Dear Colleagues and Friends,

We are midway through the school year, and another calendar year is now behind us. The first year students have acclimated well to grad school life (i.e. 24/7 studying and looking for free lunches), and second year students are thinking about the transition to a working life (i.e. actually getting paid to do what they love). All are doing well in terms of meeting their academic goals and setting new standards for the next class. We have been very busy this past year. Some highlights include:

• We hosted our first Genetic Counselor Open House, an opportunity for prospective applicants to learn more about a career as a genetic counselor.

• All recent grads were gainfully employed by the end of the summer in locations ranging from right here in Madison, the beaches of California, down south in Texas y’all, in the heartland of Ohio, and the far reaches of New Zealand.

• Our students performed excellently on the national certification exam in 2013 with a 100% pass rate! The average scores continue to be well above the national average. Congratulations to all.

• We were again able to award scholarships to all of our incoming students due to the generosity of friends and alumni donors. There is still time to have your gift matched dollar for dollar. Donate now!

• The interest in our profession continues to be strong - last year we had over 130 applications for admission to the UW program. For this next year, we are seeing a similarly competitive pool of applicants.

• As seen in our Alumni Update on page 9, UW alumni continue to be involved in various leadership roles within our profession.

In summary and in the spirit of the US presidency, the state of the Program is strong! Thank you for your continued support of the UW Genetic Counseling Program and its graduates.

On Wisconsin!
Welcome to the Class of 2014

Aime Agather – Recipient of the Genetic Counselor Training Program Alumni Scholarship for Leadership

I am originally from a Minneapolis suburb, and I graduated in May 2010 from UW Madison with a degree in Genetics. There were many factors which inspired me to think about a career in genetic counseling; my undergraduate courses, being a volunteer counselor at a teen crisis center here in Madison, and here at the Waisman Center attending case conferences and viewing counseling sessions. On top of these great experiences I would have to say two alumni from this program were truly helpful in informing me of my decision to become a genetic counselor. I am honored to receive the Genetic Counselor Training Program Alumni Scholarship for Leadership, for which I believe shows our alumni’s commitment to step up and have a positive role in the greater communities both within genetic counseling and in other advanced fields. It is inspiring to hear the numerous accomplishments of these men and women. I am gracious to the program for seeing my potential for leadership, whether it be from my undergraduate job as the head student supervisor at an on-campus dining hall, to being the director of philanthropy for my sorority. I look forward to meeting the many dedicated alumni of the program and hearing about their diverse leadership experiences. One thing to know about me is that I am very proud of my Norwegian heritage. I just visited Norway in June to hike and see the beauty of the fjords, and here at home I make krumkake (a cookie) and lefse with my family. I am very excited to be back in Madison for this next great step in my life. U-RAH-RAH Wisconsin!

Meghan Grow – Recipient of the Joan Burns Founder’s Scholarship

I grew up in Lake in the Hills, Illinois and graduated from St. Norbert College in De Pere, Wisconsin in 2011. I majored in Biology and double minored in Chemistry and Psychology. After deciding I wanted to pursue a master’s degree in genetic counseling my senior year of college, I began looking for ways to gain valuable experience to make my dream a reality. I worked as a direct support professional at an adult developmental disability day program, where I worked with clients who have a multitude of developmental disabilities on their vocational and daily living skills, community integration, positive behaviors and individual goals. I also volunteered at a sexual assault hotline for two years. I am very honored and grateful to have been awarded the Joan Burns Founder’s Scholarship, which symbolizes the foundation of the genetic counseling program here at the University of Wisconsin, Madison. Ms. Burns’ ambition to aid individuals with disabilities and their families is inspirational, and I believe I was awarded this scholarship because of my experience and passion to do the same. I look forward to using the knowledge I will gain in my studies here to continue this desire to educate patients and their families. I am excited to be in the genetic counseling training program at UW Madison and I cannot wait to begin this next chapter in my life!

Brianna Nelson – Recipient of the Dr. Renata Laxova Scholarship in Patient Advocacy

