

Leading Voices and the Power of One

2002 Presidential Address to the National Society of Genetic Counselors

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I dedicate this presidential address to my father Paul Bennett—"Pablo" as he is affectionately called. My father retired as chief test pilot at Boeing. He demonstrated the power of only choosing a career that you love, so that some days you shake your head marveling that you actually are paid for doing what you love best. He showed me that a sense of humor is a critical life characteristic. But most important, he taught me the thrill of living your career at the edge—to push the envelope to try new things. Granted I do not have the same sense of adventure that compels me to eject from a speeding jet. But it is probably a bit of this genetic spirit that convinced me that I should sing "I'm My Own Grandpaw" (Latham and Jaffe, 1947) when I presented the National Society of Genetic Counselors (NSGC) genetic counseling consanguinity guidelines to the Royal Society of Medicine (Bennett *et al.*, 2002). It is also the thrill seeker in me that allows me to meet the challenges of being President of the NSGC.

My father and I have many parallels in our careers. At age 19 when he first became a fighter pilot and headed off to the Korean War, radar was not a fine art (Fig. 1). You flew in formation watching your squadron mate's wing-tip. If your comrade misjudged direction, you followed, even if that meant into the ground. When I first walked through the doors of Sarah Lawrence College 20 years ago, the

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Fig. 1. Paul "Pablo" Bennett, fighter and test pilot. (Reprinted with permission. All rights reserved.)

landscape of genetic counseling was being formed. There were no “flight manuals” to dictate the “hows” of genetic counseling; unlike today where we have Baker, Schuette and Uhlmann’s *Guide to Genetic Counseling* (Baker *et al.*, 1998). We did not have Schneider’s classic text on cancer genetic counseling (Schneider, 2002). The NSGC was only 3 years old. There are currently as many genetic counselors in the NSGC’s Cancer Special Interest Group as were in the whole NSGC in 1982. The coffers of the NSGC budget consisted of a grand total of \$13,645 (less than my graduate school tuition). Look how far we have come! Like test pilots, genetic counselors continually take leaps into uncharted skies. Our intensive training and our Code of Ethics (National Society of Genetic Counselors [NSGC], 1992) guide us in knowing the route that is the best practice to serve our clients with genetic knowledge delivered in a compassionate and noncoercive manner.

The year 2003 marks the 50-year anniversary of Watson and Crick’s discovery of the structure of the DNA molecule. The advances in molecular medicine over this time period are stunning; but so are the accomplishments of the genetic counseling profession. This is a time to celebrate the dawning and growth of the profession of genetic counseling. Genetic counselors are pioneers too. NSGC will be doing our part to assure that our profession is well represented at this celebration. We plan to have a display at the Smithsonian describing the profession of genetic counseling as a consumer service and a career choice.

To have the opportunity to serve as President of the NSGC is the greatest honor I can imagine. I first decided to be a genetic counselor when I was 14 years old. The problem was, I really did not know the profession of genetic counseling at the Master’s level existed. My mother’s best friend had a profoundly retarded son, who years later would be diagnosed with Angelman syndrome (www.genereviews.org). I saw the devastation and the gifts he brought to his family. If you asked me at age 14 what I wanted to be when I grew up, my reply would have been, a doctor or maybe an embryologist. No career counselor ever told me about the Master’s level programs in genetic counseling (www.kumc.edu/gec/prof/gcprogs.html). Granted there were only about five programs at that time. Thank goodness that one day in my Senior year I stumbled upon the description of the Sarah Lawrence Human Genetics Program in the library (Marks and Richter, 1976).

Today, certainly more career counselors know about the field of genetic counseling, but genetic counseling has hardly reached the mainstream radar as a career choice. Through the work of Stephanie Kieffer and the Membership Committee, NSGC will continue to strive for recruitment to the field of genetic counseling with an emphasis on diversity. Wouldn’t it be amazing if someday genetic counseling was at the same level of elementary career choice as pilot, doctor, nurse, police officer, and firefighter?

