



NCC Advocate Leader Program 2015

In 2004, the Genetic Services Branch (GSB) in the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) awarded grants to support seven Regional Genetic Service Collaboratives (RC) and the National Coordinating Center (NCC). The mission of the NCC and the RCs is to strengthen and support the genetics and newborn screening capacity of the states, to improve the availability, accessibility, and quality of genetic services and resources for individuals having, or at risk for, genetic conditions and their families across the lifespan.

Through a cooperative agreement with the American College of Medical Genetics and Genomics (ACMG), the NCC supports the activities of the RCs through a myriad of activities. To ensure the engagement of advocates and support the regional efforts, the NCC provided funding support to the RCs to send an Advocate Leader to the 2015 ACMG Annual Clinical Genetics Meeting. Individuals were nominated through their RC and received notice of participation from the NCC. In total nine Advocate Leaders were sponsored to participate in Salt Lake City this past year. Advocate Leaders were provided the opportunity to engage with other advocates, as well meeting participants. Participants of the program selected meeting sessions that were of interest to them and then met with the other Advocate Leaders for breakfast and lunch to share their experiences both at the meeting and in their life. The varying background of each advocate leader provided unique perspectives during the program discussions. Additionally, Advocate Leaders were able to converse with genetics professionals in session enabling their unique perspective to be heard. Advocate Leaders shared their perspective through reflections found in this special edition.



In addition to Advocate Leaders participating in the NCC Advocate Leader Program, eleven genetic counseling students were able to attend the 2015 ACMG Annual Genetics Meeting. Through support from Arkansas for the Medical Sciences, University of Oklahoma Health Sciences Center, and Western States Genetic Service Collaborative, second-year genetic counseling students were able to interact with consumers as well as become more fully exposed to the professional world of genetic services. To learn more about the experiences had by the genetic counseling students, please read below.

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Selected Quotes from Advocate Leaders

“To say it was an honor to be selected to participate in the Advocate Leaders Program would be an understatement. As an avid learner, I am always looking for opportunities to broaden my education and to share new research and resources with the families and professionals I serve. This program was one of the best learning experiences I have ever had.

Rosslyn Bethmann
WSGSC Representative

Many of the sessions at the ACMG Annual Meeting were extremely technical, but I was able to choose sessions that seemed relevant to the families I serve and to glean a good deal of information from all of them. We advocate leaders were then able to ask questions and discuss our sessions in a safe environment that provided another layer of information and insight”

Teresa Nold
Heartland Representative

“I have a number of reflections on my experience as a first time attendee at the ACMG Annual Meeting and a participant in the 2015 Advocate Leaders Program. One of the most memorable sessions for me was *Undiagnosed: Medical Refugees*. I was both moved and saddened to hear from families and physicians about the work they have all done to find answers, without much success. I was also fascinated by several sessions covering syndrome-specific information; it was wonderful to hear about new research and treatment options. The pictures used in these sessions were very helpful to me, as was hearing about real-life situations. Being able to put “faces” to the names of various syndromes greatly assisted me in understanding their impact on the lives of those affected by them. I walked away with greater respect for the presenters and for the knowledge and passion they bring to their work.

What I will always remember are the times we advocate leaders, parents, and genetic counseling students spent together. All the discussions we had at our breakfast and lunch meetings were valuable to me. I was reminded that each family has its own story, its own daily struggles, and its own causes for celebration. I do hope, however, that we can all move beyond our own personal stories and become advocates for everyone. There is more to our children than their diagnoses and their genes. The genetic counseling students I met left me

Selected Quotes from Advocate Leaders

Kristen Entwistle
Region 4 Representative

“At our first breakfast meeting, I observed people from all walks of life-- parents, patients, students--all with their own stories and struggles. Listening to the others introduce themselves, I wondered what I was doing there. I hadn't created an organization for Sickle Cell Patients and Families. I hadn't gone through a 12-year process to discover what rare genetic disease my child had. I hadn't been diagnosed with a genetic condition through newborn screening. But as I continued listening, I realized that we could all relate to parts of each other's stories. We could all understand, to some degree, the struggles the others were facing. And eventually, we all opened up to each other--not just about the good things, but the hard things as well.

