

Rutgers University Genetic Counseling Program



This fall has been both an exciting and busy time for both the class of 2020 and 2021! We were thrilled to welcome the nine amazing and bright students who make up the class of 2021. So far, our first-year students have been settling into the program and working hard in all of their classes. They have also had the opportunity to begin observing at specialty rotations such as the Huntington's Disease clinic. To get to know our new class, make sure to read their bios later on in the newsletter! Our second-year

students have been working hard in both their classes and clinical rotations and had the opportunity to go to NSGC in Salt Lake City. We are so proud that all eight of our second-year students had abstracts accepted at NSGC and had the opportunity to present at the national conference. Our second-years also have been learning about hot-topics in genetics including the use of telemedicine. Read our interview with Sandra D'Elia to learn more about this exciting topic!

Directors Note

Here's a word from our director on the what's going on in the program.

Page 2

Faculty Spotlight

Hear more about telegenetics and the way that it increases access to care for patients in need of genetic services.

Page 6

Student Highlights

Meet the class of 2021 and catch up on the busy lives of the class of 2020!

Page 10

A word from the Director

By Jessica Rispoli Joines



Thank you for your support!

The Genetic Counseling Master's Program is very grateful to the following organizations for their generous scholarship support:

- Rutgers Div of Life Sciences
- Amicus Therapeutics
- Johnson & Johnson, Janssen
- Human Genetics Assoc of NJ
- Bioreference Laboratories

Their support provides tuition assistance to many of our students and helps our program attract the best of the best. If you are interested in making a scholarship contribution, please contact Jessica Joines.

Dear Rutgers GCMP Community,

Another busy fall at the Rutgers GCMP and it feels like the best one yet! With the addition of Christine Seymour last winter, we were able to increase our class size to nine. We once again had a very successful admissions cycle resulting in another cohort of high caliber students that were selected from an applicant pool of over 160. The Class of 2021 has quickly adjusted to life as graduate students and have already made many positive contributions to the program.

A big highlight this past semester was bringing our 2nd year students to Salt Lake City for the NSGC annual conference. They fully embraced all that the professional environment had to offer including attending a variety of talks on cutting-edge topics and networking for future employment purposes. A busy final semester lies ahead and we are very excited to see what the next few months will bring!

The program leadership is quickly preparing for the 2020 admissions cycle as we moved our deadline up to December 18th in response to National Match Services deadlines. We are also preparing to submit our self-study to the Accreditation Council for Genetic Counseling as we pursue full program status. We feel very positive pursuing this milestone and we want to thank our entire team and all of you for the continued support you have shown our program and students.

Best wishes for a healthy and happy New Year. Please stay in touch with us!

Warm regards,

Jessica Rispoli Joines



Our second-year class had a great time at NSGC in Salt Lake City, Utah, networking, presenting their posters, and learning more about hot topics in genetic counseling

Class of 2020 Updates

This fall, I have been rotating at Robert Wood Johnson University Hospital in the department of Obstetrics and Gynecology, which has been a great experience. I am also working on collecting data for my thesis project. I recently returned from Salt Lake City, where my classmates and I had the opportunity to present posters at NSGC! We made sure to take some time out of our busy conference schedules to explore Salt Lake City and the beautiful state parks nearby. This semester has been very busy and very rewarding!

Sarah Belsky

This semester, I completed my pediatric/adult genetics rotation with Atlantic Health System at Morristown Medical Center. I was able to see a variety of indications that challenged me to be flexible when preparing for cases. I also had the opportunity to work with research patients with metabolic conditions. Another highlight of this semester was the beginning of my data collection for my research project. My thesis is on diversity in the genetic counseling profession with a focus on perspectives and barriers experienced by current genetic counseling students and recent graduates. I am excited to see what kind of results I will obtain from my study and look forward to beginning my final semester in the program.

Emily Chien

The fall semester has been both the most challenging and rewarding part of graduate school thus far. Between getting my thesis approved, being in my prenatal clinical rotation, and studying for medical genetics, I have certainly kept busy. The highlight this semester was definitely attending NSGC with my classmates and getting to explore Salt Lake City and the surrounding areas! I know that this trip will be one that I never forget and will always be one of my fondest memories of graduate school.