My 5-year-old daughter Maren wants to be a genetic counselor. She is quite intrigued by the whole idea, especially that her mother is President of the NSGC. She is one of our best spokesmen as she boldly tries to explain to grocery store

clerks about what I do. This summer she had the unfortunate experience of being hospitalized in the pediatric intensive care unit. As she was being loaded into the ambulance, she sought preferred status with the emergency technicians with the comment, "You know my mother is a President." Upon arrival at the hospital she promptly informed the phlebotomist, "Please do not take all my DNA." Perhaps ours will be among the first families with two generations of genetic counselors. Evan, my 7-year-old son has more humble aspirations—he wants to be a postal worker; that way he can see me everyday when he delivers my mail. Colin, my 9-year-old son has no interest in being a genetic counselor, although he has watched me draw so many pedigrees that he actually has taught his first and second grade classmates this art form. He thinks that we are crazy for calling them family trees, because pedigrees look nothing like trees. But, I figure if first and second graders can draw pedigrees with standard pedigree symbols, there is hope that pedigrees can become part of mainstream medicine (Bennett, 1999).

We need to be better advocates to explain our professional training. How many of you have ever sat on a plane praying that your seatmate will avoid asking "So, what do you do?" You were really looking forward to reading the latest best selling novel. You cringe at the idea of once more explaining that "No, I am not a geriatric counselor" or "No, I am not a generic counselor" (although we certainly feel like it sometimes). You answer the usual questions about cloning, and even at the end of this conversation, you are not quite sure you have convinced your seatmate of what you do. Even our patients often do not seem to realize that our title is "genetic counselor." I often wish I had a sticker or a pin that I could give my clients stating "I just saw a genetic counselor." We must continually educate our clients as to our specific training and certification. With such advocacy, perhaps genetic counseling will become a household word, just as the average person knows the basic skill-set of an occupational therapist, a physician assistant, or a nurse practitioner. Wouldn't it be amazing if there were signs in office complexes listing a genetic counseling practice sharing space with mainstream professional practices such as law firms, dental practices, and chiropractors?

How exactly do we define our profession? The (Ad Hoc Committee on Genetic Counseling, 1975) American Society of Human Genetics' definition of genetic counseling is widely quoted.

Genetic counseling is a communication process which deals with the human problems associated with the occurrence or risk of occurrence of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family to: (1) comprehend the medical facts including the diagnosis, probable course of the disorder, and the available management, (2) appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives, (3) understand the alternatives for dealing with the risk of recurrence, (4) choose a course of action which seems to them appropriate in view of their risk, their family goals, and their ethical and religious standards and act in accordance with that decision, and (5) to make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder.

Has this definition really evolved with our profession? Does it really define what we do? As challenges to this definition, I refer you to Beisecker and Peters's presentation at this meeting (Beisecker and Peters, 2002), "Genetic counseling: ready for a new definition?," as well as Walker's discussion in a *Guide to Genetic Counseling* (Walker, 1998). Genetic counselors should define our scope of practice. It is time that NSGC either claim this definition as our own, or we develop our own definition. Therefore, as NSGC's president I will form an ad hoc committee with the assistance of Kristin Shannon of our Professional Issues committee, to take a critical look at this definition.

The NSGC membership is composed of an incredibly talented group of professionals. You are expert geneticists, educators, therapists, business and marketing professionals, authors, communicators, researchers, and managers among countless other skills. The NSGC is not an organization that values one skill-set or cluster of credentials after a name above another. However, licensure is essential to the continued existence of the genetic counseling profession. This is a protection for the public. A genetic counselor who is not licensed is still a valued member of the genetic counseling profession, but that person will not be able to provide direct clinical service.

