

National Society of Genetic Counselors Natalie Weissburger Paul Lifetime Achievement Award Address: *The Power of Connecting*

Wendy R. Uhlmann

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I am truly honored to receive the Natalie Weissburger Paul Lifetime Achievement Award from the National Society of Genetic Counselors (NSGC). The NSGC has played such an important role in my professional life and I feel fortunate to have had the opportunity to play an active role in this organization. I want to thank the Awards Committee, Samantha Baxter, MS, CGC for her introduction and congratulate the other award recipients who no doubt will be standing up here one day given all of their impressive contributions and achievements.

Receiving this award in California is particularly meaningful. I attended my first NSGC conference in San Diego in 1987 and my whole class was here – all two of us. It was in 1996 in San Francisco, that I received NSGC's Regional Leadership Award. I was not notified about the award in advance as was the custom in those days. It was the end of the meeting and I went to the awards presentations just prior to meeting my cousins who were taking me to the beach and so I was wearing underneath a purple blazer a T-shirt that read "DNA is Life, The Rest is Just Details." Today, I am more

professionally attired! It was also in California, in Oakland, in 1999, that I gave my presidential address and started my term as NSGC's President (Uhlmann 2000a).

While this is a lifetime achievement award and came as I turned 50 and received my AARP (American Association of Retired Persons) card, I like to think that I have many more years ahead of being active in genetic counseling and contributing to our profession. Writing a speech that is befitting of this award is a daunting task, especially as one thinks about the prior awardees and their accomplishments. Ultimately, I decided to take this opportunity to reflect on my career and share lessons learned. After much thought, I settled on these words which capture my journey in genetic counseling and my overall philosophy: Volunteer. Network. Collaborate. Be a Lifelong Learner. I will start by sharing some career highlights where these words were put into action:

- **A Guide to Genetic Counseling.** Working on both editions of this book (Baker et al. 1998; Uhlmann et al. 2009) was an incredible opportunity. This is the first book in our field written by genetic counselors (Fig. 1). Program directors and leaders in the field shared their wealth of expertise and it was exciting to see our work described and to have a text for both a reference and teaching.
- **Serving as Co-Chair of the 1995 NSGC Annual Education Conference** and seeing the conference successfully come together after 2-years of planning.
- **Serving as President of NSGC (1999–2000)** and working with the dedicated and talented Board of Directors.
- **Testifying to the Secretary's Advisory Committee on Genetic Testing (SACGT)** on NSGC's behalf (SACGT website, Meetings and Conferences section [SACGT, 2000a, 2000b, 2000c]) and later serving on their Work Groups on Test Classification and Informed Consent. It

W. R. Uhlmann (✉)
Department of Internal Medicine,
Division of Molecular Medicine and Genetics,
University of Michigan Health System,
300 North Ingalls, N13 A03, SPC 5419,
Ann Arbor, MI 48109, USA
e-mail: wuhlmann@umich.edu

W. R. Uhlmann
Department of Human Genetics, University of Michigan,
Ann Arbor, MI, USA

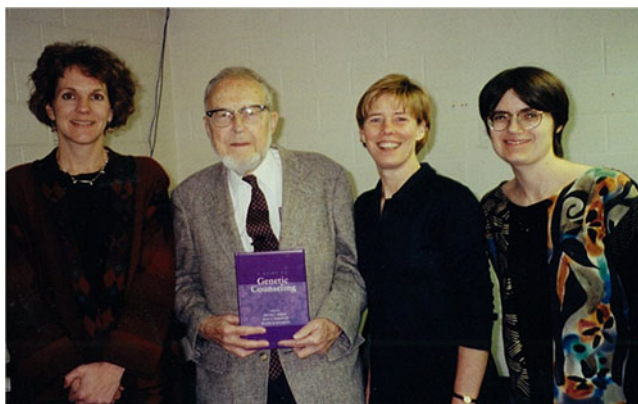


Fig. 1 Co-Editors of the first edition of *A Guide to Genetic Counseling*, Jane Schuette, Diane Baker and Wendy Uhlmann with Dr. James V. Neel (University of Michigan Professor of Human Genetics and Internal Medicine and “Father of Human Genetics”) in 1998. Photo courtesy of Diane Baker, MS, CGC

felt like genetics had hit “the big time” with the Federal government taking note of genetics, looking at oversight of genetic testing and related issues. Both NSGC and individual genetic counselors shared expertise and provided input on the work of the SACGT.