We cried. We laughed. We sympathized with each other's stories and struggles. We were humbled. We were encouraged. No matter what else this program was supposed to accomplish, it accomplished this: creating a community of advocate leaders who could understand and strengthen each other. Some of us had never had someone else understand what we are going through. That meant the world to us...”

“As a participant in the 2015 Advocate Leader Program, I was able to share not only the unique challenges we face in Alaska, but my unique perspective as the parent of two children with a rare genetic disorder. For example, during the poster presentation on Russell Silver Syndrome, I was able to give the presenter much more information on the topic, including some to pass on to the parents of the Canadian child she wrote about...

Rachel Vandiver
WSGSC Representative

I was also able to bring home a great deal of information I gleaned from the vendors at the conference. I plan on sharing these resources whenever I can. I was completely amazed at the advances in technology now available to genetics professionals. I believe that if some of these new technologies had been available a few years ago, my son would not have had to wait five years for diagnosis and treatment. I was also interested to learn of all the emerging advances in preventive genetics. I am excited at the prospect that many lives can be prolonged or saved in the future. However, I left concerned about how and when genetic professionals will share information on new tests patients and who will decide if the tests are worth the cost”

Selected Quotes from Genetic Counseling Students

“The discussions that were part of this program also gave me entirely new perspectives on a myriad of topics. Hearing parent stories about upsetting and unsatisfactory encounters with genetics professionals when they first learned of a diagnosis made my heart ache. I already knew these results disclosure sessions were important, but the stories told by family members really hit home. For the first time, I truly understood how these sessions can shape a family’s whole experience during the initial phases of a child’s disease. Additionally, hearing in-depth stories about how these patients and their families felt at certain periods during their diagnostic journey helped me learn how I can improve my own counseling skills in order to best help my patients through difficult times.”

Jordan Hills

University of Arkansas for Medical Sciences Representative

“One of the many things [my advocate leader pair] taught me, which I will certainly take into my practice, is that one size does not fit all. She told me always to ask, “How can we best accommodate you?” rather than assuming that what we have to offer is best for the family. She explained that she has different needs for a translator than do her son and husband. She also stated that getting adequate translation services is a problem they encounter every time they attend an appointment. When using interpreters, I will never again assume that the translations they are providing are what a specific patient or family member needs.”

“As providers we need to be able to meet families where they are and create a trusting relationship that is truly a two-way street leading to the best outcomes for the patients. Each family of a patient with a genetic condition and each individual within that family have different perspectives on the patient’s condition and its impact on his or her life. Each needs the opportunity to be heard. Providers also need to be heard, and I think the advocate leaders came away with an appreciation of providers’ desire to help support them and improve their lives. I believe they were able to hear the frustration we feel when when we are not able to provide answers that are useful to them.”

Michelle Takemoto

University of Minnesota

Christine Bruha
University of Arkansas for Medical Sciences Representative

Selected Quotes from Genetic Counseling Students

Kristina Hermann
*University of Oklahoma Health
 Sciences Center*

“...During one meeting in particular, the advocate leaders described negative interactions they have had with health care professionals and the feelings with which these interactions left them. To me, it was clear that a negative interaction with one health care professional can color a patient or parent’s impression of an entire clinic or health care facility. This was a little hard to swallow, but is a good thing to know. Through that conversation, it also became clear to me, in a way it hadn’t before, that there is a difference between what a health care provider says and what the patient or parent hears or absorbs. Serious miscommunication can happen, even if a health care provider is well intentioned. I now understand that I must keep in mind this potential for a communication gap when I communicate with patients and their families.”

