

2000 Presidential Address to the National Society of Genetic Counselors

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The National Society of Genetic Counselors (NSGC) and the genetics community in general have experienced a year of unprecedented activity. The first rough draft of our genome has been completed. Think about the enormity of that statement—The first rough draft of our genome has been completed. This has truly been a banner year. The NSGC, and many of its members, has been quoted in print and television news, featured in documentaries, and acted as advisors to legislators at both the state and federal levels. We have gained access to federal committees, to lobbying groups, and to international genetics federations. Counselors in California will soon have the ability to apply for licensure, and will enjoy the exclusive use of the title “genetic counselor” in their state. We have engaged a marketing firm which will spearhead our efforts to raise awareness of the services we provide, of the growing need for those services as the secrets of the genome are unraveled, and of our leadership in the genetics community.

These achievements are extraordinary, and can be attributed to the commitment of past presidents, past and current board members, but equally importantly, to those in our membership who have assumed leadership roles in their communities and within our society.

These successes must be tempered, however, by the tasks we have yet to accomplish. Many of our colleagues continue to have difficulty obtaining reimbursement for the services they provide, or work for centers that have decided to abandon attempts to obtain reimbursement for genetic counseling. Many members work every day in fear of losing their positions. Our patients have yet to enjoy protection from genetic discrimination in their workplaces and the Americans with Disabilities Act has been severely limited by recent Supreme Court decisions. Our patients’ right of reproductive freedom is in grave peril, and could be lost with the

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appointment of the next Supreme Court justice. At a time when an unprecedented number of new jobs are advertized, the perception of some of our membership is that genetic counseling is a career that offers little advancement and low salaries. There is much work yet to be done.

As I look ahead to my role as president in the coming year, ironically I find myself looking back as well. Looking back, to the time when I was a young, impressionable, and difficult genetic counseling student. I find many similarities between the hurdles we must overcome as students, and the hurdles we now face as a profession. I had the privilege of training at the UC Berkeley genetic counseling program with some extremely gifted, wise, and, thank goodness, patient, genetic counselors.

Early in my training, I was convinced that I would never master the “art” of genetic counseling. Perhaps there are some students in the audience who can empathize with this fear. I have vivid recollections of panicky discussions with my supervisors, desperate to be imparted the secret recipe. . . . the “how to” book of genetic counseling. Much to my frustration, when I pressed my supervisors to share the secret, which I was certain was being withheld from me, they would reply with the most hated phrase of my graduate training: “Trust the process,” they would say, “trust the process.” Unfortunately, “Trust the process” didn’t comfort me much at the time. In fact, my reply to this statement usually sounded like “What do you mean, trust the process? That’s no help! I pay tuition, and you should be teaching me how to do this!”

Perhaps there are some program directors who have had similar salvos fired at them, and can empathize with my teachers. Trusting the process was much too threatening a concept for me. I interpreted “Trust the process” as a completely external process. I thought it meant that if I waited long enough, my teachers would get around to teaching me. That the truths would be revealed in time, and I just needed to be patient. I thought that “Trust the process” meant trust the supervisors, the curriculum, the required reading, and the faculty. It never occurred to me that “Trust the process” meant I should consider trusting myself, that I should trust my instincts, my intuition, and my ability to establish rapport with patients. Trust that I could be nondirective. Trust that I could advocate for my patient, even if it meant standing up to her obstetrician or oncologist, her husband, father, partner, or grandmother. It slowly began to dawn on me that trust the process wasn’t meant to be passive at all. This revelation came as an extraordinary relief, and I began to take responsibility for my training. I developed a narrow focus and concentrated on what occurred in my office, and a genetic counselor was born. In those early years of work, as I fine-tuned my technique, the outside world rarely intruded.

I worried less about whether I was going to get it right, and more about actually doing the work. I began to feel successful, and thought I had left “trust the process” behind. It was a distant memory of a challenging time, a time of growth,

but no longer relevant in my professional life. I was a genetic counselor, and I was helping my patients.

Slowly, though, it became clear that I could not limit my practice to the goings on within my office. The outside world and its impact on my patients began to intrude. Each of us has his or her own stories. The patients denied genetic counseling or testing because these benefits were uncovered, and who could not afford the out-of-pocket expense. The patients who decline presymptomatic testing because of the perceived risk of genetic discrimination at work, in insurance, or within their own families. When we concentrate only on that which occurs within the confines of our offices, we miss the bigger picture, and deprive our patients of our expertise, our drive, our persuasiveness, and our determination. It is outside our offices where we advocate, where we empower. We need not confine our ambition to make a difference only for the individual patient. We can, and must, think bigger than that. But how?

