol. 12, No. 3 Fall 1990

1990/91 Officers Elected

Congratulations to the following officers, who have been elected to serve the NSGC in 1990/1991:

President Elect ... ... Ed Kloza, M.S.
Secretary ...Linda Nicholson, M.S., M.C.
Regional Representatives:
Region II ... ... Jill Fonda Allen, M.S.
Region IV ... ... Laura Turlington, M.S.
Region VI... ... ... Kurt Fenolio, M.S.

The nominating committee is pleased to report that 65 percent of the eligible Full members voted for President-Elect and Secretary, a record response.

Thanks for a job well done to committee members: Debra Collins, Chair, and to Nancy Callanan, Caroline Lieber, Janice Cox Palumbos and Vickie Venne.

on the inside

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

INTEGRATED GENETICS

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

Point CounterPoint
Can Non-Directiveness by Non-Helpful? Three Views

CK (CR# 17, PGC, 11:3, Fall 1989) was in a state of acute anxiety due to an inability to reach a decision to pursue additional prenatal diagnostic studies after a mosaic CVS result. CK continued to fixate on the "right decision" and on my professional opinion. Traditional counseling techniques were not effective with this patient. On multiple occasions, she asked, "What would you do?" I finally told her what I thought my decision would be, but took her step by step through the reasons for my decision and focused on the unique aspects of my situation. This process helped demystify the "right decision" and aided the patient in coming to her own decision. (CK did not make the same decision that I would have made.) Caution must be used with this technique since most patients are able to reach their own decision without this type of assistance and counselor intervention may unconsciously sway the patient. However, it can be a very effective counseling tool. — *Karen Copeland, M.S.*

The question, "What would you do if you were in my place," was posed to three colleagues. How does your response compare?

Selective Assistance PRN

by Janice Edwards, M.S., Asst. Director, Genetic Counseling Program, University of South Carolina in Columbia

The essence of genetic counseling lies in the principle of autonomy, suggesting that our patients have the basic right to make reproductive decisions free from coercion. When we define the process of genetic counseling, we wave the banner of non-directiveness, and rightly so, as it is derived from the principle of autonomy. Genetic counselors respect the patient's capability to make appropriate reproductive choices and strive

continued on p. 6

Experience, Intuition are Key

by Lynn Godmilow, M.S.W., Director, Genetic Counseling Services, Pennsylvania Hospital in Philadelphia

Non-directiveness has been the hallmark of genetic counseling since early in the formalization of the field. I was trained on-the-job, and early on in my career, I certainly practiced non-directive counseling exclusively.

This coincided well with my formal training which had been in social casework. Social workers are trained to help people help themselves, not to help

continued on p. 7

Directiveness: 0% Professional; 100% Trap

by Scott Polzin, M.S., Lutheran General Hospital, Park Ridge, IL

Among the many arguments against directive genetic counseling, one of the most significant is that it can potentially violate one of the basic tenets in medicine, that is, above all else to do no harm. It is obvious that in a global sense, there are no "right" or "wrong" answers in genetic counseling. It is also true that it is difficult or impossible to gain a complete understanding of a client's social and moral background in relation to the options being presented in a typically brief genetic counseling session. Consequently, a counselor cannot always be certain that the choice a client makes will

continued on p. 6

from the President

PARTING WORDS

You have been an active Society this year...and no Cheshire Cat has directed your course. You have challenged yourselves, and one another, and you have grown professionally as a Society.

At the Annual Education Conference, you will respond to a position statement on non-master level counselors. You will review a professional code of ethics. You will be confronted by issues of licensure. It is your presentations which will be published as the premier issue of our professional journal.

You have increased public awareness of genetic counseling by providing interviews and texts to the media. You will continue to enhance professional awareness by planning for the counseling needs which will be generated by the Human Genome Project. Also, you will have identified legislative initiatives, beyond freedom of choice, which will direct actions of the Society. And, in the future, you will vote on policies which describe the stance of the NSGC on several professional issues.

Within the field of genetics and beyond, the role of genetic counselors and the NSGC is more prominent. We have made great strides in promoting our professional values. I am proud to have served as your president during these exciting times and look forward to taking a continued active role in our Society.

Barbara Bowles Biesecker, M.S.

from the Editor

STARTING WORDS: TRANSITION, CONTINUITY AND CHALLENGE

If I had to choose one word that summarizes my feelings at this moment, *Transition* would be my choice. Even as I assume responsibility for *Perspectives in Genetic Counseling,* our Board of Directors has approved the establishment of a Journal, to begin just about one and one half year from now. I am excited about this new direction and am looking forward to working with Deborah Eunpu,...who had her humble beginnings on these pages! ...to create companion publications that will address the growing needs of our Society.

These next few years will bring many changes to *Perspectives* as we sort through which information is best transmitted to you in the Journal and which will be maintained in *Perspectives.* Please feel free to call me with your input. After all, the purpose of this newsletter is to provide useful information to you.

Our membership is also in a transition. This issue of *Perspectives* comes to you with the newest edition of the NSGC Membership Directory. The number of changes from last year's directory reflect incredible transitions in the lives of our members — professionally as well as personally.

If I were given the privilege of choosing a second word, I would then choose *Continuity.* Several members of the Editorial Board have elected to continue their commitment to *PGC* and I would like to publicly thank them for their interest in this publication and for their professional and personal support during the trials and deadlines that have brought you this, my first issue as your editor.

Seth Marcus is responsible for *Point CounterPoint.* Susan Jones will handle Professional Resources and Sylvia Mann, Resource, the general patient resource contributions. Barbara Bernhardt will continue to solicit for *Case Reports.* Trish Magyari comes in with our latest breaking *Legislative Briefs* and Karen Copeland will continue to monitor Professional/Personal Issues. Last, but not least, the person who pulls all this together is Bea Leopold, who, as Executive Director, is responsible for the layout and logistics, the deadlines and distribution, and has been invaluable in helping me learn the ropes.

As a third choice, I would take the word *Challenge.* This position is certainly that, and I have certainly gained a renewed respect for Ed Kloza, who is making this transition so easy for me. I also admire Joe McInerney and Debbie Eunpu, who, prior to Ed's tenure, were both instrumental in the development of this newsletter.

As your editor, however, my responsibility is to work with the raw material...the articles *you* have written. Therefore, as *PGC* continues and as we plan for our professional Journal, I challenge you to write and submit quality articles. It is through this public forum for our organization that we maintain a national dialogue and present our professional selves. Take my challenge. Write about your exciting professional experiences. I'll be looking for them.

Vickie Venne, M.S.

Your help is needed! The Technology Editor's position for* Perspectives in Genetic Counseling *has been vacated. If you are interested in soliciting and reviewing submissions for this category, please send a letter of interest to Vickie Venne. (Address on page 6.)

IN APPRECIATION FOR ANNUAL EDUCATION CONFERENCE SUPPORT

NSGC is pleased to announce the following support for our 10th Annual Education Conference, *The Interface Between Public Health and Clinical Genetics:*

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It is through the generosity of these companies and friends that we are able to produce high-quality conferences to our membership.
Please be sure to acknowledge their support of your Society.