We as genetic counselors cannot afford to sit idle as the palette of options of genetic testing explodes. We must face the hard reality that not every person who has a genetic test will see a Board certified genetic counselor. Like my father the test pilot, there are many people who can fly an airplane, but when things get complicated, I am sure that you would much prefer that my father be at the controls of that plane rather than a Sunday afternoon flyer. We must lead by example. We must be open to considering different models of delivery of genetic counseling. We need outcomes research on alternative methods of genetic counseling such as telemedicine and possibly phone counseling.

Let me share with you an example of the muddy waters of defining our scope of practice, and the need for broad education as to exactly what it is genetic counselors do. A client with a strong family history of cancer suspicious of retinoblastoma (www.genereviews.org) was referred to us for genetic counseling by her surgeon. The referral was denied because the insurance company requested that the surgeon, "... document the family history, define the genetic test requested, assess the likelihood of a positive test result, and define the management if the test is positive." This was the surgeon's reply:

"To whom it may concern,

I am responding to your letter refusing genetics consultation on my patient, and suggesting that we do pedigrees, etc. on her. You are forgetting who you are writing to. I am a surgeon. Remember, we are not cognitive professionals. I don't know how to do pedigrees. The only people who do pedigrees are genetic counselors and dog breeders. Since she is not a dog I thought the geneticist would be the best fit, and thus my request.

Frank and Ernest



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Fig. 2. Frank and Ernest. (Reprinted with permission. All right reserved.)

Perhaps you will still refuse our small and humble request. Then, in keeping with Frank and Ernest (Fig. 2), we will send her to you for genetic counseling.”

The preauthorization was promptly granted.

There is a medical practice in my region that is providing cancer genetic services. The nonphysician practitioner has taken training courses in cancer genetics, but has no formal training in genetic counseling. While I believe that this person has excellent skills, our practice sees many of the clients who were told in this clinic that they had a low risk for developing breast cancer. Many of these clients tote along beautiful graphs of Gail and Claus model risks demonstrating a bottom-line low risk calculation for developing breast cancer. After our evaluation, we find the family actually has Cowden syndrome or Li-Fraumeni syndrome (www.genereviews.org). Cancer genetic counseling is more than Gail (Gail *et al.*, 1989) and Claus (Claus *et al.*, 1991, 1994) model risks, and determining the likelihood of finding a BRCA1 or BRCA2 mutation. I hear from these clients, “I already had genetic counseling, but, it wasn’t the same as this.” While I do my best to not criticize their former professional interaction, I also do my best to define the “this” that they receive from me, and to educate them as to my professional credentials and training.

I recently saw a woman with a family history classic for a BRCA1 or BRCA2 mutation. Her primary health care professional easily assessed the family history, and told her “You need to have this genetic test, but first your sister with a diagnosis of breast cancer needs to be tested.” Initiating conversations about genetic testing with her family had basically brought all communication among my client, and her mothers and sisters to a halt. Her family was trying to survive their cancer, and they did not want to embark on genetic testing. My client had no children. She had always accepted her increased risk for developing cancer. She was appalled at the thought of her body being mutilated by prophylactic surgery. She was tearful throughout our session. My client’s referring health professional made all the appropriate diagnostic choices; but no one, until our session, listened to the words

and emotions of this woman's choice. She was comforted to learn about support groups, and that she could always choose to be tested. We talked about what medical advances would need to occur for the BRCA1 and BRCA2 testing to be meaningful to her so that she would know when she did "need to know" this information. She agreed to keep in contact with me. She thought her sisters would benefit from formal genetic counseling, and they were referred to a genetic counseling center nearby. The genetic risk assessment took me 5–10 min; the counseling took years of my training. This is what we do differently.