Two years ago, I returned to my native Seattle after completing my BS in psychology and minors in biology and biotechnology at California Polytechnic State University. As an undergraduate, I worked with a close friend in founding and presiding over the Huntington’s Disease Awareness Project: a university affiliated club oriented towards fostering the understanding of HD from a humanistic perspective. The three-year, multifaceted project primarily hinged upon our presentations to undergraduate classes and clubs. My involvement in HD led me to genetic counseling and will likely shape my future career as a counselor. I also worked as an academic advisor for fellow psychology students, as well as a research intern for the San Luis Obispo Probation Office administering psychological evaluations to perpetrators. During the summer months, I kept myself busy by volunteering abroad, most recently in rural Mongolia. Since moving back to Seattle, I’ve worked at a commercial antibody company as a purchasing agent and datasheet editor. During this time, I volunteered at Harborview Medical Center as a patient-family liaison. I’ve also volunteered at a local domestic violence shelter, eventually leading my own classes on resume building and interview skills for residents. I am incredibly grateful to be receiving the Dr. Renata Laxova Scholarship in Patient Advocacy. The principle of understanding patient-perspective defined my work within HD awareness and is the foundation for my future goals within medicine. Genetic counselors have both enormous opportunities and responsibilities as patient advocates and I look forward to investing my education and career in improving patient experience and care. Given the University of Wisconsin’s exemplary commitment to producing
Laura Otto – Recipient of the Dr. Raymond Kessel Scholarship in Outreach

I am coming to Madison from Rochester, Minnesota where I have lived for the last five years, but I am originally from Cottage Grove, Minnesota. After graduating with a BS in Biomedical Science from the University of Wisconsin - La Crosse in 2008, I worked as a clinical laboratory technologist in cytogenetics at Mayo Clinic in Rochester. I became interested in genetic counseling after being able to work closely with GC’s in the cytogenetics lab and observing them outside of the lab in cancer and other specialty clinics. After learning about Dr. Kessel, I was inspired by his dedication and influence on the genetics community in Wisconsin and across the globe. His value on education and community involvement are easy to identify with and I am honored to be receiving The Dr. Raymond Kessel Scholarship in Outreach this fall for my graduate studies. As an advocate for the United Way of Olmsted County and as a youth volleyball coach, I was a mentor and leader in my community and hopefully demonstrated a small amount of what Dr. Kessel has committed to outreach in his communities. I have always put a high value on giving back some of what I have been given. Whether it was using the physical and leadership skills I have acquired to coach volleyball, or to draw upon my compassionate personality to volunteer to sit with dying patients as a part of Mayo Clinic’s No One Dies Alone program, being selflessly involved in a community organization has inspired me to take the next steps to become a genetic counselor and continue to give back as my career. I hope to model my time here in Madison after Dr. Kessel’s philosophy and expand my dedication to outreach to educating and advocating community members about genetics and public services available to them. I am thrilled to be completing my education in genetic counseling at the University of Wisconsin and look forward to every experience to come in the next two years.

Shelby Sieren – Recipient of the Dr. Richard Pauli Scholarship in Clinical Research

My hometown is Keota, Iowa, which is a rural community in southeast Iowa. This past May 2013, I graduated from Wartburg College in Waverly, Iowa with a BA in Biology and a minor in Psychology. I first learned about genetic counseling in my high school biology class, but my deep interest in this career was not sparked until my undergraduate course in genetics. After job shadowing a variety of genetic counselors, gaining clinical experience with patients while working for a genetics research laboratory, and attending Northwestern University’s summer internship in genetic counseling, I knew this career was everything I desired. During my time at Wartburg, I greatly enjoyed working as a certified crisis counselor at a domestic violence and homeless shelter, volunteering as a Special Olympics team leader and campus peer counselor, and completing a research project that sequenced mutations in a gene of interest in fruit flies. I am honored to have been awarded the Dr. Richard M. Pauli Scholarship in Clinical Research. Like Dr. Pauli, I believe genetic counselors play a vitally important role in the advancement of clinical research as it applies to patient care. For the past three years, I have worked with families affected by cleft lip/palate and other craniofacial anomalies through my role as a research assistant for the Murray Laboratory at the University of Iowa. My purpose was to explain the importance of genetic research to individuals during their cleft clinic visits to the hospital, recruit and consent both affected families and control subjects, elicit their medical history, and collect saliva samples for DNA analysis. This experience embodies the kind of critical thinking and involvement in clinical research that Dr. Pauli represents. I am ecstatic to begin making my dream of becoming a genetic counselor a realization at one of the best genetic counseling programs in the country! Go Badgers!

Best Wishes to the Class of 2013

In keeping with our mission of training students to think critically and participate in research, all students enroll in three research credits during the second year of the program. They work under the direction of a research mentor toward the goal of producing a publishable research or other project that contributes to the body of knowledge of the discipline. As shown below in their project abstracts, there was a range of research this year reflecting their unique interests. Two graduates went on to have their research presented at the 2013 Upper Midwest Genetics Conference in Minneapolis, MN.
Social Media Use by College Students with Mobility Impairments

Presenter: Lisa Daniels
Project Advisor: Megan A. Moreno, MD, MSEd, MPH

Purpose: To identify what ways college students with mobility impairments use social media sites (SNSs) and to identify if these students network with other individuals with similar impairments, support groups, or advocacy groups.