Case No. 22

Individual Concept of Burden

by Janice Rinsky-Eng, M.S., Queens Hospital Center, Jamaica, NY

This case demonstrates the need for critical listening and flexibility in the counseling session. Additionally, protocol sometimes needs to take a back seat as the patient's needs and the overall picture are considered. This author accepted the challenge to clarify information that had been delivered in a time of great stress. She also adjusted her perspective to appreciate the burdens of different diagnoses through the eyes of the patient. Your comments and cases are invited. — *Barbara Bernhardt, M.S.*

Ms. L is a 34 year old black female who was referred for genetic counseling when her newborn son was found to have hemoglobin AS by routine hemoglobin electrophoresis.

When a baby is born with sickle cell trait at our institution, the parents are sent a letter signed by the genetic counselor, telling them their child has sickle cell trait and requesting that they call for a genetic counseling appointment. Ms. L's medical and family histories were not obtained prior to the counseling session.

After introducing myself, I asked Ms. L if she understood why she was referred for genetic counseling. She said she did, but she had been afraid to open a letter from the genetics department. I inquired as to why she was so nervous about receiving the letter, which had been addressed to the parents of the newborn. Ms. L explained that her son, Ted, who is now 2 years old, has Down syndrome. She explained that when she saw our department on the return address, she was afraid that her newborn had Down syndrome or some other type of genetic defect. Even though she had carefully examined her newborn son and was told by the delivering obstetrician that he looked perfect, the mere presence of the letter from our genetics department caused her anxiety.

Ms. L then started talking about Ted, what a joy he is, and how much she loves him. Her eyes filled with tears when she explained to me that although she loves Ted, she couldn't give Down syndrome to another child. She said that during her pregnancy with Ted, she had a dream that he had Down syndrome and that dream came true. Ms. L believes that the way you feel both physically and emotionally during pregnancy will have an impact on the health status of the baby. She felt that Ted's Down syndrome was somehow her fault.

I asked Ms. L if she had genetic counseling after Ted's birth. On direct questioning, she remembered something about chromosomes, but could not recall accurate information. Based on what Ms. L told me, it seems she was given all the appropriate information. Ted's father had left her during the pregnancy. Because of her emotional state at the time, and the adjustments and time required to care for Ted, much of the vital information was lost. Therefore, Ms. L filled in the cause of his problems with explanations that seemed to make sense to her.

At this point, I felt my original objectives for this counseling session (to talk about sickle cell trait) were of secondary importance. I called our affiliate institution and confirmed that Ted has a 47,XY,+21 karyotype. I then talked to Ms. L about chromosomes and the inheritance of Down syndrome. I was careful to stress that an extra chromosome is received by the baby at the time of conception, before a woman ever knows she is pregnant. I also stressed that the extra chromosome could have possibly come from the father's sperm cell. I wanted to make it clear to Ms. L that nothing she did, felt or dreamed caused Ted to have Down syndrome.

Ms. L was appreciative of the new information and seemed to be relieved at this point. She said she had made every excuse imaginable to delay prenatal care with her most recent pregnancy because she didn't think, if she had the option, that she would be able to make a decision about terminating a pregnancy because of Down syndrome, considering how much joy Ted has given her. Both she and her fiance, who is not Ted's biological father, felt they would take what God gave them and just pray for the best. Her fiance cares for and loves Ted as his own.

Ms. L's inaccurate knowledge about her recurrence risks caused her unnecessary anxiety during her subsequent pregnancy. She was lost to follow-up care after the initial counseling session regarding Ted. Consequently, she missed information which may have been valuable to her. I reviewed prenatal diagnosis and her risks of giving birth to another child with chromosome abnormalities. Ms. L said she is not planning to have any more children.

I then talked about sickle cell, autosomal recessive inheritance, the difference between sickle cell trait and disease and prenatal diagnosis. Ms. L knew that she had sickle trait and that her fiance had hemoglobin AA. He had been tested prior to the pregnancy because she had a friend who died at age 20 of sickle cell anemia. Ms. L described her friend as weak, fragile, sickly and in chronic pain. Ms. L also had a 4 year old niece who died of sickle cell anemia. Both of these deaths occurred many years ago, but Ms. L had vivid memories of the pain and suffering sickle cell anemia had caused both her niece and her friend.

Ms. L then stated that she would definitely terminate a pregnancy if her fetus had sickle cell disease but would probably not terminate for Down syndrome. Based on her experiences, sickle cell disease in a child would be worse than having a child with Down syndrome. Based on my own counseling experiences, her feelings are not the same as the majority who come in for genetic counseling about their risks for giving birth to a child with a chromosome abnormality.

Ms. L was not currently involved in any support groups. She talks to the social worker and mothers who take their children to United Cerebral Palsy where Ted is enrolled in school. She also receives emotional support from her mother and fiance. I gave her some literature about local support groups for families with Down syndrome. She was not sure she would get in touch with them, due to time constraints.

This case demonstrated that a person's feelings regarding what is acceptable may be largely based on that person's life experiences and ability to cope with different types of challenges. It also demonstrated how emotional stress at the time of receiving bad news may seriously hamper the ability to comprehend important information. It also reinforces the importance of providing *ongoing* counseling and support.

California Survey Reveals Salary and Benefit...

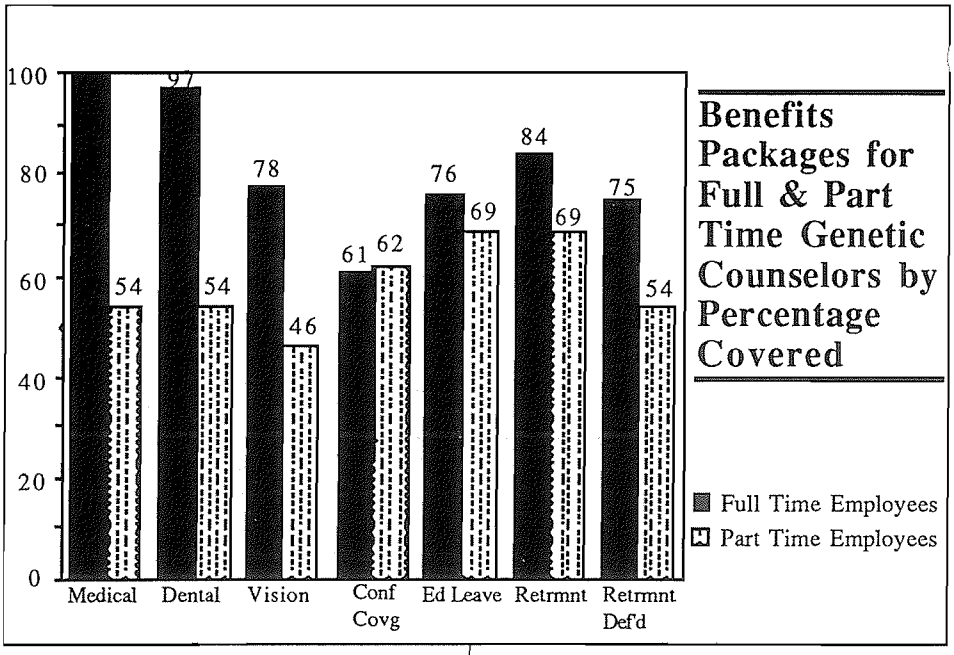
by Barbara Briscoe, M.S., UC Davis, Sacramento, Ann Stembridge Kung, M.S., Kaiser Permanente, Oakland and Kathy Boland, M.S., M.P.H., UC Davis, Sacramento

As a result of the increased demand for genetic counseling services, salary and benefit packages are an interest to newly entering and well-established genetic counselors. To address this need, we surveyed genetic counselors' salaries and benefits in California.