The field of genetic counseling is in critical need of published outcomes research to prove whether genetic counseling as provided by master's trained genetic counselors makes a difference. I would argue that just because genetic testing and the ability to define genetic disease became more accessible, the genetic counseling issues did not become any simpler. In fact, in the realm of complex disorders like cancer, mental illness, dementia, and heart disease, the clinical and family issues grow even more complex—particularly because it is difficult to have a true negative test result (King *et al.*, 2002). The course of action given a positive (abnormal) test result is also murky because of such complicated issues as penetrance and variable expression. Our clients are dealing with complicated and emotionally charged decisions. Don't clients deserve more than a 15-min interaction when they are considering tests where the options are removing their breasts or ovaries? Let's prove it.

The NSGC is dedicated to educational opportunities for genetic counselors to gain new skills in research, and to have funding opportunities for projects. The Engelberg Foundation has made an amazing commitment to advancing research and education in genetic counseling by establishing a 1.5 million dollar endowment for the perpetual continuation of the prestigious Jane Engelberg Memorial Fellowship award of the NSGC. The expansion of the Audrey Heimler Special Projects Award with a generous \$25,000 gift from the Engelberg Foundation and additional private donations, is also an opportunity for research expansion in outcomes of genetic counseling. Over the summer I met with leaders at the National Human Genome Research Institute (NHGRI) to discuss ways of facilitating outcomes research in genetic counseling. We are planning a grantmanship seminar sponsored by the NSGC, with speakers from NHGRI and JEMF awardees. This will be modeled after the successful grantmanship seminar sponsored by the JEMF in 1996 (Bennett, 2002). With an educational grant of \$75,000 from Transkaryotic Therapies, the NSGC will be able to provide fellowships for participants to attend this seminar. We are planning to offer this seminar at least three times.

How does NSGC continue to be the "leading voice, advocate and authority of the genetic counseling profession?" I refer you to the quarterly reports of the Board and the NSGC liaisons (www.nsgc.org) as proof that your leaders have been busy! They provide public testimony in many venues, give media interviews, and comment on misconceptions in the press. Several NSGC leaders were active in the

Secretary's Advisory Committee on Genetic Testing (SACGT). Kathy Schneider sent a letter requesting NSGC representation on the newly formed Secretary's Advisory Committee on Genetic Health and Society (www4.od.nih.gov/oba/sacghs.htm). At the NSGC Board meeting we will be considering the value of hiring a lobbyist, now or in the future. We are morphing into a new corporate identity. Your NSGC leaders are doing everything possible to "sit at all the right tables." But we need your assistance. As an NSGC member you should notify the NSGC leadership if you are aware of activities where NSGC should have a presence. For example, recently a colleague posted on our listserv wondering why NSGC is not an member of a large umbrella organization for allied health professionals. From this e-mail, a group has now gathered under the auspices of the Professional Issues Committee to consider membership in this and similar organizations, so that NSGC can continue advocacy for genetic counselors to be recognized as nonphysician health providers.

Over the next year I plan to facilitate the beginnings of our new strategic plan. The Board and the NSGC membership will look at our vision of success for NSGC, compare our organizational strengths and weaknesses, and analyze opportunities, challenges, and threats to NSGC. We need an environmental scan—a critical look inward at NSGC. How are NSGC and the profession of genetic counseling perceived by other health professionals, by our genetics colleagues, by consumers of genetic services, and by the public? The NSGC Board will take the pulse of our profession, to assure that the NSGC and our executive office are meeting the demands of the profession, just as genomic medicine places new demands on our professional skills.

The one voice of NSGC is composed of the individual voices of our members. You can make a difference. You should jump at any opportunity to speak about the profession of genetic counseling or your individual area of expertise. Accept and even solicit media interviews. Publish, publish, publish! Write about your daily practice. I know how much time some of you spend in case preparation for your clients. Why not share this diligent work with your colleagues—transform your work into a genetic counseling practice guideline with the assistance of Barbara Pettersen and the Genetic Services Committee.

