The University of South Carolina Genetic Counseling Program was well-represented this past July at the National Down Syndrome Congress (NDSC) 2010 Convention at the Coronado Springs Resort near Orlando, FL.

Ravin Winfrey ('10) presented her research findings from her thesis, “Assessing the Social Support Utilization and Needs among African American Parents of a Child or Adult with Down Syndrome.” During the discussion portion a parent asked, “What are genetic counselors and genetic counseling programs doing to provide support for our families?” Ravin responded with examples of her experiences at USC including how students are encouraged to pursue research involving families with Down syndrome, and to participate in community events such as Buddy Walk.

Moreover, she was supported by alumna Katie Sheets ('09), and current student Emily Rosebrough ('11) who provided additional examples such as visiting with families of children with disabilities through the Physician Education and Awareness Program (PEAP), volunteering with Family Connection, and providing respite care. All of which highlight the foundation of community involvement and patient advocacy within the Genetic Counseling Program. The parents appeared pleasantly surprised when these claims of giving back to the community were validated by the example set by recent alumna, Sara Rhode ('10) who was attending the conference as a volunteer.

Shortly thereafter, Dr. Ferrante, Katie Sheets and Emily Rosebrough provided a workshop, “Building Consensus: Ensuring New and Expectant Parents Receive Accurate Information About Down Syndrome.” The room was filled by parents, as well as pediatricians, genetic counselors, and other health care providers.
Dr. Ferrante reviewed the Consensus Statement established at USC (Toward Concurrence, 2009), for which several genetic counseling alumni were present, including Cam Brasington ('89), Ashley Noack ('09), Allison Bellomo ('09), and Katie Sheets ('09). Many people in the audience had questions in regard to how and when a consensus will be formed. Katie Sheets ('09) elaborated on the difficulties of establishing a consensus on what is considered balanced information about Down syndrome from her thesis, “Parents and Genetic Counselors Define Essential Information about Down Syndrome,” which is in revision for publication.

As further evidence that USC is continuously committed to serving the Down syndrome community, Emily Rosebrough ('11) outlined her current study, “Identifying the Practical Needs of Fathers Raising Children with Autism and Children with Down Syndrome.” Emily aims to assess the genetic counseling needs of this underrepresented male population. One father was typing the web address for Emily’s survey into his Blackberry as she was talking to ensure that his voice, as a father, could be heard. Her study was also featured, and applauded in the “Why D.A.D.S.?” workshop.

During the keynote presentations, word about the active involvement of the USC genetic counselors had spread to the majority of conference attendees, as plenary speaker Elizabeth Harry remarked on their impressive contributions. In summary, the 38th annual NDSC Convention was a great experience and a success for the USC genetic counselors. Congratulations to all on a job well done!

Special Recognition at NSGC: The 2010 International Leader Award

Janice Edwards received the 2010 International Leader Award from the National Society of Genetic Counselors at the October Annual Education Conference. As Founding President of the Transnational Alliance for Genetic Counselling, her efforts foster communication and collaboration among genetic counselor educators throughout the world. Janice incorporated the alliance and has chaired TAGC meetings in Manchester, Barcelona, and more recently, Gothenburg, Sweden. This is no small feat, considering the inaugural meeting gathered genetic counseling educators from 18 countries and included the 15 professional organizations in the world that represent genetic counselors.

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Hi All,
You can imagine me beaming with pride as I learned about our genetic counselors connecting with parents and professionals at the NDSC Conference in Orlando. Indeed, the Program has been increasingly involved in promoting collaborative exchange among Down Syndrome advocates, medical and genetic professionals. You might have already seen the Consensus Statement generated in 2009, “Toward Concurrence: Understanding Prenatal Screening and Diagnosis of Down Syndrome from the Health Professional and Advocacy Community Perspectives. (Google it.... its even been translated to Spanish!).

More recently, Dr Richard Ferrante and I facilitated the collaboration of the American College of Obstetricians and Gynecologists, the American College of Medical Genetics and the National Society of Genetic Counselors in providing input to the National Down Syndrome Society and the National Down Syndrome Congress as they finalized a new booklet to be made available to parents at the prenatal diagnosis of Down syndrome. Look for the new resource soon entitled, "Understanding a Down Syndrome Diagnosis". Connecting with the Down syndrome advocacy community has been a truly enriching experience for the faculty and students of the Program, and we look forward to our continued collaborations.

