

Presidential Address

What a fabulous opportunity; to address ones colleagues. To share ones philosophy with those who practice genetic counseling. On an individual basis, I enjoy philosophical discussions emensely. I only wish there were opportunity for each of you to respond with your ideas in an open exchange.

One fantasizes about this opportunity as soon as one becomes President-Elect. Right now Joan Scott is imagining what she will say when she takes the podium next year. I bought a new suit immediately. It was a size six. It became apparent in April that I would have to reconsider my wardrobe choice. In July, I bought a beautiful red maternity dress for the occasion. I have since had the opportunity to see a photo of me in that dress. Once again, I had to reconsider my plans.

Once my wardrobe dilemmas were solved, I then settled into serious consideration of my personal philosophy of the profession of genetic counseling and my visions for the National Society of Genetic Counselors.

One of my long-standing hopes for the profession has been for us to establish a unique and recognized professional identity. My impression is that this dream has been realized.

I have observed and participated in many professional discussions over the years which centered on what genetic counselors do or what they felt they should be doing. Insecurities about our roles caused us to sometimes sound defensive. Such discussions occur less and less often and there appears to be a more widespread acceptance and understanding of the field within the health care community.

During the NSGC-sponsored meeting at Asilomar conference center in September, training program directors along with professional and lay advisors gathered to discuss several aspects of graduate training. Despite the diversity of the group, few, if any, discussions ensued regarding professional identity. It was assumed that we recognized and agreed upon the roles of genetic counselors. This was very rewarding in that it provided an atmosphere condusive to exploring future expanded roles and training for genetic counselors.

Several other of my initial dreams for the profession have been realized as well. Professional roles have expanded, increasing opportunities for autonomy exist, and senior level positions have been created. The tenth anniversary of the NSGC provides us with a reminder of the many accomplishments of our profession. It also provides us with a platform to focus on the future.

Until now, the Society has faced many administrative tasks,

such as establishing an Executive Office and becoming fiscally responsible. While an enormous amount of forethought and diligence has been required to establish and run the Society over the past ten years; we can entertain where we want the Society to be ten years from now.

Cheshire Puss, she began, rather timidly, as she did not at all know whether it would like the name: however, it only grinned a little wider. "Come, it's pleased so far," thought Alice, and she went on. "Would you tell me, please, which way I ought to go from here?" "That depends a good deal on where you want to get to," said the Cat. "I don't much care where," said Alice. "Then it doesn't matter which way you go," said the Cat.

In these familiar words, Lewis Carroll challenges us with two concerns which apply to the future of our profession. First, that we consider where we hope to go. And second, whether we look to the Cat for that direction.

Alice was in an unfamiliar place and sought direction from the Cat. In establishing the genetic counseling profession, many other health care providers and colleagues were consulted for direction, ideas and support. During our orientation, we looked to the Cat. This trend has oftentimes continued and I suggest to you that ten years later, we should be looking more to ourselves. We are embarking on a future which we can influence, create, expand and discover.

There are some current trends in our profession which should cause us to consider the consequences and act to influence their direction. As many of you are aware, there are more positions available than the genetic counseling training programs fill with new graduates. While this increase in demand allows us more negotiation power, it has also lead to a loss. Individuals without graduate training in genetics are being hired to fill positions entitled, "Genetic Counselor," oftentimes at competitive salaries. This trend could continue and challenges us to respond constructively, both as a Society and as individuals.

Several books have been published recently which describe genetic counseling. For example; Barbara Katz-Rothman wrote in The Tentative Pregnancy. "By avoiding the whole issue of abortion, and instead focusing the session on the test, how it works and what it does, counselors can separate the decision to have an amnio from deciding about abortion, and preserve their feeling of nondirectiveness. Unfortunately, when a bad result comes through, the counselor often loses control of the situation as the physician steps in." Clearly we do not benefit from being depicted in this manner. Yet the public purchases such resources in the absence of texts authored by genetic counselors. And such descriptions reappear in articles which target the lay community.

Simultaneously, state governments are limiting reproductive options for our patients. Perhaps this represents one of the greatest challenges we face in the next ten years. Funding and institutional resources are less readily available and the future looks bleak. Our Society has a pro-choice policy and an obligation to protect our patients' options. Until the future of prenatal gene therapy has arrived, termination remains a less than ideal, but important choice for families. Women have less rights to make personal choices, faced with restricted reproductive freedom.

In addition, direct billing for a genetic counselor's services rarely occurs. One argument is that genetic counselors are not licensed. Lack of licensure also limits our access to medical malpractice insurance and independent practice, despite the gains made by ABMG certification.