Methods: College students with mobility impairments from four University of Wisconsin campuses were asked to complete a survey 33 question survey. The survey assessed their current habits and interests in making connections with like-abled individuals or disability support groups through SNSs, and the amount that they share, discuss, or search for disability related topics on the SNSs they use.

Results: A total of 26 surveys were collected. 56% of respondents stated that it was unimportant for them to be connected with individuals who have similar mobility impairment as them. The majority of respondents said that they never or rarely discuss disability related topics on Facebook (77%). 54% of participants stated they prefer to meet someone with a similar mobility impairment offline instead of online. Most participants (73%) stated that they would learn about new health care topics related to their mobility from their health care provider, from an online or offline news source (54%), from a family member (46%), or from a friend (42%). Finally, 92% of respondents said that they would not want to be connected with their health care professionals via social networking sites.

Conclusions: Though the use of SNSs, people are able to stay or become connected when physical location is a barrier. Though the students in this study use social media tools to network with like-abled individuals, disability groups and organizations, the level of interest to connect with these groups was generally low. It can be concluded students prefer to make connections related to their disability offline or in person first, then they may be motivated to continue that connection via social media sites.

Airway Malacia in Children with Achondroplasia

Presenter: Kimberly Dessoffy
Project Advisors: Richard M. Pauli, MD, PhD & Peggy Modaff, MS, CGC

Children with achondroplasia are well known to be at risk for a variety of respiratory problems. Although not previously described in the literature, it was our clinical impression that airway malacia might be rather common in this population. In this retrospective review of 236 children with achondroplasia under the age of 3 years, 13 patients (5.5%) were found to have airway malacia. Although estimates of the frequency of airway malacia in the general population are limited, this frequency is significantly higher than any published estimate. The presence of airway malacia was correlated with an increased occurrence of obstructive sleep apnea and the need for oxygen supplementation, airway surgeries, and tracheostomy placement.

Genetic Testing in Embryo Adoption/Donation: An Investigation

Presenter: Sarah Hamilton
Project Advisor: Elizabeth Petty, MD

The process of adopting or receiving a donated embryo is a relatively new way of family building that has emerged within the last 30 years. There are currently over 600,000 embryos that are in frozen storage. Of these, a small but growing percentage has been made available for adoption and/or donation. Embryo adoption involves the transfer of leftover fresh or cryopreserved embryos that were originally created for the use of one family and are donated for use by another individual or family.

Agencies that facilitate the transfer of these embryos have only developed within the last 10-15 years. The first credited embryo adoption (not the first anonymous embryo donation) occurred in 1998 and was handled with the key elements of adoption: a home study, interaction between donating and recipient families through an agency, and social worker mediation. Interestingly, very little primary literature exists that describes this process. Furthermore, information regarding the use of genetic testing on these embryos is virtually non-existent.

Therefore, the aim of this study was to investigate the current practices, use of, and attitudes toward genetic testing in embryo donation and adoption. More specifically, it sought to identify embryo adoption/donation agency policies and practices related to the genetic testing of these embryos. To do this, interviews were conducted with representatives from eight different agencies that facilitate the transfer of embryos to adoptive or recipient parents.
The results of this study suggest a wide range in the types of clients served, process of matching donors and recipients, and the policies regarding the use of genetic testing in embryos.

**Women with Fragile X: A Case Series Describing their Well-being, Parenting Behavior/ Coping, and Outcomes for their Children and Marital Status**

**Presenter:** Sheryl Walker  
**Project Advisor:** Marsha R. Mailick, PhD

**Background:** Fragile X syndrome (FXS) is the most common inherited form of intellectual disability and is nearly always caused by an unstable CGG repeat in the promoter region of the FMR1 gene on the X chromosome. Normal repeat numbers range from 5-40. The premutation range is considered to be between 55-200; the expansion is considered a full mutation if it is greater than 200 repeats. Because Fragile X syndrome is an X-linked condition, it is best described in boys and men; however, approximately 1 in 8000 females are born with a Fragile X full mutation. Females may experience behavior problems, learning disability, anxiety, mental illness and impairment in executive function. Additionally, one third of female full mutation carriers have significant intellectual disability. Most women who have sons with Fragile X syndrome are assumed to be premutation carriers if they have not undergone molecular testing. However, some of these women actually possess the full mutation. While some research has been done to learn more about stress and functioning of mothers of children with disabilities, little to no data has been analyzed regarding this population of mothers affected with the same genetic disorder as their child. We hoped to explore the impact of their expanded repeat with the compounded effect that they are parenting a child or children with disabilities.