- **Representing NSGC at the White House ceremony** on June 26, 2000 when the draft of the human genome was announced (Fig. 2).
- **Representing NSGC when President Clinton issued an Executive Order** (# 13145) on February 8, 2000 prohibiting discrimination in federal employment based on genetic information ([National Archives](#), [Federal Register](#), [Executive Orders Disposition Tables website](#)).

Fig. 2 Genome Announcement, White House, June 26, 2000. Francis S. Collins, MD, PhD at podium. President Clinton and Craig Venter, PhD seated behind podium from right to left. Kathy Hudson, PhD, (Assistant Director, National Human Genome Research Institute) Wendy R. Uhlmann, MS, CGC (NSGC President) and Vivian J. Weinblatt, MS, CGC (NSGC President-Elect) in first row, from right to left. Photo courtesy of Diane Baker, MS, CGC



This was the first Executive Order of the 21st century and the first Executive Order NSGC has ever endorsed. NSGC was listed in White House publicity statements as an endorser (White House website).

- **New York Times article.** After being quoted in the *New York Times* about President Clinton’s Executive Order (Pear 2000), I was asked by the *New York Times* to write an opinion piece “When Genes Are Decoded, Who Should See the Results?” (Uhlmann 2000b). At that time, my knowledge of genetic discrimination issues was quite limited but using case prep skills, I quickly searched the literature, made some calls to some genetics policy experts and wrote.
- **JAMA article.** In 2008, *JAMA* did a special issue on genomics. Thinking that it was important to share our expertise with the wider medical community, I co-authored an article entitled “Key Internet Genetics Resources for the Clinician” (Uhlmann and Gutmacher 2008). With an acceptance rate of 9%, I knew it was a long-shot to get an article accepted in *JAMA* ([JAMA website](#)). I also knew that the surest way not to get a paper accepted was not to submit one. “Nothing ventured, nothing gained” is something I firmly believe. This experience taught me that it is important to aim high and to keep our eyes open for opportunities to share our genetics expertise.
- **Serving on the Board of the Genetic Alliance** for 5 years (2002–2007), I saw what can be successfully accomplished when organizations partner and work together on global issues. I met some amazing individuals who launched genetic support group organizations from their kitchen tables, created resources and partnered with researchers all

the while they were handling multiple medical issues associated with their or a family member's genetic condition.

- **Working at the University of Michigan.** I have been fortunate in my career to work at a university with a long-standing strong tradition in genetics. Since 1993, I have served as the genetic counselor/clinic coordinator of the Medical Genetics Clinic, which is the oldest and one of the few adult genetics clinics in the country. I have great respect and have learned a lot from colleagues as we have worked together providing clinical care, conducting research and teaching students.

Each year, I interview authors who have written essays on the topic “why I want to be a genetic counselor” – in other words, our future students and next generation of genetic counselors. With this award, I figured it was time to dig into my files and see if I could find the essays I wrote back in 1986. The excavation was worth the effort as I did find copies of my essays for graduate programs that were typed with a type-writer! In my essay, I found themes that echo with today's current students. I found it interesting reading to see how I envisioned using my degree. So what did I write 25+ years ago? I am not going to read my essay in its entirety but will share some excerpts that I feel I can publicly share:

“Since February 1984, I have been working as a cytogenetics technologist at the University of Michigan. Working in cytogenetics has made me even more committed to pursuing graduate work in genetic counseling. Through my job, I have learned all the steps that are required for a chromosome study, from setting up and maintaining cell cultures to analyzing, photographing and interpreting metaphase spreads...As much as I love my work, it is not satisfying enough for me to be involved only in the laboratory end of the clinical picture. I constantly find myself wondering what happens next? How are the parents and the patient going to deal with the genetic disorder? How is this going to affect their family life? It is with these questions and a host of others that I have realized that my career interests lie more in seeing how the chromosome study results are put to use.”