Methodology and Study Rationale

The survey was mailed in November 1989 to 136 genetic counselors. Eighty-five of the 136 (62.5%) recipients completed and returned surveys, most of whom were NSGC members (88%). Of the 85 returns, five were not used in the study; three were not employed in the field, one was in a research position and one was paid according to the number of patients seen. Thirty-two (40%) of respondents were from the San Francisco Bay Area, 26 (32.5%) from Los Angeles, 14 (17.5%) from Sacramento, three (3.75%) from San Diego, three (3.75%) from Orange County and two (2.5%) from Fresno. Due to very small sample sizes in some areas and for the purpose of anonymity, San Diego, Orange County and Los Angeles were tabulated together and hereafter referred to as the LA Area. Similarly, Fresno is included with Sacramento in the Sacramento Area data.

Eighty-four percent of the remaining 80 respondents held Master's degrees in genetic counseling; 16% held other single degrees, most commonly RN or Master's in Psychology. Six percent held dual degrees. Sixty-three percent surveyed (50/80) were board certified; however, 19 of 80 had been in the field for less than 2.5 years and may not have had the opportunity to sit for the exams. Eighty-four percent of respondents (67/80) were employed on a full-time (FT) basis; 16% (13/80) were employed part-time (PT). For the purposes of this study, FT employees will be considered separate from PT employees.



Benefits Packages for Full & Part Time Genetic Counselors by Percentage Covered

Results: Full-time Employees

The mean for years of experience of FT respondents was 5.4; 46% had held just one position, one respondent for 17 years. Analysis of covariance was used to examine factors that specifically affected FT salaries, especially years of experience and geographic location. The only statistically significant effect on salary was years of experience: In 1989 salaries increased by approximately 1.4% per year of experience in real terms, ($F=27.27$, $p=.0001$), whether or not a person is board certified ($F=12.44$, $p=.0005$). If they were board certified, they were paid about 7.5% more. (See Table 1.) The geographic location of FT respondents did not have a statistically significant effect on salary, although genetic counselors in the LA Area received somewhat higher salaries. A greater proportion of these genetic counselors are board certified (70% opposed to 50%); however, only 8% indicated salary increases following successful completion of board examinations.

For most FT employees, the benefit package was quite extensive. As shown in Figure 1, all FT employees received medical benefits and over 75% received dental, vision, education, retirement and a retirement deferment package. Only 61% of those surveyed received conference coverage with 13% of respondents (9/67) quoting dollar amounts from $500 to $1500 per year with $1000 being quoted the most often. The majority of FT employees (88%) received sick leave, most commonly averaging one sick day per month. Vacation days ranged from five to 33 days (mode=15). Institutions paid NSGC dues for 7% of the respondents. Twenty-two percent indicated that child

Salaries in California by Years of Experience

Table 1: Full-time

Yr Exp	Low	High	Median	Mean	N
<1	29,725	36,480	31,200	32,007	5
1	30,000	40,000	32,450	33,608	9
2	30,000	36,600	35,042	34,031	6
3	32,000	38,500	35,800	35,758	12
4	34,800	43,000	36,000	36,859	7
5	34,000	37,000	35,600	35,533	3
6	36,000	40,000	37,100	37,550	4
7	36,821	40,102	40,000	38,974	3
8	37,750	42,000	39,000	39,438	4
9	36,436	44,000	41,000	40,508	5
10+	37,500	51,300	41,000	41,943	9

Table 2: Part-time

<7.4	35,350	53,333	36,369	39,460	6
>7.4	36,477	65,000	44,597	47,152	7

care facilities were available at their institutions with an equal number from the San Francisco and LA Areas. Among those polled in the Sacramento Area, none indicated the availability of child care.

Results: Part-time Employees

Of the 13 PT respondents, 11/13 (85%) worked more than 50% time. The mean years of experience of the part time respondents were 7.4. Due to the small sample size of 13, salary based on years of experience was divided into two groups: those working less than 7.4 years (N=6) and those working more than 7.4 years (N=7) with the maximum number of years in the field equal to 17. In Table 2, the salaries have been calculated based on 100% time.

Results: Full-time/Part-time

The survey also reflected statistics for both FT and PT employees. Of the total polled, 10% held faculty appointments, 48% had supervisory roles and 56% had administrative duties. Compensation time was accrued by 46% but overtime was paid to only 4%. Eighteen percent (14/80) had board certification fees paid by their institution. Sixteen percent of respondents stated they had "on call" duties after hours. (As we did not define "on call," we are uncertain as to the magnitude of responsibilities.)

Discussion

Genetic counseling is recognized and respected by the allied health and medical communities. Within the California medical community, there is a shortage of genetic counselors. The results of this survey suggest that to meet this demand, institutions are increasing their starting salaries for newly graduated counselors, without adequately compensating the more established genetic counselor. In addition, board certification does not reflect a merit of accomplishment by increase of salary or benefits. Therefore, newly graduated as well as established genetic counselors must arrive at a position of satisfaction regarding salary base and stratification. As a professional group, it will be important to establish and promote a practical and rewarding salary/benefit package.

Acknowledgements: We gratefully acknowledge the technical assistance of Lydia Soon and John Hansen as well as the editorial assistance of Scott Adams and Cheryl Busman.

Letter to the Editor

Case In Favor of Triple Test for Down Syndrome Qualified by Research Results

To the Editor:

As the director of a large AFP screening program, I wish to comment on the *PointCounterpoint* article (*PGC* 12:2, Summer 1990) regarding multiple marker screening for Down syndrome.

Our ongoing studies have convinced us that James Macri's contentions ("Triple test premature, counterproductive") are unfounded. We have studied serum samples from 54 women with confirmed Trisomy 21 outcomes gleaned from over 20,000 women who initially received an MSAFP screen alone. We analyzed the effect of maternal age on screening sensitivity. The results show that uE3 is of particular value in women under age 35, as it raises the detection rate from 33% (with AFP and HCG alone) to over 50% in this age group.* With all three markers, the detection rate was three times that with AFP alone. The improved detection rate warrants the inclusion of uE3 in the screen.

We have been performing the three-parameter screen, which we call AFP-Plus, for over a year. The results from routine use of the AFP-Plus screen have been remarkable. Of the first 35 women who received an amniocentesis as a result of a positive AFP-Plus screen, one fetus was detected with Trisomy 21. Interestingly, one other of the 35 pregnancies was affected with Turner syndrome (45,X) with a cystic hygroma. The number of women with a positive screen for Down syndrome, after ultrasound dating correction, is only 4.0%, which confirms our retrospective findings.