**Methods:** We reviewed the case files from the Family Adaptation to Fragile X Syndrome study of six mothers of boys and/or girls with Fragile X syndrome who were found to have full mutations themselves (3 classic full mutation, 3 mosaic for the full mutation). Three data collection times took place over the five-year study. Four areas of investigation were included in the case series: maternal functioning/well-being, parenting behavior/coping, outcomes for children and marital status. Data from questions falling into each of these categories was retrieved from their case files and from the coding system to summarize for comparison.

**Conclusions:** While Fragile X syndrome has a spectrum of symptoms, the mothers in this series report few to none of the symptoms classic to females with the full mutation. However, their daughters with Fragile X syndrome appear to be affected by more symptoms related to having a full mutation. Responses for each of the four categories investigated were generally similar between premutation carriers and the women with the full mutation but did show some variation. This descriptive case series will hopefully serve as a foundation for future research efforts into the lives of full mutation women parenting children with Fragile X syndrome.

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**Genetic Counseling Graduate Student Debt: Impact on Program, Career and Life Choices**

**Presenter:** Ashley Klein  
**Project Advisor:** Elizabeth Petty, MD

The cost of education is rising, increasing student financial aid and debt issues for students pursuing higher level education. A few studies have assessed the impact of student debt in medicine, physical therapy and social work, but little is known about the impact of student debt on genetic counseling students. To address this gap in knowledge, a web-based study was used to assess the impact of student debt on program, career and later life choices for genetic counseling alumni of the last five years. Over half of the alumni reported that loans were extremely important in their ability to attend their program, with most using subsidized loans no longer available to current graduate students. While alumni made clear that they are satisfied with their genetic counseling education, 83% (n=282/342) of alumni with student debt reported feeling burdened by their debt, which averaged approximately $55,750. This is dangerously close to the average current salary reported by survey participants ($56,000), breaching the 20-10 rule for student debt and revealing the unsustainable nature of this current financial path. In response to this crisis, we have proposed recommendations for programs, alumni and current students that would alleviate student debt impact and burden.
UW-Madison Genetic Counselor Training Program Open House

On Friday, August 16th, 2013 we hosted our first annual open house for prospective applicants. The goal was to help those interested in pursuing a career as a genetic counselor learn more about this great profession. We had 23 individuals attend the conference. The day was filled with interactive discussions from professionals in the field, current genetic counseling students and patients that have worked with genetic counselors. Thank you to the following genetic counselors that participated: Craig Adamski (2010), Children’s Hospital of Wisconsin, Kim Anderson (2009), WI State Lab of Hygiene, Jill Ciske, Madison Women’s Health, LuAnn Weik, Children’s Hospital of Wisconsin, and Cristina Zaleski, Prevention Genetics. Thank you to the Class of 2014 for providing insight into the student experience and a warm thank you to the patients who shared their stories and insight about their perspective of the genetic counseling process. Comments from attendees were all positive including the following statement: “I really appreciated the panels. They shed light on the experience of becoming and being a genetic counselor and gave me a good deal of inspiration regarding the future of genetic counseling.”

Unique Educational Experiences for our GC Students

Genetic Counseling students learn about the profession in a variety of ways ranging from the traditional to experiences outside the classroom and clinic. Students were asked to provide insight into three of the unique educational experiences they participated this past summer.

Myriad’s Student Internship Program

Rosy Ebel - Class of 2014

Each summer, one student is selected from each genetic counseling training program to attend a two-day workshop “designed to introduce them to Myriad, allow[ing] them to experience a day in the life of a molecular diagnostic lab, and to expose them to the many roles genetic counselors play within the field of hereditary cancer genetic testing. “To be considered for the internship, UW students must submit a statement of interest for review by our Performance Review Committee. This year, Rosy Ebel was the recipient of this great experience. In her own words, Rosy provided us with this reflection: “I was very fortunate to have the opportunity to visit Myriad Genetics in beautiful Salt Lake City, Utah, during the month of July. Although I was only there for two days, I found that participating in experiences such as a laboratory tour, discussions on the variant reclassification program, and observation of Myriad’s genetic counselors in action to be extremely valuable. Additionally, I had the privilege of meeting eight other genetic counseling students that attended from programs all over the country. Not only was it fun to bond over the joys and woes of being a student in this field, but I also added eight more peers with unique perspectives to my network of future colleagues. Whether or not I become a laboratory counselor, I look forward to applying my experiences at Myriad to my future career.”

