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## 2005 National Society of Genetic Counselors Presidential Address: Raising Our Voice

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### INTRODUCTION

I feel very fortunate to have the occasion to serve as president in this exciting time of tremendous opportunity for the National Society of Genetic Counselors (NSGC) and the profession of genetic counseling. The NSGC began with an amazing vision, almost 30 years ago, by genetic counselors who understood that in order for the profession to grow they would need to seek opportunities and take risks. Today, members of the NSGC embrace our responsibility to continue to enhance and develop this profession by doing what our founders did—seeking opportunities and taking risks. The stated vision of NSGC is that we are the *leading voice, authority and advocate for the genetic counseling profession*. By looking at the sizable list of our accomplishments, it is clear that, through hard work and dedication, the NSGC has been true to its vision; we are indeed the leading voice of the genetic counseling profession. We are now in a unique moment full of opportunity, and it is time for us to raise the volume and to extend the reach of our voice, so that the values of this profession will be more widely heard around the nation and beyond. *This is our challenge. This is our opportunity.*

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### WHAT WE VALUE

As the leading voice of the profession we must continue to clearly articulate our values. We do this in many ways, for example, through our published position statements, practice guidelines and Code of Ethics. We value client autonomy and informed decision making. We value the scientific research that daily provides us with new options for diagnosis, prevention, treatment, management, and cures for genetic health problems. We value ourselves as health professionals, and our colleagues with whom we work to promote access to high quality clinical genetic services, as well as responsible social policies related to genetic research, testing and health care. We value the competencies we share in communication, critical thinking, counseling skills and professional ethics. We value the genetic counseling research that serves to describe, develop, assess, and measure the effects and effectiveness of how we apply these skills to better serve our clients.

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### OPPORTUNITIES

The practice of genetic counseling has changed dramatically over the past three decades, and will

continue to evolve at a more rapid rate than ever before over the next years. As a profession, we need to expand our skills and define our roles to meet the challenges of providing clinical genetic services in the 21st century. Acting on our Strategic Plan, NSGC has already begun this process in two crucial ways—by developing our Scope of Practice, and by delineating effective and efficient genetic counseling service delivery models. Jointly, these are crucial steps in defining, refining and expanding our role in genetic health care. NSGC's ongoing efforts to promote the value of certification and licensure in genetic counseling assure that our clients will continue to be served by well-trained, competent and caring health professionals. Genetic counselors have a history of developing new skills to meet new challenges. An increasing number of us are extending our expertise in emerging areas of practice, such as adult genetics and cancer, research, policy development and industry. Our roles and responsibilities as well as the settings in which we work have grown in breadth and depth, and will continue to expand.

There is an urgent need to increase not only the number of genetic counselors, but also diversity within the profession. Each of us is responsible for promoting the profession to assure that there will be adequate numbers of genetic counselors to meet the current as well as future increased demand for services. We must implement strategies for increasing and welcoming diversity in our profession. Several of our members have already shown great leadership in this arena, and we need to continue to support and contribute to these efforts. We also need to deliberately join forces with our sister organizations, the American Board of Genetic Counseling (ABGC), and the Association of Genetic Counseling Program Directors (AGCPD) on these and other issues where the missions of our organizations intersect.

Another part of NSGC's current strategic plan is to build key relationships and increase our visibility. We must use our "voice" to promote our values by engaging in conversations outside our organization. We have challenged ourselves to build on and expand our current partnerships and collaborations with outside groups, and have developed mechanisms for doing this in a deliberate and strategic way.

There are also opportunities for NSGC to engage in conversation and build partnerships and collaborations internationally. Among us are members who have already embraced opportunities to increase our understanding of global issues in training

and practice in genetic counseling. We need to continue to engage in conversations and form collaborations to address common issues and meet common goals that exist among our international colleagues despite differences in systems of health care delivery. It is by embracing these and other opportunities that we continue to meet the NSGC mission and live our vision. But the responsibility for making this happen lies within the entire membership.