I started my career in genetics in 1984 as a cytogenetics technologist at the University of Michigan, analyzing amniotic fluid and solid tissue samples. I continued to work in the Cytogenetics Laboratory throughout graduate school. To this day, I make a “chromosome cake” (Fig. 3) (chocolate cake, fudge frosting with maize and blue chromosomes, pedigree, block M logo and gel) for the graduating genetic counseling class. In the early days, I used nonpareils to make bands on the chromosomes but this proved to be quite



Fig. 3 Chromosome cake made each year by Wendy R. Uhlmann, MS, CGC for the graduating class of genetic counseling students at the University of Michigan. Photo courtesy of genetic counseling student Lesli Kiedrowski, BS

time-consuming! My chromosome cakes are just one example of my passion for genetics. When the Class of 2006 graduated, I was given the mug “Eat. Sleep. Genetics.” Therefore, it is probably not surprising to learn that when I went to Barcelona with my husband this past summer to celebrate turning 50, I remembered to download the genetics articles I had wanted to read for the plane ride but forgot to download the directions to where we were staying!

When I graduated from the University of Michigan in 1987, the program was 18 months long and there was no research requirement. The research requirement was instituted in the University of Michigan program in 2004. I began to mentor students' research projects, a challenge given that my prior research experience was limited to laboratory technician work years ago and consisted of tasks like feeding geckos and iguanas and slicing and staining brain sections. In all honesty, genetic counseling students were also my teachers as they negotiated the IRB (Institutional Review Board) and research process. I will publicly admit that I did not submit my first IRB until I was in my forties! Now research is a central part of my work and I spend more than 25% of my time doing research. In addition

to genetic counseling students' projects, I am working on research projects with faculty members at the University of Michigan and other institutions.

So what did I say in my essay that I wanted to do as a genetic counselor? How was I planning to use my degree?

"I would be interested in working as a genetic counselor in an urban medical center, including satellite clinics. Having successfully organized several get-togethers for Jewish students and Oberlin alumni, I feel that I could similarly bring together parents, whose children are afflicted with the same genetic disorder, so that they could provide each other with emotional support. I would also be interested in working with clergy, helping them gain an understanding of the complex issues associated with genetic disorders. This would enable them to disseminate accurate information to their congregants and provide appropriate counseling. I would like to be involved in programs that educate the public on genetic disorders and active in community genetic screening. I am most of all interested in working directly with patients, helping them to understand the nature of the genetic disorder, what it will mean for them and other family members and giving them emotional support during this stressful time."

Consistent with what I wrote in my essay, I am working in a medical center, and although Ann Arbor is not urban, I did work 5 years in a prenatal genetics clinic at Wayne State University in Detroit. I served on the Board of Directors of the Genetic Alliance, an organization that brings together individuals with genetic conditions. I also have been involved in programs that educate the public, including programs at synagogues. I have worked directly with patients in prenatal, cancer and adult genetics clinics.

You will note that I made no mention in my essay of editing a textbook, conducting research, being active in genetics policy issues or becoming a leader in the field of genetic counseling. And that is my point. We do not know where our journeys will take us in life. It is important to be open to different opportunities, new experiences and venturing outside of our comfort zone. With our training, we have the ability to broaden our skills in different areas and apply our skills in new arenas. Central to expanding the use of our skills are the concepts: Volunteer, Network, Collaborate, Be a Lifelong Learner.

Volunteer

There are several professional (Fig. 4) and personal (Fig. 5) reasons to volunteer. The fact that you graduated from a genetic counseling program means that you have skills that you can contribute to NSGC and other organizations (Fig. 6).