The Center for Patient Partnership

Erin Borchardt and Katie Gallagher - Class 2014

The Center for Patient Partnerships offers a summer internship for genetic counseling students with an interest in patient advocacy. At this program, students become part of a team of experienced advocates and graduate students from other programs such as law, pharmacy, and medicine. Students are assigned clients (including patients with serious illnesses and their families) who need help with a variety of healthcare issues. Examples of some of the issues students can help with are researching clinical trials, sorting through treatment options, assisting with insurance denials, finding financial aid, and contacting support groups. Many of the clients who call the Center really only need to talk to someone who will listen to their story without judgment. There is the opportunity to talk to clients over the phone or meet them in person, depending on their needs. Through helping clients with their issues and listening to their stories, students learn how to step out of their comfort zone to navigate the complex healthcare system, empower patients to advocate for themselves, and practice deep listening. These skills are an important part of a genetic counselor’s role in clinic. Genetic counseling students Erin Borchardt and Katie Gallagher, who participated in this internship in 2013, found the experience eye opening and beneficial: “CPP provided a unique opportunity outside
of the structured genetic counseling program. We learned invaluable skills that can translate to clinic, such as listening to someone’s story without an agenda and taking a step back to look at the big picture rather than focusing on the minor details, as we so often do as students. We will never forget the powerful stories we heard, and would highly recommend the CPP internship to all genetic counseling students."

The PEOPLE Program

Kim Dessoffy and Sheryl Walker - Class 2013

This summer, we taught genetics class for the PEOPLE Program (Pre-College Enrichment Opportunity Program for Learning Excellence) held at UW, a 3-week intensive opportunity for students from low-income high schools. Lisa Daniels also taught for the program in the past. The main goal of the program is to enable and inspire minority and low-income students to pursue a college education. Students from partnered high schools apply for the program during their freshman year, and, if selected, participate in the program every summer in high school. If they complete the program successfully and are admitted to UW-Madison, they earn a full-tuition scholarship. The objective is to reach students who would probably not be able to attend college otherwise. In addition to scholarship, the program gives them exposure to college-prep curriculum, as well as talks on college life, majors, and career paths. Our course was part of the program for rising juniors, and along with our 2-hour class, our students were also attending math, writing, ACT-prep, and fine arts classes each day.

In our genetics & genetic counseling class, we tried to reinforce basic genetics concepts the students may have learned in their high school, and engage them in new ways by presenting clinical genetics information that they would not have exposure to in school. We also spent time discussing the various career paths available in science and college life.

We organized our class into “themes”; the first week we focused on basic genetics and careers in science, the second was related to bioethics, genetic counseling, and college life, and the third focused on life course stories (an idea we adapted from the MCH LEND curriculum) and researching genetic conditions. Some of our favorite activities included a DNA transcription and translation race activity (where two groups had to race to transcribe and translate a DNA sequence that was hung on clothespin lines across the room using index cards with RNA sequences and amino acids written on them), a dragon activity where students learned about genotype/phenotype connections, and a mock hospital ethics committee (inspired by an ethics committee we did during a professional issues class). The students also learned about the genetics of blood type during a “Whodunnit?” CSI-like activity, and they enjoyed competing in teams against each other at our weekly Genetics Jeopardy competitions.

We found that teaching high school students was a very different experience than being graduate teaching assistants. Our students came from a wide variety of backgrounds; some were highly motivated to participate in the program, while others were less enthused about spending their summer in the classroom. The program (and our students) really valued activity-based learning, and so we spent a lot of time trying to come up with ways to teach our students with very minimal time spent lecturing. The curriculum and activities were ours to develop, which gave us a lot of creative liberty and flexibility.

We were excited by how interested our students became in several topics we discussed. Although there were times that it was hard to get our students engaged, overall we felt that they did a good job of asking questions, participating in activities and keeping an open mind. We tried to give our students plenty of opportunities to tell us what they were interested in learning about. We had requests to talk about sickle cell disease, Huntington’s disease, cloning, and “hybrids” or chimeras, among other topics. It was fun to teach students about topics they were truly interested in, and to dispel some common myths about cloning and genetics.

The PEOPLE program was a great experience for us both. We practiced teaching concepts in many different ways. We got to meet some incredible students who we know are really taking advantage of a great opportunity to make college an option for them. We pushed our creative comfort zones to come up with new activities, and we learned it takes a lot of patience to teach high school students on their summer break. While we are not convinced all of our students are future applicants to genetic counseling programs, we do think we opened their eyes at least a bit by showing them that genetics goes beyond Mendel’s peas and Punnett squares, which is a success in our minds!