“As a genetic counseling student, I spend most of my time reading and learning. In trying to remember all the information I need to share with patients, I have a difficult time keeping in mind the whole picture and remembering that my appointments with them constitute only a sliver of time in their complicated lives. I heard stories about how the advocate leaders felt during their diagnostic odysseys, as well as how they’re currently coping with health and other issues. I learned that, even though genetics education is an important part of genetic counseling sessions, the psychosocial discussions that take place during those sessions may be much more meaningful to patients and their families. I now know it is okay if those I am counseling are upset and want to end the conversation; I need to give them space. I learned that not having any information at all to give can be much more difficult for me and for the patients/families than an actual diagnosis would be.”

Alleigh Hebner
*University of Oklahoma Health
 Sciences Center*

“The 2015 Advocate Leader Program was a great opportunity for a developing genetic counseling student such as myself to gain insight into the patient and family perspective outside of the clinical setting. As we program participants gathered for breakfast and lunch each day of the ACMG Annual Conference, we had ample time to discuss the highlights of the sessions we attended and to explore issues from both our professional and personal perspectives. I really appreciated being able to meet other LEND trainees and to share the principles of LEND with the other attendees. The conversations beautifully wove together aspects of cultural competence, family centered care, interdisciplinary teaming, advocacy, and policy issues in genetics. family member needs.”

Lauren Tuttle
*University of Arkansas for Medical
 Sciences Representative*

Advocate Leader Program Participants

Advocate Leaders

[New England Genetics Collaborative](#)

Sondra Solomon, PhD
Associate Professor of Psychological Science
Clinical Associate Professor of Psychiatry
University of Vermont

[New York- Mid-Atlantic Consortium for Genetics and Newborn Screening Services](#)

Jana Monaco
Advocacy Liaison
Organic Acidemia

[Andrea Williams](#)

Founder/Executive Director
Children's Sickle Cell Foundation

[Southeast Regional Newborn Screening and Genetics Collaborative](#)

Jodi Kotrady-Hatin
Parent
St. Augustine, Florida

[Region 4 Midwest Genetics Collaborative](#)

Kristen Entwistle
PhD Candidate
Michigan State University

[Heartland Genetics and Newborn Screening Collaborative](#)

Teresa Nold
Outreach Specialist
SD Parent Connection

[Mountain States Genetics Regional Collaborative](#)

Gina Pola-Money
Director
Utah Family to Family Health Information Center

[Western States Genetic Services Collaborative](#)

Roslyn Bethmann
Parent to Parent Coordinator
Parent to Parent

Rachel Vandiver
Parent
Stone Soup Group

Genetic Counseling Students

[University of Arkansas for the Medical Sciences](#)

Christine Bruha
Jordan Hills
Lauren Tuttle

[University of Minnesota](#)

Michelle Takemoto

[University of Oklahoma Health Sciences Center](#)

Allison Hebner
Jiani Chen
Kathryn Matthews
Kristina Hermann

Advocate Leader Program Faculty

The NCC Advocate Leader Program was fortunate enough to bring together professional faculty members to aid in the discussion held at the breakfast and lunch sessions. Through these discussions, faculty members were able to lend their expertise to the group. By providing a fresh perspective as well as the ability to answer technical questions that may have been posed, the faculty helped foster lively conversation.

The faculty members listed below were selected due to their expertise in a multitude of areas including public health, clinician/lab experience, as well as with their work in the NCC/RC system. We would like to take this opportunity to thank each faculty member for volunteering their time to be apart of the program.

David Flannery, MD, FACMG
Medical Director
American College of Medical Genetics and Genomics
Bethesda, MD

Deborah Maiese, MPA
NCC Evaluator
American College of Medical Genetics and Genomics
Bethesda, MD

Sylvia Mann, MS, CGC
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Western States Genetic Services Collaborative
Honolulu, HI

Jana Monaco
Advocacy Liaison
Organic Acidemia

James O'Leary, MBA
NGECN Project Director
Genetic Alliance
Washington, DC

Marshall Summar, MD
Division Chief, Genetics and Metabolism
Children's National Health System
Washington, DC

Lori Williamson Dean, MS, CGC
Project Manager
Heartland Genetic Services Collaborative
Little Rock, AR

Meredith Weaver, PhD, ScM, CGC
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