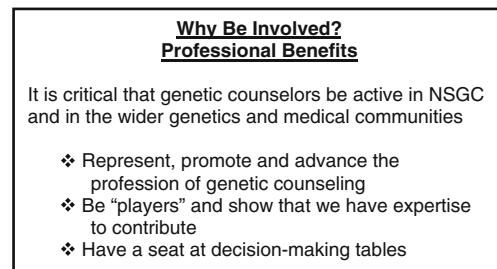


Fig. 4 Professional benefits and reasons to volunteer

These are slides I use in teaching genetic counseling students each year. I started out volunteering for conference planning, reviewing abstracts and working on the professional status survey. While volunteering, I realized that it was ok to say that I wanted to help but I wasn't sure what to do – genetic counselors (and other colleagues) were happy to share their knowledge and mentor so that I could fully participate. I also realized that with volunteering, I was not only helping NSGC but was also gaining skills and knowledge useful in my work.

Network

Networking within the genetic counselor community is a starting point and an important aspect of our professional development and experience. But it is the networking we do beyond the genetic counselor community (Fig. 7) that will contribute to our global effectiveness, expansion of professional opportunities, the advancement of our field and reciprocally will provide others with a greater understanding of the work that we do, skills and expertise we can contribute. At meetings throughout my career, I have frequently found myself at tables where I have been the only genetic counselor. Rather than be intimidated by other degrees and titles, I see these meetings as valuable opportunities for networking and the chance to learn from others. I approach these interactions with the recognition that I have unique expertise as a genetic counselor to bring to the table. For example, the front line experience with patients and with

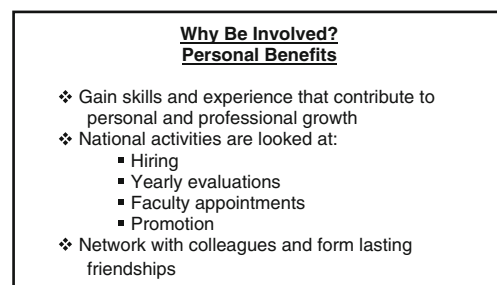


Fig. 5 Personal benefits and reasons to volunteer

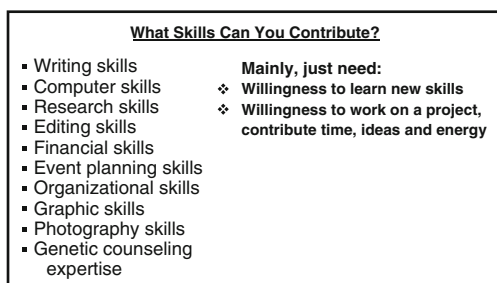


Fig. 6 Skills genetic counselors can contribute to NSGC and other organizations. Several of these skills are learned through training as a genetic counselor

genetic testing issues is a valuable perspective, beneficial to policy discussions and helps ground these discussions in reality.

Collaborate

Over the years, I have learned so much from collaborating with genetic counselors and with others outside of the genetic counselor community. For example, I have worked since 2007 on the REVEAL (Risk Evaluation and Education for Alzheimer’s Disease) research team on an NIH funded R01 study. For over 10 years, this multidisciplinary team has studied the psychological and behavioral impact of providing Alzheimer’s disease risk information using APOE genotyping in a randomized controlled study (Green et al. 2009, Roberts et al. 2011). This research has led me to rethink some of our approaches in providing genetic counseling. For example, what information really needs to be conveyed to patients? Do patients need a genetics mini-lesson? Is less more?