The expanded screen is also of value in older women who wish to avoid an amniocentesis if at all possible but desire the reassurance of a serum screen for Down syndrome. About 5% of the women in our MSAFP screened population are over age 35. Between age 35 and 40, nearly two-thirds of women screened with MSAFP alone will have a positive screen for Down Syndrome and an indication for amniocentesis! In contrast, with all three markers, the amniocentesis rate is reduced to 1 in 5 women, while the detection rate for Down syndrome is doubled. If a physician chooses to offer a screen to these women, AFP-Plus is clearly superior to MSAPF.

Finally, the levels of AFP, HCG and uE3 are all low in maternal serum of fetuses affected with Trisomy 18 (Canick *et al., Am. J. Human Genet.* 1989; 45:A255). With additional data, it will be possible to design an additional screening cutoff that should detect a significant proportion of cases of Trisomy 18. It is most likely that two markers alone will be less effective than all three in regard to Trisomy 18. The ability to screen for Trisomy 18 will further increase the predictive value of the three-parameter screen.

Although we continue to collect and examine carefully our prospective data, our results to date show that all three markers provide the best possible screen at the current time.

* *Results submitted for publication.*

Marnie L. MacDonald, Ph.D.
Director of Biochemical Genetics
Southwest Biomedical Research Institute of Genetrix, Inc.

Editorial Policy for *Letters to the Editor*

Letters to the Editor are welcome and encouraged. All letters must be signed and must include a professional affiliation as well as a daytime telephone number. Authors may request to have their names withheld. The decision to publish letters will depend on the availablility of space, the timeliness of the issue and the relevance to the readership, as determined by the Editor.

EDWARDS, *from p. 1*

to foster autonomous decision making.

Patients are not accustomed to the tenet of non-directiveness in the medical setting. Describing the nature of our counseling is one technique for helping patients feel comfortable exchanging thoughts with the counselor. When they realize that we do not plan to judge or influence their procreative decisions, patients feel freer to discuss their questions and emotions.

The nature of genetic counseling frequently forces patients to examine their personal values and life plans. Many lack experience in sorting through tough choices. The professional's opinion is often sought, hence the question to the counselor, "What would you do if you were in my place?" Most counselors would agree that a blunt answer to the question is considered directive counseling and certainly risks coloring the patient's decision. It also risks losing the milieu of the session; the patient may no longer feel safe exchanging thoughts, particularly if they conflict with the counselor's. For these reasons, counselors are taught *not* to answer the question, "What would you do?"

Karen Copeland's case allows us to consider this question as an opportunity to illustrate a decision making model for the patient. Emphasizing the importance of individual values, the counselors could use themselves as examples to effectively define sides of the issue that the patient has not realized or suggest ways to "try on" potential outcomes of the decision. The patient may be satisfied with the description of the counselor's approach to the decision without specifically needing an answer to the question. In reality, we *do not know* what we would do in the patient's position. However, giving an answer to the question, when care is taken, is not *necessarily* directive genetic counseling.

"...the counselors could use themselves as examples to effectively define sides of the issue ...or suggest ways to 'try on' potential outcomes..."

Genetic counselors agree that respect for patient autonomy and non-directiveness are central to our practice; every effort should be made to preserve these principles in each genetic counseling session. We have, however, been ingrained with the idea that we should *refuse* to answer the question, "What would you do?"

After reflecting on this issue, my personal feeling is that the question can be carefully answered in some sessions. It could serve two purposes: 1) to teach decision making techniques through modeling and 2) to reinforce the non-directive nature of the session, thereby supporting the patient's autonomous decision.

Perspectives in Genetic Counseling is published quarterly by the National Society of Genetic Counselors, Inc. Editorial Staff:
Vickie Venne, *Editor-in-Chief* • Nichols Institute, 26441 Via DeAnza, San Juan Capistrano, CA 92675; 800-642-4657; FAX# 714-240-5381
Karen Copeland, *Professional/Personal Issues* • Baylor College of Medicine, 6550 Fannin, #921, Houston, TX 77030; 713-798-4691
Trish Magyari, *Legislative Issues* • Georgetown University Child Development Center, CG52 Bles Bldg., 3800 Reservoir Road NW, Washington, DC, 20007; 202-687-8635
Seth Marcus, *Point Counterpoint* • Lutheran General Hospital, Perinatal Center #325, 1875 Dempster St., Park Ridge IL 60068; 708-696-7705
Sylvia Mann, *Resources* • Shriners Hospital, 1310 Punahou Street, Honolulu, HI 96826; 808-948-6872
Barbara Bernhardt, *Counseling Approaches* • U Maryland School of Medicine, Div Human Genetics, Bressler Bldg 11-037, 655 W. Baltimore St., Baltimore, MD 21201; 301-328-3815
Susan Jones, Professional Resources • 126 Grandview Ave, Buffalo, NY 14223; 716-878-7545
Bea Leopold, *Executive Director* • 233 Canterbury Drive, Wallingford, PA 19086; 215-872-7608; FAX# 215-872-1192
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The opinions expressed herein are those of the authors and do not necessarily reflect those of the Editorial Staff or the National Society of Genetic Counselors, Inc.

POLZIN, *from p. 1*

do no (or the least) harm to that client. Therefore, a counselor can not always predict the correct choice toward which to direct the client. Directive counseling, from the counselor's standpoint, always runs the risk of doing more harm than good.

Along with aversion of harm is the problem of counselor responsibility in the event of a negative outcome. If the client is directed in any way by the counselor to a specific choice which the client later regrets, at least part of the blame can be laid on the counselor. If a counselor remains completely neutral, no harm can be done since (s)he has had no active part in the decision making process.

"Along with aversion of harm...If a client is directed in any way... to a choice which the client later regrets, at least part of the blame can be laid on the counselor."

Responding to "What would you do if you were in my place?" is related to the issue of directive counseling. Answering that question using oneself as an example is fraught with pitfalls. It is never possible to *completely* gauge how a couple will view and use the response. Further, no amount of prior disclaimer can completely remove the possibility of the client giving undue weight to the choice a counselor would make. Given the divergent backgrounds present, the counselor can never truly be in the cohort of the client. Thus, it cannot be instructive for the client to consider an example of the counselor's decision making process.

The best response when confronted with clients who are unable to make decisions or who ask "What would you do?" is to first make certain that all of the facts are understood. Then, assist them to explore their situation and address in a non-judgmental fashion all of the ramifications of the various options. If the clients remain undecided, they must be given time. In the end, if clients decide to do nothing, they still have made a choice.

The argument that undecided clients may be benefited by a counselor providing direction or using oneself as an example is fallacious. Clients *always* make decisions, and those decisions *must* be theirs alone. In addition, the ever-present possibility of a negative outcome, though unforeseen by the counselor who directs clients to that choice, makes directive counseling or using oneself as an example a risk genetic counselors should *never* take.

GODMILOW, *from p. 1*

them directly by doing for them.

My first experience which demonstrated that it is not always in the best interest of the client to be non-directive occurred while I was in graduate school. I was assigned a client in a family services agency who had been with the agency for many years. She was a rather dysfunctional person in a difficult marriage and had three children. One of her problems was a teenage daughter who was acting out and challenging her mother to set some limits. After several months of traditional counseling, she related an incident which demonstrated that our efforts were not achieving the desired effect. It seemed almost certain that the daughter would do something drastic to get her mother to act.