Single disease counselors or genetics assistants are new terms used to describe individuals trained to provide alternative genetic counseling services. Concern has been raised by some counselors that these allied health workers may overlap with genetic counselors in job roles. Their training is more limited in scope and does not provide them with the expertise to provide general genetic counseling. Yet, due to the limited number of graduate trained counselors and the rising costs of health care, employers may choose to hire them.

Each of these trends challenges the Society and its members. Who should take action on these issues and how? If your answer is the NSGC, who do you perceive that to be? One of my personal objectives for this year as president is to attempt to remove any mystique you may have about the Society. This professional organization represents you, it is you. It should function under your direction and as a result of your efforts. It is not sufficient to assume that someone else is going to address the trends I have outlined or the many other growing professional, social and educational issues before us. The Board of Directors is nominated by you, voted upon by you and represents you. You compose the committees. The active members of this Society did not all graduate from the same graduate program or come from the same region of the country. We do not all share the same philosophy or have the same priorities. As it should be, we now represent a diverse and fascinating group of professionals. And it is indeed a priority and challenge to ensure that actions taken by the Board represent the majority of your concerns and values.

I urge you to get more involved in your professional Society. Because we remain part of a relatively small profession, we need to have a significant proportion of the membership active in order to address the issues at hand. Impact your

professional future. If you are a new member or have not been active in the past, serve on a committee or help to plan next year's annual education conference. Write an article for "Perspectives in Genetic Counseling." If nothing else, communicate your priorities for the Society to your regional representative so that your voice is heard. Its your direction that the Society should follow.

There is an urgent need for you to recognize your political power and communicate with your legislators; on an ongoing basis. Educate legislative aides about our profession and the services we offer families. They are often the ones who guide the legislators. Meet with the budget advisors. They may influence legislation to the greatest degree. Join political organizations which represent your views. Contact the media. If you are discouraged from doing so by your institution, do so as a private citizen. Respond to NSGC legislative alerts. Become an active member of the Social Issues Committee.

Due to the onslaught of new genetic discoveries and the current manpower shortages, single disease counselors are going to continue to exist and should exist. Educate yourself about their training and discover ways you may become involved in that. Work to insure that your institution differentiates between their role and yours. Discover ways the roles may complement one another. Propose different job titles, position descriptions and salaries. Identify ways in which genetic counselors may oversee these individuals. Of course, you can sit back and simply voice your concerns. The Cat seems friendly and would clearly be willing to direct our future.

Spend a day in the bookstore perusing books which address topics you are competent in. You will be convinced that you can write something more accurate or more useful than what you find. Address the general public who is bombarded with misinformation or sensationalized information. Genetic counseling suffers from a serious public relations problem. We need to be informing the public about what we do and how we serve them. When others write about us, we are not necessarily depicted as we would choose to be.

If you arrange an interview, set some guidelines to help guarantee that the outcome is acceptable to you. Recently, I was misquoted in the Winter/Spring 1990 Special Edition of Newsweek. While public relations experts claim and Gza gza Gabor claim that some publicity is better than none; misinformation will not clarify the confusion about our profession. I have spent more time writing to parent groups to explain the misquote than I spent doing the interview. But if we do not agree to interviews, there will be little opportunity for accurate exposure.

If your area of expertise is clinical research, then publish professionally. We may choose to develop a professional journal. If so, there will be a tremendous demand on us to publish our work. The clinical research we produce will help to further our academic recognition. Professional writing may be our springboard into the development of doctoral programs in genetic counseling; one of the topics discussed at Asilomar in September and one which begs further consideration.

My last challenge to you is that you help to recruit bright, energetic people to enter this field. Contact college career offices, at least your alma mater. Attend college career nights. Invite interested students to visit your center. Lecture to undergraduate classes, as well as high school. If you are enthused by the unique contribution you have to make in the health care community, spread the word. Form an attachment to an apprentice and encourage him to strive for excellence in his graduate training. Contribute to identifying who will continue on in our profession.

Each year I attend this conference, I am struck by your energy and intelligence. You have a passion for your profession that is quite apparent to those of us who share it. That passion breeds opinions about your Society and the future of your profession. Make them known to more than just your close colleagues.

You may not all agree with me about what I have identified as current issues or trends in the profession. I took a risk in sharing my personal thoughts with you. If they cause discussion and even some controversy, then I have succeeded in lighting a spark. I hope to launch you into a responsive second decade. Just as I have hopes and dreams for Baby Boy Biesecker, so do I for the National Society of Genetic Counselors. He is sure to let his needs be known to me, and I hope you will do the same. I look forward to the honor of serving you as your President in the coming year.