Jessalyn Gerber

This semester I am loving my pediatric rotation! I've been able to counsel patients for a variety of different indications, disclose results from genetic tests such as whole exome sequencing, and I really enjoy working with a multidisciplinary team of genetic counselors, medical geneticists and nurses. I've also been able to attend the metabolic clinic, which is helpful as we conquer metabolic genetics in the second semester of our Medical Genetics course. I loved attending the NSGC 38th Annual Conference in November and getting to present a poster regarding parallel screening in a prenatal setting. On a fun note, Ollie, my registered therapy dog, and I have been visiting students at a local school for children with Autism, and really enjoying the new friends we have made.

Kendall Snyder

During this semester I have been immensely enjoying my fall rotation at NJ perinatal associates. This experience has reaffirmed my desire to become a prenatal genetic counselor. Additionally I have also started the LEND program as a fellow. The didactic courses at LEND have really complemented my genetic counseling experiences. Through LEND I have had in depth lectures on neurodevelopmental disorders such as Autism and Down syndrome. Listened to experiences from parents of children with special needs and even visited with a family that has a child with Angelman syndrome.

Deirdre Sumski

I am currently in my cancer rotation at Hunterdon Regional Cancer Center in Flemington, NJ. It is a big change from being in pediatrics last semester, but I am really enjoying the new challenges, and the chance to work with a different patient population at a different pace. I have finished collecting data from my thesis project survey and it's time to start analyzing! I'm excited to see what we learn and to hopefully have some good information/data to share. We got a chance to go the annual NSGC conference in Salt Lake City, Utah this November which was really fun! It was great to get to experience that for the first time with all of my classmates, to hear about many diverse topics, and to be able to present a poster. I'm looking forward to Thanksgiving and winter breaks to spend time with my family.

Erin Swartz

This semester has been both the most exciting as well as the most stressful of my graduate career. While wading through what seemed like an insurmountable number of conditions in medical genetics II, I also worked furiously to finish my IRB. All of the work has been worth the reward of a successful grade in my courses and finally sending out my research survey! I am also finishing up my cancer rotation and looking forward to my industry rotation in the spring. I am proud of how far my classmates and I have come in the past 18 months and I can't wait to see where we go in the next 6.

Jillian Tokarczyk

This summer, I had the opportunity to attend a qualitative interview workshop through Geisinger. This workshop will aid in conducting my thesis project. While I was there, I was able to stay in their genome house, or private housing Geisinger provides for students and researchers. It was nice to meet other GC students during my stay and learn from my thesis advisors. This semester, I'm completing my pediatric rotation at Rutgers Robert Wood Johnson Children's Hospital. On top of this, I did a lot of networking at NSGC in November, have been conducting my research project, and working for the online consumer-initiated genetic testing company PWN. It has been a busy and rewarding semester thus far!

Julia Weston



Faculty Spotlight



Sandra D'Elia, MS, CGC

1. What was your path to becoming a genetic counselor who sees patients through telemedicine?

My path to becoming a telegenetics professional was a very fortunate one. I have worked for The Rutgers Cancer Institute of NJ since April 2012. I have had the opportunity to work alongside and learn from many talented clinical oncology professionals. I have fostered many productive and cohesive working relationships over the course of my tenure at The Rutgers Cancer Institute of NJ. In April 2018 we learned that my husband's company would be transferring him to Binghamton, NY. After discussing this news with Dr. Deborah Toppmeyer, my boss and the director of the LIFE Center, she suggested that we look into the option of providing remote, telegenetic services for our patients. I started on my new journey as telegenetics professional in June 2018.

2. What was the biggest challenge in transitioning from in-person to video counseling?

The biggest challenge for me has been relinquishing control over the logistical pieces of the session.

3. What do you see as the main differences between in person and video counseling?

Other than the obvious difference of me being in another room I don't consider the genetic counseling session itself to differ from an in-person visit. Contracting requires slightly more effort and intention compared to an in-person visit because I miss the opportunity to greet the patient as he/she arrives.