At that point, I attempted a radical new approach. I suggested that the next time an incident occurred when her daughter dared her to set some limits, she should stop and think to herself, *"What would Miss Godmilow think I should do?"* Then she was instructed to act accordingly.

I gave my client direction. This strategy proved to be effective, much to the consternation of my supervisor.

After several years as a practicing genetic counselor, I began to recognize that while most patients could use the non-directive approach effectively, some patients were overwhelmed by the information and the choices. A small number of patients were immobilized by their situations and begged to know "what would you do if you were me?" I *have never and would never* answer that question. I am not the patient and what I would do is not necessarily the right thing for that patient to do.

However, there are times when I have a good sense of a family's values and goals. If I offer support in the general direction I think the couple is leaning, that will give them enough help to be able to make the choice and feel comfortable with it.

For example, a patient is referred to discuss CVS and amniocentesis for a routine indication such as advanced maternal age. She is confronted with a great deal of information. Sometimes, as I give information to the patient, she becomes overwhelmed, and it is difficult for her to make a choice and act on it. By this time I know a great deal about the patient and her family. It may be very clear to me that the patient wants information about the chromosome status of the fetus but that her primary priority is preserving a normal pregnancy.

I might say to such a patient, "It seems to me that you want prenatal testing, but this is a very precious pregnancy for you and you are most worried about miscarriage. It makes sense to me, under these circumstances, to have a 15 week routine amniocentesis, which will give you the most information about the baby with the least chance of complication or of needing another invasive procedure later."

"(when) the patient is so overwhelmed with information and anxiety... this kind of directive approach is almost always appreciated."

In other words, the patient is so overwhelmed with information and anxiety that despite the fact that I think I can see what the correct decision is for her, she can't focus well enough to see it for herself. The response to this kind of directive approach is almost always appreciated and the patient usually expresses a great deal of relief that I am willing to provide some assistance with making what for her, seems like an impossible decision.

I would like to stress that, in my opinion, this kind of approach is only suitable for experienced counselors.

Non-directive counseling should remain the standard for less experienced professionals and for *all* counselors with *most* patients. Most of our patients can decide these difficult issues for themselves and the patient who needs direction is the exception. However, there are situations when it may be appropriate to offer *some* direction or guidance.

SOLUTION OFFERED TO COUNSELING DILEMMA

To the Editor:

I have interviewed numerous counselors for my current research project and have encountered several who have voiced frustrations similar to that expressed by Karen Copeland in her case report, "Can non-directiveness be non-helpful?" I would like to share a counseling technique which I have used when asked, "What would you do if you were me?"

I simply ask them to imagine being approached by a person identical to themselves in tastes and values and with an identical problem. I ask them to imagine what their gut reactions would be to someone in this situation. Then I add, "You should be at least as kind to yourself as you are to a friend in a similar dilemma."

Perhaps this inversion of viewpoint gives a useful distance for the decision maker. In any case, each time I have used this technique, I have found it facilitates making a comfortable decision. This technique also allows the counselor to maintain a non-directive stance.

B. Meredith Burke, Ph.D.

Dr. Burke, a demographer and medical sociologist currently residing in Los Angeles, has collaborated on several studies of decision making based on prenatal diagnosis.

Transitions often mean changes. In this issue, we are experimenting with a new direction, the result of Seth Marcus' creativity. The idea began when several individuals responded to Karen Copeland's case report with diametrically opposed views. Three were invited to present their different viewpoints about an issue that may be considered routine for many...the issue of non-directive counseling.

You are being challenged to look at the style in which you 'routinely' practice, using methods which may be very different from that of your colleagues. Your colleagues are asking you to re-examine the manner in which you practice both the art and science of genetic counseling. In this issue, we have enclosed a poll to allow each of our members the opportunity to share their opinion about a particular topic.

Our membership is facing other issues which are creating significant dialogue in our organization. As our members and our Board deal with issues such as a code of ethics, non-masters level counselors and CVS as routine practice, we will ask our readers to take an active part by sharing their views. With your feedback we will continue to solicit opinions to continue our national dialogue.

Vickie Venne, M.S.

Planning a Meeting? Call Us

A subcommittee of the Education Committee has been formed to oversee NSGC national and regional meetings. The objective of this subcommittee is to act as an advisory group to NSGC members planning both national and regional education conferences. It is not necessary to obtain approval for regional meetings from this committee, but members are happy to be of assistance.

The committee will be developing a new meeting evaluation form, revising the NSGC Meeting Manual developed in 1987 and overseeing topic and chair selection for the annual meeting. We welcome your thoughts and comments.

Committee members are Beth Fine, Joan FitzGerald, Rosalie Goldberg, and Bill Herbert.

Susie Ball, Chair
Education Conference Committee

Journal Update

At its July 8 meeting, the NSGC Board of Directors voted to proceed with the establishment of a Journal of Genetic Counseling. It further appointed Deborah Eunpu as Editor designate and accepted the *ad hoc* Journal Committee's recommendation to negotiate a publishing contract with Plenum/Human Sciences Press.

Because of the delay, we are not anticipating a premier issue until 1992. This will allow the Editor and our Committee to select an editorial board carefully, to solicit and process articles and to negotiate successfully with Plenum.

This Journal will serve as a testimony to the NSGC's progress in developing and publishing a body of literature unique to our profession. Its success requires a commitment by the membership to undertake and document research, submit papers, review manuscripts and resources, read and refer to the Journal and to promote it to other professionals.

Ed Kloza
***Ad hoc* Journal Committee Chair**

NSGC Applies for Membership in National Perinatal Assn

The NSGC Board voted at its summer meeting to apply for membership in the National Perinatal Association (NPA), a non-profit umbrella agency representing 22 maternal and child health organizations. Among the many benefits of joining is that NPA has a paid lobbying staff in Washington which would represent the NSGC on issues for which we share common concerns. NSGC would participate in the setting of NPA's Federal legislative agenda, which currently includes Access to Care issues (discussed in *PGC* 12:2, Summer 1990) as well as increasing treatment and prevention efforts related to prenatal substance use.

Our application for membership will be voted on at the NPA Annual Council meeting in November.

Trish Magyari
Social Issues Committee Chair

March of Dimes Sponsors Conference

The Nurse Advisory Committee, Greater New York March of Dimes, will present its 14th Perinatal Nurses Conference, "In Search of the Perfect Baby," on March 11 - 12, 1991 at the New York Marriot Marquis Hotel. For more information, call 212-353-8353.

Judith E. Steinhart
Director of Professional Education

Proceedings Available

The Proceedings of the NSGC's Seventh Annual Education Conference, *Strategies in Genetic Counseling: Tools for Professional Advancement*, ed. Nancy J. Zellers, are now available for purchase through Human Sciences Press at a rate of $35 (U.S.) and $42 elsewhere.

Contributors to this volume present a variety of techniques for expanding professional roles for the genetic counselor in new and challenging areas. From counseling pregnant women with the AIDS virus to the systems theory of family therapy as applied to genetic counseling to ethical issues, this volume addresses a myriad of issues related to professional growth.

Orders are being accepted by Human Sciences Press, Inc., 233 Spring Street, New York, NY 10013-1578; 1-800-221-9369. New York residents must add 8.25% sales tax.