My publishing career has been blessed with several popular articles, pamphlets, book chapters, and two books. Do I have incredible research skills? No. I simply write about what I do. For example, I wanted to teach people the art of drawing pedigrees, an everyday occurrence in genetic counseling. Yet pedigrees symbols were not standardized (Bennett *et al.*, 1993; Steinhuis *et al.*, 1995), and the method of collecting family history was not committed to paper. With a great deal of support from my colleagues, I accomplished both of these tasks (Bennett, 1999; Bennett *et al.*, 1995). The April publication of the NSGC genetic counseling guidelines for consanguinity received a mind-boggling amount of media attention that no-one anticipated (Bennett *et al.*, 2002). In fact, a journalism student contacted

me because she is writing her thesis on the media stir these guidelines created. The idea to write the consanguinity guidelines started simply with a group of genetic counselors and medical geneticists who wanted to commit to paper their everyday knowledge; and, with a \$3000 grant from the NSGC Special Projects Fund, we were able to do so.

I have the good fortune of working with some of the most successful medical geneticists in the world (<http://depts.washington.edu/medgen/>). Their feathers were a bit ruffled when the NSGC genetic counseling guidelines for consanguinity received such remarkable media attention; they are the researchers discovering major disease genes. They teased me about why my work received this attention. I told them “not everyone has some of the rare conditions that you study, but everyone has had a crush on their cousin.” We do important work that reaches the lives of everyday people. You as genetic counselors must take every opportunity to publish your work, to continue to validate the profession of genetic counseling.

You are probably thinking “fine Robin, but I do not have time”; but you do. Take the airplane challenge, and next time you are sitting on an airplane, do not wait for the person next to you to ask “So, what do you do?”—tell them who you are and what genetic counselors do. Ask the clinicians in your workplace to join NSGC. The NSGC welcomes to our membership anyone who shares our passion for genetic counseling in the many arenas of practice that this passion can be expressed. Your colleagues will be intrigued by the many benefits of NSGC membership, including our excellent journal, informative listserv and educational conferences. Agree to write one article about any aspect of your work; case studies are just as valuable as more complex research. I published a case study on a woman with mental retardation, schizophrenia, and a deletion, and a putative locus for schizophrenia was mapped through this family (Bennett *et al.*, 1997). Even if you offer to give one additional lecture a year, think of the people you can reach. If each person at this conference reached an additional 20 people over the next year, that would be over 20,000 people educated about genetic counseling. If you would stretch just a little further, and fill that lecture hall with a few more people, we can easily reach enough people in one year to fill Seattle’s Husky Stadium. If you still cannot donate your time, considering donating money directly to NSGC or our soon to be formed Foundation.

I confess that when I graduated from Sarah Lawrence College in 1984, I did have the dream of being president of this organization. I also dreamed that the meeting that year would be in Hawaii. I never dreamed that my work would eventually lead to being “above the fold” of the New York Times (April 4, 2002). My husband now boasts that he is married to a “Cosmo girl” (October 2002). I can tell you that it is very fun to be distracted from dictating because Robert Siegel of NPR’s “All Things Considered” and Martin Short from the BBC are “on-hold.” Don’t be shy. If you have an article about to be published, contact Angie Trepanier of the Communications Committee or Bea Leopold, our executive director, so that our public relations firm can be notified, and the appropriate interviews can be

arranged. You may see your work featured as one of the top 10 news stories on CNN or MSN!

I am honored to serve as your President. Over the next year I commit to doing my part to assure that NSGC as a professional organization is speaking with one voice, as the leading voice, advocate and authority of the genetic counseling profession. I commit to continuing to search for funding opportunities so that the NSGC has the financial means to do our work. I commit to assuring that the Board is working as a team to reach the objectives of their committees and regional activities, and to steer the course of NSGC in the future. The 2002–2003 NSGC Board is an incredible group of volunteers advocating on your behalf. But, you must do me a favor. You must take that extra step to make your voice heard—through committee work, professional and lay publications, public speaking, recruitment of new members, perhaps even private donations. I look forward to hearing your voice.

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