If any current UW Madison genetic counseling students are interested in learning more about the PEOPLE program so that they can apply to teach in the summer, please contact Kim Dessoffy at Kimberly.Dessoffy@uhhospitals.org or Sheryl Walker at Sheryl.Walker@baylorhealth.edu. We encourage you to take advantage of this great opportunity to educate students about genetics, teach for a great cause, and earn a little extra money to help with your schooling!
The Adam Rennebohm Perinatal Bereavement Conference

In 2007, an endowment fund was established by Mary Anne and Bob Rennebohm as a memorial to their son, Adam. This fund supports the Adam Rennebohm Perinatal Bereavement Conference. To honor this wonderful conference and to spread word about its value, the following information was created for our website.

Although pregnancy and the birth of a baby are often joyous times, for some the unthinkable happens. When a baby is found to have a lethal health condition, the provider to first meet with the family and those that walk with them through their difficult journey all will make a lasting impression. Knowledge of and embracing perinatal bereavement services is critical when working with such families.

Adam’s Story

Mary Anne and Bob Rennebohm had two healthy daughters when they discovered they were pregnant with their third baby. Early in the pregnancy, she unexpectedly experienced a miscarriage. The doctor in the emergency room offered what he must have considered empathetic words of advice: “It was meant to be. You’re young, and you can have another baby.”

Soon afterwards, she and her husband discovered they were expecting again. Excitement grew as it became clearer with time that this baby would make it through the pregnancy. A nursery was created with their daughter’s help. Anticipation was high. Would it be a boy or a girl, a brother or a sister?

Their son, Adam Rennebohm, was born on August 23, 1983. The day of his arrival turned from excitement and anticipation to anxiety and unknowns. At birth, Adam’s doctors recognized that he needed special help and he was quickly taken to the neonatal intensive care unit. In the words of Mary Anne, “a difficult journey had begun.” Adam was diagnosed with a genetic syndrome known as trisomy 13 or Patau syndrome. Given the severity of this diagnosis and his related health concerns, Adam passed away a week later on August 30, 1983.

Adam’s short but brilliant life has influenced the Rennebohms forever; small footprints were left on their hearts. Reflecting back on this time in their lives, they have since recognized a lack of resources and invaluable information that they wish had been available to them. How were they told the news about their son’s life and death? How should they tell their young daughters that their baby brother died? Do they have a funeral for their son? What do they say to friends and family and how do they field their questions and comments? When do they take down the nursery? Questions and experiences such as these have made Mary Anne and Bob dedicated to helping health care providers understand the family experience when a baby dies.

About The Adam Rennebohm Perinatal Bereavement Conference

The Adam Rennebohm Perinatal Bereavement Conference is a biennial, daylong seminar hosted by experts from Resolve Through Sharing®. Although conference attendance was initially offered to genetic counseling students, participation by others dedicated to perinatal care such as nurses, medical doctors, physician assistants, certified nurse midwives, social workers, and chaplains is encouraged and supported. The goal is to create a strong knowledge and experiential foundation for learners so that they can support families whose baby dies.

With a focus on family-centered care, participants learn about grief associated with perinatal loss and the importance of communication between providers and families. Through expert-led discussions, students can identify strategies for caring for families who experience perinatal loss, recognize the value of medical genetics diagnostic resources, and ultimately provide perinatal hospice services and long term bereavement assistance.

At the most recent conference, genetic counseling students from the programs at the University of Wisconsin, the University of Minnesota and Northwestern University have all appreciated this conference. Reflections from past attendees include:

- “I really appreciate all that I have learned today. My goal is to be a strong support to the families I encounter and these bereavement lectures have given me some of the tools to do that. Thank you.”
- “As students we’re often presented with the range of outcomes that surround fetal loss but are not always sure about those choices. This information was extremely helpful and will be useful in patient care. Thanks!”

How You Can Help

We are thankful to the Rennebohm family and their support of this valuable conference. For more information regarding this conference, please contact Casey Reiser at (608) 262-9722 or reiser@pediatrics.wisc.edu. If you would like to consider donating to the Adam Rennebohm Endowment Fund (Account 12586142), please contact Steven Ramig with the University of Wisconsin Foundation at (608) 265-3527 or steve.ramig@supportuw.org or donate online at www.supportuw.org.
ALUMNI UPDATES

We love to hear updates from UW-Madison alumni. Please consider sharing any professional updates (e.g., new jobs, honors, memberships, publications, etc.), any personal updates (weddings, births, etc.) as well as any current photos of alumni by emailing Laura Birkeland at lebirkeland@pediatrics.wisc.edu.