Nancy J. Zellers

Can We Count On You?

There's still time to register for the NSGC's 10th Annual Education Conference, *The Interface Between Public Health and Clinical Genetics*. Highlights of the Conference, to be held in Cincinnati, October 14-16, include:

- Beverly R. Rollnick Memorial Lecture, *Can Geneticists Resist a Preventive Health Agenda?* delivered by Kathy Nolan, MD
- Plenary sessions from six renowned experts: Drs. F. John Meaney, Alan C. Crocker, Arthur D. Bloom, Muin J. Khoury, Patricia Kelly and Eric Juengst
- Your choice of workshops
  - AIDS: Genetic Counseling is Not Immune
  - The Family History in Follow-Up Care: An Innovative Use of the Pedigree
  - Population Screening for Cystic Fibrosis: Are We Ready?
  - Outreach: A Commitment to "Old" and "New" Americans
  - 9 to 5: Screening and Exposure in the Workplace
  - Licensure: Benefit or Burden?
  - Use of Coercion: Substance Abuse in the Genetic Counseling Setting
- Issue-oriented open forums presented by *ad hoc* committees on Code of Ethics and Non-Master Level (genetic) Counselors
- Curbside Consultations — *bring your difficult and puzzling cases to the experts*
- Combined Platform Presentations and Poster Sessions with International Society of Nurses in Genetics (ISONG)
- Special Event at Oldenberg Brewery
- Our Exhibitor area will be bigger and better than ever! (See list and acknowledgement on page 2.)

Register Now! Call our Executive Office for Last Minute Instructions.

It won't be the same without you!

In Memorium

It is with deep regret that we announce the death of Lorraine Friedman, a genetic counselor at King/Drew Medical Center in Los Angeles. Lorraine graduated from Sarah Lawrence in 1976. Acknowledgements may be sent to her husband, Bud Friedman, c/o 32700 Coast Site Drive, Rancho Palos Verdes, CA 90274.

BOOKS

INFERTILITY AND PREGNANCY LOSS
By: Constance Hoenk Shapiro, Ph.D.
Publisher: Jossey-Bass, Inc., San Francisco, 1988. 251pp
Price: $24.95, hardback
Reviewed by: Juli Horwitz, M.S.

In her preface, Constance Hoenk Shapiro, director of the social work program at Cornell University, suggests that this is a book which could aid helping professionals (including genetic counselors) to offer emotional support to infertile people. Shapiro has divided the book into three sections: The Experience of Infertility; Educational and Therapeutic Strategies; and Special Counseling Issues.

Chapters in the first section delineate the emotional impact of the realization and ongoing experience of infertility as an acute, then chronic, crisis. Shapiro shows how infertility affects self-perception and one's relationships with spouse, family, friends, co-workers and physicians. She offers some helpful pointers for professionals who are involved with couples during these stages.

Section Two is the most practical part of the book. It shows how to teach assertiveness skills, aid with decision-making and help a couple cope with their continued stressors. Shapiro offers some useful suggestions to help prevent the erosion of the marital relationship that infertility can impose. These include: limiting discussion of infertility issues to a certain room of the house (never the bedroom or dining room) and taking a "vacation" from infertility by foregoing treatments for a few weeks. The chapter dealing with decision making reinforces the importance that the couple take ample time to decide whether they would like to pursue treatment and which type(s) would be best. Shapiro's discussion of possible treatment options is cursory and light-handed regarding complications and other adverse outcomes.

The last section deals briefly with emotional aspects of miscarriage, stillbirth and pregnancy after infertility. The appendix includes a glossary, a comprehensive listing of reading materials and other resources such as adoption organizations and infertility associations.

The potential reader should be aware that *Infertility and Pregnancy Loss* is concerned predominantly with infertility. Shapiro's tone is often one of commiseration, to the point of portraying the infertile couple as passive victims.

"If a diagnosis is lacking or is not definitive, the couple may be plunged into years of exploratory efforts and treatments." (p. 34)

As genetic counselors, we try to see our patients as strong and capable of choosing among the options available to them. Shapiro makes no mention of the significant risk of pregnancies with three or more fetuses as a result of fertility drugs and treatments. Having talked with two previously infertile couples who were pregnant with six fetuses as a consequence of hMG (human menopausal gonadotrophin) therapy and were considering selective reduction, I will not soon forget the tragic irony and grief of their experience.

Because of Shapiro's emphasis on infertility rather than couples who have had multiple miscarriages, and the scanty review of possible therapeutic options, I would not recommend this book to genetic counselors or to their patients. However, I suspect that many genetic counselors would find the bibliography useful.

•••••

DWARFS DON'T LIVE IN DOLL HOUSES
Author: Angela Muir VanEtten
Publisher: Adaptive Living, P.O. Box 60857, Rochester, NY 14604; 714-458-5455
Price: $17.20 (includes shipping and handling) pbk, 248 pages
Reviewed by: Jodi Ruquoi, MS

Angela Muir VanEtten spent her first two years of life in the Wilson Home for Crippled Children in New Zealand, where she was known as the "little blond doll." Born with Larsen's Syndrome, she was one of five children whose parents have some wonderful ideas about their daughter: that shortness of stature did not mean "short-comings" and that she would be treated just like her siblings. If her siblings have even one half of her sense of humor and one fourth of her intelligence, their mealtimes must have been something to experience.

This extraordinary young woman, who earned a degree in law, has written a warm, humorous, personally revealing, and very realistic book about her life as a short statured person.

It is a book for parents, relatives, educators, professionals, disabled people, and short statured people. Chapters include medical considerations, social skills, independence, sports and recreation, school experiences which include higher education and career planning. She speaks honestly about her experiences, emotions and sexual relationships as well as her physical limitations, such as shopping for groceries and going to the movies.

Her capacity to love and be loved in founded in her faith in God. Her joy in life and unwillingness to give an inch to discouragement is a model for all of us. She willingly tells us of her emotional pain and attempts to find that "perfect soulmate."

Some new parents may not be ready for her directiveness and humor, while others may be grateful for it. This an anecdotal narrative which will make you tearful, thoughtful and cause you to smile in recognition of the commonality of the human experience. You will never again look at a dollhouse, or a little blond doll, in the same way.

ORGANIZATIONS

OXALOSIS AND HYPEROXALURIA FDT

This new support organization provides support, information and referral for patients with hyperoxaluria and their families. The organizers are trying to locate affected families in the United States to offer support and research opportunities. For information, contact Anne M. Dayton, 24815 144th Place SE, Kent, WA 98042; 206-631-0386. Collect calls accepted.

SOTO'S SYNDROME SUPPORT ASSN

This support group currently consists of about 85 affected children. They would like any other affected families to contact them for information and support. Also, if anyone is conducting research on Soto's syndrome, please contact this group c/o John and Robin Teeple, 4686 Vinton Street, Omaha, NE 68106; 402-556-2445.

STURGE-WEBER FOUNDATION

This organization functions as a clearinghouse for information on all aspects of Sturge-Weber syndrome; acts as a support group for all interested parties; provides information to the general public, medical professionals and government agencies; and facilitates and fund research. For more information, contact Karen L. Ball, P.O. Box 460931, Aurora, CO 80015; 800-627-5482.