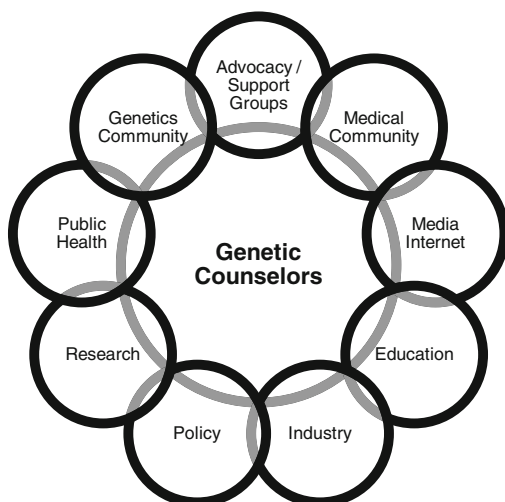


Fig. 7 Networking beyond the genetic counselor community. Networking within and outside the genetic counselor community is important

More genetic tests are likely to be like APOE genotyping for Alzheimer’s disease, providing risk modification and not a “yes or no answer.” Work being done in other fields can benefit our work as genetic counselors and vice versa. There is much to gain from looking through other lenses into the field of genetic counseling. At the same time, we can use our genetic counselor lens on other fields and to provide input on other aspects of health care, research and life. I wrote a piece for newsweek.com entitled “Why We Need to Talk Openly about Death: The Ultimate Homework Assignment” shortly after my father died. I noted in my essay that I was a genetic counselor and dealt with loss issues in my work (Uhlmann 2008).

Be a Lifelong Learner

A commitment to lifelong learning is critical given the rapid pace of advances in our field and doubling of knowledge over shorter time periods. At the beginning of my career, it was much easier to keep up in our field. Now, it is challenging enough to keep up with advances in our own specialty, let alone other specialty areas in genetic counseling. My work with patients and students has been one of the most rewarding aspects of my career. As a result of teaching students and addressing their questions, I too am learning and thinking about our work in new ways. Our patients have much to teach us as they share their journeys about seeking a diagnosis or living at risk or with a genetic condition. Giving lectures, conducting research and writing are other effective ways to keep learning and simultaneously contribute to others’ learning.

Closing Thoughts

The key challenge that lies ahead for our profession is the successful translation of genetic advances into clinical care and the implementation of genomic medicine (Guttmacher et al. 2001). In 2009, Bob Resta wrote a Commentary in the *Journal of Genetic Counseling* articulating how another breast cancer gene discovery would significantly impact the genetic counselors’ workload and appropriately urged us to think about these issues and be proactive (Resta 2009). In my invited response (Uhlmann 2009; 2010), I wrote:

“With the era of genomic and personalized medicine, everyone in the population is potentially a patient. Therefore, there will be a “flood” of patients who will need genetic issues addressed and genetic testing but not all of these patients need to be seen in genetics clinics...Genetic counselors and geneticists do need to be proactive in developing triaging guidelines and

genetic testing algorithms... The genomic train has already left the station and we need to do what we can to keep it on the right track." (Uhlmann 2009, pages 525–526)

Keeping the genomic train on the right track will require that we volunteer, network, collaborate and continue our commitment to lifelong learning. These are exciting times for our profession with many opportunities and I look forward to seeing where our journey takes us in the years ahead.

I want to acknowledge and express my appreciation for Diane Baker, MS, CGC who has been my program director, teacher, advisor, role model and mentor. My pathway to leadership started with Diane saying we had a responsibility to contribute and be active in NSGC. Diane introduced me to her colleagues and leaders in the field, thus facilitating my networking and volunteering. When I became president of NSGC, Diane let me know that I was not just accepting a leadership role in NSGC but was committing myself long-term to be active in the genetics community. I like to think that I have heeded Diane's words over the years and have played them forward by supporting and encouraging students, colleagues and leaders in being active in NSGC and the wider community.

In closing, I would like to express my appreciation to the genetic counseling community, my colleagues at the University of Michigan, my parents (Frank Uhlmann, Ruth Uhlmann and Craig Mathews) and especially my family - my husband, Michael (Simon), an oncologist who directs the Cancer Genetics program at Wayne State University, works closely with genetic counselors and is here today, my daughter Rachel and son Jeremy. Their love, caring, support and even understanding of missed meals have enabled me to do all that I do. To the genetic counselors who have been mentors, collaborators, co-workers and good friends, I would like to express my deep appreciation and gratitude. It has truly been an amazing journey that we have shared and will continue to share.

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