- Thanks to Quinn Stein (2000) and his hard work as Chair of the 2013 AEC in Anaheim, CA. We asked him to write up a bit about this experience: “I was honored to Chair the NSGC’s annual conference, which was held in Anaheim, CA October 9-12. Last year I was the vice-chair for the same meeting, held in Boston, MA. The role of the Chair actually starts about 15 months before the meeting itself with tasks such as theme design and forming the subcommittee, though the bulk of the work takes place December-February. During those months it’s not uncommon to devote up to 20 hours a week. Planning a conference is kind of like putting together a big puzzle. You have to judge proposals on the quality of the content, the quality of speakers, and the presumed appeal to the NSGC membership. And, in doing all of this, you want to plan a conference that is very forward thinking with “something for everyone.” I had a vision of what I wanted everything to look like, but a lot of things have to go right that aren’t totally in your control. That being said, the feedback from the 2013 conference has been overwhelmingly positive, thanks to the work of a lot of people going above and beyond what they were asked to do.”

- Great work to the following speakers who co-presented at the 2013 AEC in Anaheim, CA:
  - Jacquelyn Riley (2001), Cleveland Clinic, “Making a Difference: Case Management, Communication and Professional Experiences with Laboratory Genetic Counseling.”
  - Amy White (2002) and Regan Veith (2005), Children’s Hospital of Wisconsin, “How to Develop a Genomics Service: A Practical Guide to Patient Selection, Data Generation Variant Analysis, Results Disclosure, and Medical Management Using Whole Genome Sequencing.”
  - Janet Williams (1979) and Quinn Stein (2000) are serving on the Board of Directors for NSGC. Always good to see UW alumni involved with our professional society!

- Great news for our fearless program director, Casey Reiser (1980) – she was promoted to Associate Professor (CHS).

- Dinel Pond (2001) helped to organize the Upper Midwest Clinical Genetics Conference in Minneapolis, MN on September 20th. Presentations and posters were presented by our very own Dr. Richard Pauli (Airway malacia in children with achondroplasia), Dr. David Wargowski (Crane-Heise syndrome: survival into adulthood and apparent autosomal dominant inheritance) and Ashley (Klein) Kuhl (2013) (Genetic Counseling Graduate Student Debt: Impact on Program, Career and Life Choices). UW attendance was high as seen in the photo and commentary was that it was great conference.

- The WI Newborn Screening Program celebrated its 50th anniversary. Amy White (2002) and Sonja Henry (2002) were there with Bucky to help celebrate!

- Alex Yonker (2006) has taken a new position with Ambry Genetics as a genetics specialist.


- Hannah (Baker) Bombei (2012) was married to Taylor Bombei June 1, 2013.

- Ashley (Klein) Kuhl (2013) had a busy year graduating, accepting a new job as a Biochemical Genetic Counselor at UW, presenting her research project as a poster at AEC and getting married on October 5, 2013 to Nate Kuhl. Additionally, as the genetics coordinator for the Wisconsin LEND program, Ashley Kuhl (’13) attended the Association of University Centers on Disabilities (AUCD) annual conference held in Washington D.C. Ashley attended several pre-conference workshops that focused on integrating genetics education into...
LEND programs across the country. She was able to learn about new resources as well as share some of the genetics education resources used in the Wisconsin LEND program as they have been a leader in this area due to its close relationship with the UW genetic counseling training program.

- **Angela (Bewell) Thompson (2010)** is now working with GeneDX as an Inherited Cancers Specialist. Her territory includes WI, MN, and IA.

- **Lior Borovik (2012)** works for Sanford Health in South Dakota. He participate in the Ethics Committee as well as the Heartland Regional Genetics and NBS Collaborative for Individual Health Plan. He looks forward to starting up a clinic for Huntington disease for the Sioux Falls area this up coming year.

- **Jenni Mancuso (2012)** recently started a new position at the University of Iowa as a prenatal counselor.

- **Kim Dessoffy (2013)** is working at University Hospital in Cleveland, Ohio. She works part time as a clinical genetic counselor and part time as a research coordinator for various urea cycle disorder studies.

- We have UW alumni serving as directors or associate directors for five different accredited GC programs. **Casey Reiser (1980)** continues to serve as the program director at UW. Congrats to **Anne Greb (1986)** as she recently took the role of program director for Sara Lawrence’s program (the first non-SLC graduate to hold this position). **Carol Walton (1989)** is the director of the program at the University of Colorado, Denver. **Cecilia Bellcross (1990)** helped start up the training program at Emory University School of Medicine and is the current program director. **Maureen Flynn (2002)** is the associate director at Boston University.