Classified • Classified • Classified

The classified listings printed in this issue represent the most recent additions to the NSGC Job Connection 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 FRANCISCO, CA: Jan-June 1991 temporary opening for full time BC/BE Genetic Counselor.
Responsibilities: Work in large, well established pediatric genetics group; counsel in outpatient clinic, inpatient consultations and satellite clinic.
Contact: Vicki Cox, MS, University of California Medical Center, Genetics Office, Room U-100A, San Francisco, CA 94143-0706; 415-476-2757. EOE/AA

TORRANCE, (LOS ANGELES) CA: Immediate Opening for BC/BE Genetic Counselor. Full or part-time, negotiable.
Responsibilities: Comprehensive prenatal service in academic setting, serving diverse ethnic/socioeconomic population; opportunity for participation in pediatric genetic clinic, inpatient consultations, hemoglobinopathy screening; professional and community education.
Contact: Linda R. Burney, MA or Adam J. Jonas, MD, Harbor UCLA Medical Center, Medical Genetics, 1124 W. Carson, Bldg E-4, Torrance, CA 90502; 213-533-3759. EOE/AA.

PALM BEACH, FL: Immediate Opening for BC/BE Genetic Counselor. Experience preferred. Salary Range: $30,000, with excellent benefits including pension plan, liberal education allowance and all moving expenses.
Responsibilities: Counsel for CVS, amnio, MSAFP and other genetic indications. Coordinate MSAFP screening program and general pediatric genetics clinic.
Contact: Dr. Gene Manko or Dr. Jay Trabin, Genetics Institute of Florida, 1401 Forum Way, Suite 210, West Palm Beach, FL 33401; 407-697-4200. EOE/AA.

BOSTON, MA: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: Prenatal position in start-up, full-service cytogenetic laboratory affiliated with Harvard Medical School.
Contact: Michael Mitchell, MD, Beth Israel Hospital, Division of Laboratory Medicine, 333 Brookline Ave, Boston, MA 02215; 617-735-3893. EOE/AA.

CHARLESTOWN, MA: Immediate Opening for BC/BE Genetic Counselor with interest in research and clinical activities.
Responsibilities: Coordinate patients in variety of research projects - HD, NF, dystonia, tuberous sclerosis - at internationally recognized molecular neurogenetics laboratory; direct clinical responsibility at large bimonthly NF clinic; participate in ongoing and independent research projects.
Contact: Dr. Jonathan Haines or Dr. Xandra Breakefield, Massachusetts General Hospital, Molecular Genetics Laboratory, Neuroscience Center, Bldg 149, Charlestown, MA 02129; 617-726-5725 (JH) or 617-726-5728 (XB). EOE/AA.

BALTIMORE, MD: Immediate Opening for BC/BE for Genetic Counselor to serve as Project Coordinator, Huntington's Disease Testing Program. Knowledge of molecular genetics useful.
Responsibilities: Patient education and counseling related to HD, includes coordinating clinical and research visits; overseeing data collection and data analysis.
Contact: Jason Brandt, PhD, The Johns Hopkins Hospital, Division of Medical Psychology, Meyer 218, Baltimore, MD 21205; 301-955-2619. EOE/AA.

DETROIT, MI: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: Pediatric and prenatal genetic counseling, including CVS, amnio and diagnostic ultrasound. Opportunity for newborn screeening, outreach and education.
Contact: Lester Weiss, MD, Director, or Judith Johnson, MS, Medical Genetics and Birth Defects Center, Henry Ford Hospital, 2799 W. Grand Blvd, CFP-4, Detroit, MI 48202; 313-876-3188. EOE/AA.

WINSTON-SALEM, NC: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: Wide range of responsibilities including: pediatrics, MSAFP, prenatal diagnosis and specialty clinics.
Contact: I.T. Thomas, MD, Bowman Gray School of Medicine, Dept. Pediatrics, 300 S. Hawthorne Road, Winston-Salem, NC 27103; 919-748-4321. EOE/AA.

BROOKLYN, NY: Immediate Opening for BC/BE Genetic Counselor. Four/five day schedule negotiable.
Responsibilities: General genetic counseling in obstetrics and pediatrics setting at major medical school-affiliated teaching hospital.
Contact: Eve Beller, MS, SUNY Health Science Center at Brooklyn, Box 24, 450 Clarkson Avenue, Brooklyn, NY 11203; 718-270-2072. EOE/AA.

BUFFALO, NY: Immediate Openings for 2 BC/BE Genetic Counselors.
Responsibilities: 1) All aspects of pediatric and adult genetic counseling and case management; occasional obstetric patients. Community and professional education. 2) Primary responsibility for Cooley's Anemia Project. Potential for other duties. Community and professional education. Both positions carry faculty positions.
Contact: Richard W. Erbe, MD or Susan Jones, MS, Children's Hospital, Div Human Genetics, Buffalo, NY 14222; 716-878-7411 (RWE) or 716-878-7530 (SJ). EOE/AA.

NEW YORK, NY: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: Research position in major linkage studies of movement disorder group, including dystonia, essential tremor involves wide range of responsibilities from clinical to database management; opportunities for education, genetic counseling and facilitating support groups.
Contact: Deborah deLeon, MS, Neurological Institute, Box 77, 710 W. 168th Street, New York, NY 10032; 212-305-5779. EOE/AA.

NEW YORK, NY: Immediate Openings for tw BC/BE Genetic Counselors.
Responsibilities: Join comprehensive genetic program in major teaching hospital affiliated with Mount Sinai School of Medicine. Medical genetics division, pediatrics department, has on-site cytogenetic lab, providing pre/postnatal service: MSAFP screening, ultrasonography, prenatal diagnosis, dysmorphology, general genetics. Special projects include psychosocial and cross-cultural counseling. Research and educational oopportunities available.
Contact: LaChonne Walton, Personnel Recruiter, Beth Israel Medical Center, 421 E. 14th St, New York, NY 10009; 212-420-2431. EOE M/F/H/V.

DAYTON, OH: Immediate Opening for BC/BE Genetic Counselor in newly established, private, regional facility.
Responsibilities: Counsel for CVS, amnio, MSAFP and other genetic indications.
Contact: Richard J. Hildebrandt, MD, Genetics and IVF Institute of Ohio, L.P., 1100 S. Main St, Dayton, OH 45409; 513-228-GIVF.

PORTLAND, OR: Immediate Opening for BC/BE Genetic Counselor in well-established HMO setting.
Responsibilities: Join team to provide genetic counseling for wide variety of conditions; participate in prenatal diagnosis program; coordinate and administer clinical services
Contact: Judy Parmenter, Kaiser Permanente, 3600 N. Interstate Ave, Portland, OR 97227; 503-280-2991. EOE/AA.

SEATTLE, WA: Immediate Opening for BC/BE Genetic Counselor.
Responsibilities: Join comprehensive hospital-based pediatric genetic counseling team with major teaching and research programs; function independently in CF & MD clinics; serve as liaison to regional DNA bank and DNA diagnostic services.
Contact: Bonnie Pagon, MD or Linda Ramsdell, MS, Childrens Hospital and Medical Center, Medical Genetics, 4800 Sand Point Way NE, Seattle, WA 98105; 206-526-2056. EOE/AA.

