

2001 Presidential Address

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The career path of a genetic counselor can be compared to the cycle of life—from those tottering first steps after graduation from a training program to full maturity as a supervising genetic counselor. Someone once said, “The first half of life we strive for success. The second half of life, we strive for significance.”

The strive for success, professional success, is a linear journey where efforts are focused inwards and upwards and successes are personal ones: Handling that first difficult case. Giving your first “bad news” result. Getting a well-deserved promotion and raise. Earning the recognition of your peers. Once you’ve hit your stride professionally, your attention then turns to striving for significance where the motivation is making a difference and efforts are focused outwards to the National Society of Genetic Counselors (NSGC) and beyond: You will become involved in mentoring and teaching, serving on committees, writing position statements, and contributing to research. The linear track of personal successes has turned into a circular process of growth and mentoring. Going from that first “thank God I’ve got one” job to creating that perfect position for yourself and helping others do the same. From sitting in an audience listening to lectures to giving them yourself and from reading articles to writing them. Starting as a new member of NSGC to becoming one of its leaders.

More than 20 years ago a handful of people sat in a room and spoke of a professional society for genetic counselors. They spoke of a Vision, an Identity of our own. And the lifecycle of the National Society of Genetic Counselors began. An excerpt of a poem by Mary Oliver captures how I view our beginnings.

One day you finally knew
what you had to do, and began,
though the voices around you
kept shouting

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their bad advice—
 though the whole house
 began to tremble
 and you felt the old tug
 at your ankles . . .
 But you didn't stop.
 You knew what you had to do,
 Though the wind pried
 with its stiff fingers
 at the very foundations,
 though their melancholy
 was terrible.
 It was already late
 enough, and a wild night,
 and the road full of fallen
 branches and stones.
 But little by little,
 as you left their voices behind,
 the stars began to burn
 through the sheets of clouds
 and there was a new voice
 which you slowly recognized as your own, . . .

The Journey (Oliver, 1992)

And there was a new voice which you slowly recognized as your own. The NSGC has its own voice. A strong voice. An important voice. Oh, sometimes it seems as though no one is agreeing with us or even listening. But that should not cause us to falter or question ourselves. We simply need to raise our voices louder and to find different words to use. We need to stop worrying that talking with others will cause us to lose our distinctive voice. It won't. It is only by joining these discussions that our voice has a chance of being heard. And remember—a voice joined by other voices only becomes stronger.

NSGC has its own voice. But actually, we are a collection, a chorus if you will, of many different voices. What is NSGC? The answer: you are. You are NSGC. Not the executive office, not the Board of Directors, but each of you. So if there is something that NSGC should say, then find a way to say it. If there is something that NSGC should do, then find a way to do it. With each of us taking the initiative and working together, we will ensure the continuation of our successes.

The Journey to find our own voice has been filled with both challenges and accomplishments. Let us celebrate how far we have come. Take pride in our collective achievements. We have gone from having to convince Genetics Departments to hire us to having job opportunities in an array of medical specialties. Look

around you and you will see genetic counselors working in prenatal, pediatric, and adult specialties. In public health, public policy, molecular laboratories, internet start-up companies, clinical research departments, and pharmacogenetics. You will see genetic counselors who are Faculty Members, Program Directors, and PI's of projects. Our vision of "what is a genetic counselor" has expanded to a dizzying "the sky's the limit" number of possibilities. We are a success. We *are* the leading voice, authority, and advocate for the genetic counseling profession.

The first half of life we strive for success. The second half, we strive for significance. As members of NSGC, we will continue to handle challenges as they arise and add to our successes. But we also want to have an eye towards attaining "significance." As the benefits of The Human Genome Project move from the lab bench to the clinic, we need to take a lead role in the education of patients and their families—and their physicians, nurses, and other health care providers. We need to keep fighting for fair access to health care and genetic discrimination legislation. We need to ensure quality genetic counseling services—through Board certification, continuing education, supervision groups, and even state licensure. Our efforts can and will make a difference.

During this Business meeting, we heard about the many accomplishments that have occurred over the past year, thanks to Vivian Weinblatt's leadership, a lot of hard work on the part of everyone who served on the Board of Directors or on a committee, and of course the support of the Executive Office headed by Bea Leapold.

Yet there is more work to be done. The Journey continues. As President, my goals for next year fall into 4 categories: policy, membership, marketing/public relations, and education. Here is what I hope we can accomplish over the next year:

1. Policy—We need to strengthen our presence in Washington, DC. We need to increase our visibility and our clout with the people who are creating genetic policies and regulations. This includes our Senators and Congressmen and governmental agencies such as the National Institutes of Health, the National Human Genome Research Institute, the Federal Drug Administration, as well as the Centers for Disease Control based in Atlanta. The Social Issues Committee chaired by Karen Eanet Wolff and especially the Legislative Subcommittee, headed by Cheryl Scacheri, will stay busy next year. We need to speak in a louder voice and find different words to use.
2. Membership—I want to help identify new strategies for increasing our membership. Working with Nisha Isaac, chair of the membership committee, we want to encourage genetics health care providers both nationally and internationally to join NSGC. One strategy is to foster closer ties with other professional organizations, especially the American College of Medical Genetics, American Society of Human Genetics, International

Society of Nurses in Genetics, and the Canadian Association of Genetic Counselors. A voice joined by other voices only becomes stronger.

3. Marketing/Public Relations—I will work closely with our Marketing/Public Relations Consultants to increase our visibility among consumers, hospitals, and others. With the creativity and efforts of the Communications committee, chaired by Liz Stierman, we will increase coverage in the media and further expand our web site content and links. And assisted by Kristin Shannon, head of the Professional Issues Committee, we will continue efforts to improve billing and reimbursement and increase the number of licensed genetic counselors. This is how we will ensure success.
4. Education—And lastly, I will focus on efforts to educate patients and providers about genetics and genetic counseling. Together with the Genetic Services Committee, headed by Kristen Niendorf and the Education committee, headed by Kelly Ormand, we will explore ways of improving or standardizing our educational and counseling efforts. It is through Practice Guidelines and Position statements that everyone will recognize all the shades of gray inherent in what we do. These efforts increase our professionalism and can be considered our legacy. It is a way of attaining significance.

The mission of NSGC is to promote the genetic counseling profession as a recognized and integral part of health care delivery, education, research, and public policy. A friend of mine who works in finance recently remarked, “It must make you feel good going to work every day, because what you do really matters.” This was an important reminder. What we do does matter. But if your job is like mine, it isn’t always easy to remember this amidst the daily hassles of ringing phones, stressful clinic schedules, and way too many staff meetings. But I want to emphasize this point: What we do does really matter.

The world itself feels different than it has in years past with the newspaper headlines speaking of fear and hatred. Yet none of this diminishes the importance of what we do as individuals and as a society. We need to continue speaking in a collective voice filled with knowledge and compassion. As your President, together with your Board of Directors and the help of each of you, we will make sure that what we do continues to matter—both now and in the future.

REFERENCE

- Oliver M (1992) The Journey. In *New and Selected Poems: Mary Oliver*. Boston: Beacon Press, pp 114–115.