Pennsylvania native, Kathy Bet Dusenbury (2008) decided to move south for her graduate training in Genetic Counseling. After an undergraduate degree in Biology from the College of New Jersey, Kathy joined our Program in 2006. Like most genetic counselors, she wished to pursue a career that would intersect her love of science and desire to directly impact the lives of others. Upon graduation in 2008, she moved to Charleston, SC, to join her now husband, John, as he finished dental school. There, she consistently volunteered in the pediatric genetics clinic at MUSC before moving to Biloxi, MS a year and a half ago. While John is now a general dentist for the Air Force, Kathy is the first genetic counselor for Keesler Air Force Base and works for the only genetics lab for the entire Department of Defense! She serves as both a lab counselor and clinical counselor. "I enjoy my job, particularly the mix of lab work and clinical work. If anything, I'd like to see more patients." The genetics lab at Keesler AFB receives samples from all branches of the military. Kathy spends time fielding phone calls regarding samples and reviewing the paperwork for each sample that arrives (nearly 125 each day!). In addition, Kathy sees patients, primarily cancer and prenatal, at the hospital on base. "It's definitely busy. I work from 7-5:00 each day, but we do have every other Friday off. It's nice having three day weekends!" After hours, she and John stay busy remodeling their first home, a "fixer-upper". We are proud of you, Kathy!

Janice continues to lead the board of directors and manage the TAGC website, which links international genetic counseling programs and professional societies; this website (http://tagc.med.sc.edu) is a great resource for our now global profession. Janice’s work in advancing international collaboration includes other service as well, as former Chair of the ABGC’s Ad Hoc Committee on International Genetic Counseling Education and as a member of the NSGC’s International Service Providers Committee. She has given professional talks in China and Australia. And, as Director of the GeneticCounseling Program, Janice has educated international students and coordinated clinical rotations abroad for several graduate students…. for USC students, other North American students, and students from programs on other continents as they seek international experiences. Congrats Janice!
Anne-Marie Angeloff (1999) Can’t wait to hear more news from the alumni! My husband (Dann) and I had just a baby boy, Danny, who was born on April 27, 2010. He joins his big sisters Ragan (5) and Mary Kate (2 1/2). We are still living out here in Southern California.

Mary Ann Campion (2000) Life is treating me kindly here in Boston. Last November, Kevin and I had a baby, Mason, who is now 10 months old and full of smiles and giggles. He is the perfect ending to a busy day! I am also still enjoying my position with the BU Genetic Counseling Program, which provides a nice balance of seeing patients and teaching students. We welcomed our 6th class of students this fall!

Marla Jurek (2001) We have recently relocated to Houston, Texas due to David’s work. We are very happy to be back in Texas after almost 12 years. All the children are in school now, as Ryan is now in pre-school! As for me, I am still working with the Hawaii Department of Health Genetics Program, helping translate Disorder Fact Sheets for their website. Prior to our move, I was also working as an interpreter and translator for the University of Tulsa Center for Communicative Disorders. As we are now in a larger metropolitan area with some of the finest medical facilities, I look forward to growing my translation and interpreting services business!

Betsey Dempsey (2001) Since our move to Michigan two years ago I’ve been staying home with my two little ones (James is almost 4 and Caroline is 19 months). In mid-October I’ll be returning to work two days per week, doing telemedicine counseling for MUSC’s Florence clinic from home. There’s a lot to learn about telemedicine but it is an exciting opportunity!

Sharon Molinari (2003) My husband and I just had twin girls on August 20, Caroline Faith and Marie Kennedy. It is a big adjustment and we are still adjusting! I’m not sure I will ever let my mom go home!

Christina Barger Hurst (2007) I recently got married, August 7, 2010. My husband, Brian, is a Birmingham native, and we continue to live in Birmingham, AL. Also, I’ve recently changed jobs and now work as the Assistant Program Director for the new genetic counseling training program at The University of Alabama at Birmingham (UAB). We have a busy and exciting year ahead of us, and a great first class of students. I’m excited about both these changes, and hope to see everyone soon at the NSGC reunion.

Allison Bellomo (2009) Hey! I am now full-time at the Greenville Greenwood Genetic Center doing peds and cancer. I will be helping out with student supervision for the first time in October! I will also be learning all about enzyme replacement therapy and helping coordinate treatment for our patients.
The Genetic Counseling Fund continues to grow with contributions from alumni, faculty and friends of the Program. Through the USC Educational Foundation, the fund assists with special student needs and educational events throughout the academic year. Your help in growing the Fund is greatly appreciated...for today and into tomorrow as we strengthen the future of Genetic Counseling.

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