- Congrats to the most recent group of UW alumni to pass the Board exam: **Hannah (Baker) Bombei (2012), Lior Borovik (2012), Max Wilson (2012) & Kimberly Dessoffy (2013)**. Our 100% pass rate over the past few years has been maintained. No pressure for those next up!

- Not surprisingly, **Dr. Richard Pauli** was recognized for his outstanding communication with patients and is ranked in the top five percent of UW Health Providers based on 2012 Avatar patient satisfaction survey results. Additionally, he received an award at the Upper Midwest Genetics Conference recognizing his contributions to the medical genetics community.

- Watch out Hollywood - **Dr. David Wargowski** ‘appeared’ on Indiana Public Radio’s show “Sound Medicine” to talk about the 10th anniversary of the Human Genome Project this past summer.

- Although not a UW alumni we would like to welcome **Emi Higuchi** to the UW Genetics team. We were fortunate to host Emi for a summer rotation while she was a student in the Genetic Counseling Program in Ann Arbor, MI. She now works in our General Genetics Clinic and with the Genetics Systems Integration Hub, a program aimed at better integration of genetics into the public health systems.

### 2013 Alumni Publications

We are certain that this list is an under representation of the work that UW alumni actually completed, so please be certain to send publication updates our way to be included in the next Newsletter by emailing Laura Birkeland at lebirkeland@pediatrics.wisc.edu.


Alumni Gathering at the 2013 NSGC Annual Education Meeting

This past year in Anaheim, CA, we did not have an official UW Program alumni gathering. That being said, we heard from many of you that you stayed true to your Wisconsin roots and sought each other out of the crowd. Thanks for sharing some of the photos seen on this page. Next year, find out where our next AEC UW-Madison Alumni Gathering will be located on our Facebook page (UW Genetic Counselor Training Program Alumni).

FLASHBACK

With the first official class graduating in 1978, UW-Madison is one of the most experienced genetic counselor training programs in the United States. Enjoy these flashback photos from the graduating classes of '79, '84, '89, '94, '99, '04, and '09.

Class 1979: Joan Burns (Program Director), Joan (Westphal) Fitzgerald, Neil McMahon, Janet Williams, Donna Wälgenbach, Lisa Glinski.

Class 1984: Joellyn Gregory-Taylor, Robert Pilarski, Barbara Pettersen, Elizabeth Conover.

Class 1989: Gwen Reiser, Lisa (Gaulding) Kaepernick, Joan Burns (Program Director), Carol Walton, Carol Ludowese, Rebecca Vogt.


Class 1999: Stefanie (Noyes) Dugan, Dana (Doescher) Brown, Christopher Ho, Brian Allen, Nancy Anno.

Class 2004: Sara (Knavel) Fisher, Kimberly (Greer) Reisiger, Lindsay Zetzsche, Sonia Nanda, Kristen (Meddaugh) Rasmussen.

Class 2009: Laura (Cavanagh) Rebek, Amber (Artzer) Peterson, Cecelia (Compton) Arber, Laura (Thorson) Brzaskiewicz, Kim Anderson.


Stay in touch!

We would love to hear from you. Please stay in touch via:

Facebook: UW Genetic Counselor Training Program Alumni
Website: www.med.wisc.edu/gc
Email: reiser@pediatrics.wisc.edu or lebirkeland@pediatrics.wisc.edu
Mail: Waisman Center, 1500 Highland Ave, Madison, WI 53705
Phone: 608-262-9722

Make a Gift

Your gift to the Genetic Counseling Masters Program Award Fund will help us fulfill our mission of training competent and compassionate genetic counselors who will be lifelong learners and leaders in the field.

This fund was created to support the genetic counseling master's program. It will provide tuition assistance that will allow students to choose the University of Wisconsin-Madison for their graduate training in genetic counseling.

Genetic counselors help individuals and families sort through critical health issues. In a rapidly expanding field, they play an increasing role in research and public health. The University of Wisconsin-Madison Genetic Counseling Master's Program is committed to preparing genetic counselors who will help families and help shape the future of genomic medicine.

Gifts to the Genetic Counseling Masters Program Award Fund are administered through the University of Wisconsin Foundation, the official fundraising and gift-receiving organization for the University of Wisconsin-Madison.

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Please make checks payable to University of Wisconsin Foundation and mail to: University of Wisconsin Foundation, US Bank Lockbox, PO Box 78807, Milwaukee, WI 53278-0807. You will receive a receipt for your gift. To make a gift online, visit www.uwfoundation.wisc.edu