I am reminded of a passage in one of my most favorite John Irving novels. *The Cider House Rules* takes place in a small New England town called St. Cloud's. We are introduced to a physician who runs a maternity hospital/orphanage/abortion clinic, who is fully aware of the contradictions and synergies of his many roles.

"Here in St. Cloud's," Dr. Larch wrote, "I have been given the choice of playing God or leaving practically everything up to chance. It is my experience that practically everything is left up to chance much of the time; men who believe in good and evil, and who believe that good should win, should watch for those moments when it is possible to play God—we should seize those moments. There won't be many. Here in St. Cloud's there may be more moments to seize than one could find in the rest of the world, but that is only because so much that comes this way has been left to chance already."

So much has been left to chance already. I would substitute the phrase "playing God" for "advocate" or "empower" instead. What if Dr. Larch had said, "We should watch for those moments when it is possible to advocate for our patients; to empower them. We should seize those moments."?

I propose that our patients and we live in St. Cloud's, for genetic disease is the ultimate chance. We have embraced a specialty over which we exert precious little control (Ironic, isn't it, that a society of individuals so fond of being in control have chosen a discipline over which we exercise so little). Although we cannot change the test results, the course of the disease, the eventual onset of symptoms, or the pregnancy outcome, we believe passionately that we can help our patients to survive, to navigate through difficult circumstances.

First, always first, we must strive to help our patients when they are in our offices. We support them, encouraging them to choose the best course for themselves. We educate them to understand the risks they face. We empower them so that they can inform their family members of issues that affect them. We hope our patients will obtain from us and from themselves what they need in order to

consent to the tests that they deem appropriate, and decline those that they find to be without merit. We work to convince them that they can make these decisions without fear of our judgment or disapproval.

We must do more than all of these admirable and lofty goals. We must acknowledge that our patients live in a world that is larger than the confines of our offices. Patients cannot choose to undergo genetic testing if they do not feel safe from discrimination. They will not participate in the research that will expand our knowledge of disease if they do not believe their privacy will be protected. They will not obtain services if they have no access to care. They will not share information with their family members if they are not secure in the knowledge that we will keep confidential what they tell us. They will not make informed decisions without the ability to choose between the options presented.

We have sworn, in our code of ethics to

- Keep abreast of societal developments that may endanger the physical and psychological health of individuals.
- Participate in activities necessary to bring about socially responsible change.
- Serve as a source of reliable information and expert opinion for policy-makers and public officials.
- Keep the public informed and educated about the impact on society of new technological and scientific advances and the possible changes in society that may result from the applications of these findings.
- Prevent discrimination on the basis of race, sex, sexual orientation, age, religion, genetic status, or socioeconomic status.
- Adhere to laws and regulations of society. However, when such laws are in conflict with the principles of the profession, genetic counselors work toward change that will benefit the public interest.

A tall order, but one from which we must not shrink.

So, how do we do this? We trust the process. We approach the media, becoming the most informative, easiest to understand group of genetics professionals, positioning ourselves to be among the first approached by the media, not the last. We use our teamwork ability to join with our M.D. and Ph.D. colleagues to argue for CPT codes thereby removing obstacles to reimbursement for M.S. level providers. We use our tenacity to raise awareness of possible misuses of genetic information, and support legislation to protect our patients and their families. We advocate for our patients' right to privacy whether related to confidentiality of medical records or the right of reproductive freedom guaranteed by *Roe v. Wade*. We support access to genetic services provided by appropriately trained providers via initiatives to promote licensure in all states. We demonstrate our understanding of and sensitivity to the provision of genetic services by developing recommendations and practice guidelines. We remain sensitive to the needs of a diverse patient

population, and encourage diversity within our own ranks. We commit ourselves to genetic education so that we may keep abreast of the advances in genetics and appropriately inform our patients. We make sound fiscal decisions to protect the NSGC, and its ability to respond to the changing health care environment. We vow to teach all this to the new generations of genetic counselors.

The exploration of our genetic heritage poses both great promise and great risk. We must teach the policymakers, the media, and the community of the implications of this knowledge. We must trust that our persuasiveness and our energy can exert change. We must trust the process.