4. What do you see as the future of telehealth in genetic counseling?

I see telegenetic visits occurring with more frequency and with more reimbursement for services. Many states, NJ included, have parity laws that require coverage by Medicaid and private insurers of the service by telemedicine if it's covered in person. As billing and reimbursement for in-person genetic counseling services continue to improve so will coverage for telegenetic visits. Many, if not most, of the genetics programs that are part of NYMAC (New York-Mid-Atlantic Regional Genetics Network) that offer telemedicine report that they do indeed receive the same rate of reimbursement for telemedicine compared to reimbursement for in person genetic counseling. Telemedicine in general will occur with more frequency and this applies to telegenetics as well.

5. What advice do you have for genetic counselors entering telehealth jobs? Make an effort to maintain relationships with coworkers, referring physicians and support staff. It is very important for job satisfaction to remain a team player and feel that you are involved and valued.

Meet the Class of 2021!

Alex Barbarese is from Moorestown, New Jersey. She graduated from Temple University with a degree in Biological Anthropology. As an undergraduate, Alex worked as a research assistant at the Hospital of the University of Pennsylvania on a project that explored the needs and experiences of genetic counselors with prenatal microarray testing. After graduation, she worked in a clinical microbiology laboratory, volunteered as a crisis counselor with Crisis Text Line, and gained experience as a genetic counseling assistant at A.I. DuPont Hospital for Children. Alex is looking forward to developing the skills to become a well-rounded genetic counselor by taking advantage of the diverse clinical opportunities that the Rutgers Genetic Counseling Program has to offer.

Matt Emery is a New Jersey native from South Plainfield. He graduated from Seton Hall University in 2011 and 2014 with his BS and MS degrees in biology. After graduation he spent a year working at Bioreference Laboratories in their genpath Women's Health Lab. Matt also spent four years doing research in genetics and genomics technology development at Mount Sinai's Icahn School of Medicine. Matt chose Rutgers program because of its great rotation opportunities and its fantastic teachers and counselors.

Melissa Gandhi is from Lodi, New Jersey. She graduated from Rutgers University in May 2019, as a part of the School of Arts and Sciences Honors Program, with a major in Genetics and a minor in Psychology. As an undergraduate, she was a biology, statistics, and biochemistry tutor for the SASHP program, a member of Habitat for Humanity, and Vice-President of HOSA. She worked in a mouse lab, where she did her thesis, that studied how our touch impacts our ability to move. Melissa is looking forward to her rotations where she will see a diverse patient population.

Natalie Jacob is from Bucks County, PA and graduated from Stetson University in 2018 with a major in Molecular Biology and minors in Chemistry and Psychology. After graduation, she moved from Florida to Wisconsin to work as a Genetic Counseling Assistant for PreventionGenetics. While in Wisconsin, she volunteered with the local hospital's Child Advocacy Center and rotated as an on-call SANE advocate. After spending a year in the Wisconsin, Natalie is excited to be a part of the Rutgers Genetic Counseling Master's Program and is most looking forward to the opportunity to rotate with non-traditional specialty clinics.

Olga Latosh is from South River, New Jersey and graduated from Rutgers University in 2019, where she majored in Biology and minored in Psychology within the School of Environmental and Biological Sciences. As an undergraduate, she was a member of Phi Delta Epsilon, a fieldworker at the Douglass Developmental Disabilities Center, a TA for General Physics, and a dancer for Dance Marathon. Olga is excited to continue her education at Rutgers and has enjoyed the various observational lab rotations this semester. She is looking forward to starting clinical rotations and gaining more experience with different genetic counseling specialties

Enrique Lopez is from Marlton, New Jersey, and graduated from Rutgers University in 2019, where he majored in Biology and minored in Psychology. As an undergraduate, he worked in a genetics lab working with mice. Enrique is looking forward to learn more about and practice genetic counseling, especially in a cancer setting as well as practicing in Spanish and Portuguese. He is looking forward to being a part of the Genetic Counseling Master's Program and in getting to know his classmates.