MADISON, WI: Immediate Opening for BC/BE Genetic Counselor
Responsibilities: Join large, active team in well-established, comprehensive, expanding program. Services include: prenatal genetics, teratogen counseling, dysmorphology, pediatrics, stillbirth, metabolic, bone dysplasia, Down syndrome and other specialty clinics with cytogenetic and molecular genetic laboratory support. Opportunity for professional education includes medical students, residents, genetic counseling graduate students. Flexible assignment of responsibilites, depending on interests and desired growth directions.
Contact: Richard M. Pauli, MD,PhD or Catherine A. Reiser, MS, Wisconsin Clinical Genetics Center, UW-Madison, 1500 Highland Ave, Madison, WI 53705-2280; 608-262-9722. EOE/AA.

SURVEY OF MEMBERSHIP FOR SPEAKERS BUREAU

The NSGC is initiating a speakers bureau and media response system to meet the growing need for lecturers, panelists and experts in various areas of genetics and genetic counseling. If you are interested in participating in this program, please copy this form, complete the information and return it to the Executive Office. (See page 6.) There is no deadline for response; however, your early response will enable us to make appropriate referrals to requests for speakers and contacts within our membership.

— Maureen Smith-Deichmann, M.S., Project Chair

1 Name (please print!) _____ Telephone(day) _____ (evening) _____

2 Location (city and state, only) _____

3 Total Years of Genetic Counseling or Related Experience (as of July 1, 1990)

4 Degree(s) Held (Please specify the field, specialty or area of concentration, if applicable.)

❑ B.A.	❑ B.S.	❑ M.A.	❑ M.P.H.
❑ M.S. (Gen Coun)	❑ M.S. (Other)	❑ M.S.W.	❑ Ph.D.
❑ R.N.	❑ B.S.N	❑ M.S.N.	❑ M.D.
❑ J.D.	❑ Other (specify) _____		

5 List any special or unique interest, ability or background (i.e. foreign language, sign language, personal experience with a genetic disability or condition) _____

6 List areas of professional expertise or completed research in genetics or genetic counseling (published articles, books, video productions or unusual slides) _____

7 Do you have public speaking experience? ❑ Yes ❑ No If yes, approximately how many times do speak annually? (circle one category) 1 - 5 6 - 10 11 - 20 >20

8 Please indicate which of the following types of speaking experiences you have had. (circle one or more)
Lectures Workshops Panels Group Facilitator Workshop/Panel Moderator

9 What size audience are you most willing to address? <50 50-100 100-300 300-500 >500

10 Do you usually require an honorarium? ❑ No ❑ Yes Please indicate a range $ _____

11 Please indicate those speaking engagements in which you require travel reimbursement (TR) and/or an honorarium(H).
• Local ❑ TR ❑ H • Nearby City (> 50 mile radius) ❑ TR ❑ H • Out of State ❑ TR ❑ H

12 Rate your willingness to participate in the following: *1 = highly willing 2 = moderately willing 3 = not willing*
TV _____ Radio _____ Newspaper _____ Magazine _____

13 Use the following scale to rate those topics you are willing to address in a public speaking forum or media interview.
1. Highly comfortable and would welcome providing input
2. Moderately comfortable and still learning
Please leave blank those areas in which you do not have expertise.

_General Genetics and Genetic Counseling
_Support Groups/Family Resources
_Teratology
_Embryology
_Prenatal Testing
_Prenatal Testing for Specific Disorders
_GCs with Alternative Education
_Fetal Alcohol Syndrome and Substance Abuse
_Outreach Services
_Infertility
_Legal Issues
_Ethical Issues
_Political Issues
_Cross Cultural Issues
_Legislative/Regulatory Issues
_Professional Education and Training of GCs
_Developmental Disabilities
_Psychological/Psychosocial Issues of GC
_Newborn/Genetic Screening
_Bereavement, Loss and Grieving
_DNA Technology/Clinical Applications
_Genetic Education in Public Schools
_Expanding Professional Roles
_MSAFP Screening
_Public Health and Genetics
_Underserved Populations
_The Human Genome Project
_Reimbursement for Genetic Services
Other _____

14 Additional comments that might be helpful for our speaker's bureau database... *(Use reverse side of copy, if needed)*

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

Legislative Briefs

NEW LEGISLATION TO AFFECT WOMEN; WOMEN'S HEALTH

The following legislation has been recently introduced and needs your support. Please contact your legislators:
c/o Senator _____ ,
U.S. Senate, Washington, DC 20510;
or
c/o Rep _____ ,
U.S. House of Representatives, Washington, DC 20515.
The U.S. Capital Switchboard is:
202-224-3121.

Women's Health Equity Act (HR5397)

The Congressional Caucus for Women's Issues has recently introduced a package of bills which would increase the Federal research, services and prevention commitment to women. Legislators are increasingly aware that the majority of health-related issues have never been investigated in women (the majority of NIH clinical studies are conducted on men, only); only 13% of the NIH budget is slated for women's health issues; and neither an OB nor a GYN research branch exists at NIH. Clearly, many clinical questions related to prenatal diagnosis and the health of women with genetic conditions could be answered through increased research efforts.

The entire package of bills can be supported by backing HR5397. The following are three of the major research components of the package. Feel free to contact me for a complete list of these bills.

- The largest bill in the package is the Women's Health Research Act, HR5290, which calls for the establishment of an "Office of Women's Health" within the Department of Health and Human Services (HHS); for a Center for Women's Health, Research and Development at the National Institutes of Health (NIH); and for an NIH Intramural program in OB/GYN. These efforts would cost $20.3 million for the first year, a very small amount for the Federal government, and would greatly improve the current funding disparity for research efforts.
- The Clinical Trials Fairness Act, HR5345, would codify existing NIH policy requirements for the inclusion of women and minorities in NIH funded research.
- The Women and AIDS Research Initiative, HR 5392, would expand NIH clinical trials in women affected with AIDS.

Medicaid Family Care Act of 1990

In a major effort to increase maternal and child health, two bills (S3002 and HR5536) would expand Medicaid to fund residental alcohol and drug treatment programs for pregnant and postpartum women, their infants and their children. Currently, Medicaid does not pay for any non-hospital based residential alcohol or drug treatment. Pregnant women are particularly needy because they have traditionally been excluded from most residential centers. In addition, most residential centers that *do* accept pregnant and post-partum women cannot accomodate their infants or children, forcing mothers to choose between treatment or their children. These bills would provide Federal matching dollars to states that choose these options, providing a stable funding base for comprehensive family-centered residential alcohol and drug treatment services for up to 12 months post partum.

The availability of long-term alcohol or drug treatment for pregnant women is essential for the prevention/amelioration of serious alcohol and other drug related birth defects.

Please note: To support these bills, please contact your legislator and the Committee that has jurisdiction over Medicaid — Sen. Lloyd Bentsen of the Senate Finance Committee — address above, Zip 20510-4301; and Rep. Henry Waxman, House Health and Environment Subcommittee, address as above, Zip 20215-0524.

Trish Magyari, M.S.