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## RESPONSIBILITIES

The strength of NSGC and the future of genetic counseling depend on our shared commitment to each other and to the profession. Our leadership is strong and there are, literally, hundreds of active members in this organization. Every NSGC member shares the responsibility for moving the profession forward. There are numerous opportunities, to become actively involved in NSGC, and every volunteer activity is important and valued. I urge every member of the NSGC to consider this your *personal* responsibility. You cannot wait for others to get the job done. Instead, you must find ways that you can actively contribute to the effort. I encourage each of you to join an NSGC committee and respond to requests for volunteers that can be found at our website and in *Perspectives*. It is up to you.

Similarly, as a professional organization, NSGC cannot depend on others to do the work needed to meet our goals. For example, in pursuing our goal to achieve billing and reimbursement for genetic counseling, we did not sit back and hope that other organizations or groups would take the lead. We gathered our resources, educated ourselves, and developed strategies for moving this goal forward. NSGC invested financial resources, and volunteer leaders and members invested considerable time and energy in the process. We solicited the advice of experts, and engaged the support and collaboration of our colleagues, specifically the American College of Medical Genetics. We will continue these activities and ultimately we will be successful. NSGC will employ similar active strategies in tackling current challenges and seizing new opportunities. The Board is excited about the potential for using resources that will be available to us through our partnership

with Smith Bucklin to take NSGC to the next level. New partnerships and collaborations will be formed and new initiatives will be launched. And the success of these will depend on the active commitment and involvement of the membership. The responsibility lies with us—each one of us.

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## **BUILDING ON OUR SKILLS**

Our ultimate success in responding to challenges, seizing opportunities and meeting our goals requires that we empower our leadership and our membership with the knowledge and skills required in a given activity. For example, if we are to be effective in promoting a change in public policy, we need to fully understand the legislative process, and develop the skills needed to promote our cause effectively. We need to use the talents we have, partner with individuals and groups who have the expertise we need, and develop new skills that will enable us to have a greater impact in wider circles. We need to not only build on our own successes, but also to think beyond ourselves and seek expert advice in developing strategies for success. NSGC is committed to putting resources into activities that will educate and empower our membership. Leadership skill training that was piloted at several Regional meetings last year will continue in the upcoming years. We also plan to take full advantage of the skill building resources available to us through our partnership with Smith Bucklin so that our volunteer leaders can identify strategies for effectively and efficiently meeting their goals.

## **TAKING RISKS**

The profession was started by people who had vision and were willing to take risks. The first genetic counselors entered a profession that was for the most part, uncharted. They tackled the unknowns, and used courage and creativity to define the profession. They demonstrated their value and quickly became invaluable. They embraced genetic counseling as a profession—not just a “job”. They understood the risks they needed to take in order to secure the future of the profession. We need to continue to learn from the wisdom of these pioneers in our profession, continue to increase and promote our

value, continue to take risks and to chart our own course. At the same time, we need to benefit from the perspectives and energy of our younger members and inspire them to continue to define and revise the vision for the profession. Leadership is about having the vision to project into the future and managing change. We get to decide what role we will play in clinical genetics in the 21st century. It is up to us.

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## **CONCLUSION**

In closing, I encourage each of you speak up and speak out! Articulate our values, promote our mission, live our vision. Yes, this is a time of transition, but in reality, change is a constant. Every NSGC member shares the responsibility for achieving our mission *to promote the genetic counseling profession as a recognized and integral part of health care delivery, education, research and public policy.* We must work together to face our challenges and seize the opportunities available to us. We must use our talents while developing new skills to achieve our goals. We must recognize that leadership involves the ability to see into the future and set goals, and that growth involves taking risks. We must work together to define and secure our own future as a profession. We must respect the wisdom of our past leaders and embrace the vision and energy of our newer members and future leaders. In the words of Melissa Richter, the founder of the genetic counseling profession, the future *does* hold much promise.

## **ACKNOWLEDGMENTS**

I am grateful to my current and former students who help me keep an open mind, and with their energy and enthusiasm keep me solidly invested in the profession I love. I would also like to recognize my colleagues, family and friends for their ongoing support. They help me keep my perspective and sense of humor. Finally, I want to recognize my parents, Vera and Brandy Persichilli. They were people who faced their challenges, seized their opportunities and took risks to achieve their goals, and it is from them that I learned these important life lessons. I dedicate this talk to them.