Erin McGraw is from Youngstown, Ohio and graduated from Duquesne University in 2018. While there, she majored in biochemistry and minored in mathematics. As an undergraduate, she was a member of the American Chemical Society and the National Society of Leadership and Success. She also worked as an undergraduate researcher in a biochemistry lab that focused on learning more about Fragile X syndrome. Erin is excited to learn about the intricacies of the genetic counseling profession, while also getting to know her classmates.

Alexis Morgan is from Walnutport, Pennsylvania. She graduated from Wilkes University in 2018 with a degree in Biology and a minor in neuroscience. As an undergraduate, Alexis was involved in the National Honors Society, biology honors society, member of the women's volleyball team, and served as a teacher's assistant and resident assistant. She also participated in research for a genetics lab, studying novel genes affected by the EGFR pathway in *Drosophila melanogaster*. After graduation, she worked at Geisinger as a genetic counseling assistant in cancer genetics and research, as well as volunteering for the Crisis Text Line. Alexis is excited for the many diverse clinical rotation sites and contributing to a fairly new program.

Kelly Roche is originally from Downingtown, Pennsylvania, but spent the last few years in Raleigh, North Carolina while attending North Carolina State University. At NC State, Kelly majored in genetics and minored in psychology. During her time as an undergraduate, she enjoyed learning more about genetics while assisting in a plant biology lab studying *Arabidopsis thaliana* her freshman and sophomore year. Kelly also spent a summer during her time as an undergraduate student interning at a shelter for youth facing homelessness and other crises. She is excited to continue her journey to becoming a genetic counselor here at Rutgers.

Expanding Diversity in Genomic Databases: How the *All of Us* Project Strives to Make Genetic Research More Representative

As the amount of genetic knowledge we have access to continues to grow, countless societal issues have been brought to light in a new, genetic context. From disputes over editing human embryos to discussing racial equality in genetics research, there are always ethical debates to be had. We have known for many years that people of different ethnic backgrounds carry different genetic changes that lead to the diversity that we see in our world. Despite understanding this genetic diversity, much of the genome-wide research that has been done has been based on databases comprised mainly of DNA sequences from European populations. When research is conducted using data from these databases, it is unable to capture small differences that are seen among more diverse populations and leads to this research not being able to represent all human variation.

A project started in 2018, funded by the National Institute of Health, is aiming to break down the racial bias in genomic research and lead to more inclusive and representative data. This project, titled *All of Us* is an effort to obtain genetic and health information from over one million participants throughout the United States. As part of their mission, “*All of Us* is working to improve health care through research. Unlike research studies that focus on one disease or group of people,

All of Us is building a diverse database that can inform thousands of studies on a variety of health conditions.” Participation in this database is voluntary and is open to all Americans. In order to participate, individuals must provide a DNA sample as well as fill out numerous questionnaires about their health and their lifestyles. In addition to this information, participants may be asked to share other health information such as their blood pressure, height, and weight. Currently, the program is only enrolling adults, however within the next 2-3 years, they hope to begin enrolling children into the study as well. Currently, *All of Us* has over 293,000 participants, over 148,000 electronic health records, and has biospecimen samples from more than 232,000 participants.

One of the most exciting aspects of the *All of Us* database is the focus on recruiting a diverse participant population. One of the many efforts to do so is through the study’s tribal engagement program. This initiative “is committed to ensuring that the program reflects the diversity of the United States and hopes to engage with Tribal Nations to facilitate the inclusion of American Indian and Alaska Native (AI/AN) populations.” To achieve this, the *All of Us* team has consulted with tribal leaders to create culturally sensitive recruitment materials and is holding AI/AN specific recruitment events including in-person educational events and webinars. Not only will these efforts promote an inclusive and representative database, but it will ensure that a minority and often disenfranchised group is included in a culturally-sensitive way.



All of Us is expected to continue collecting data over the next 10 years, however the reach of the project will continue on for many years. With this expansive data set, researchers will have access to paired genomic and health data. Using this data, the goal is to increase the efficacy of research in precision medicine. Precision medicine aims to treat conditions based on personal health factors including genetics and lifestyle to ensure that patients are getting the most effective treatments. While we cannot expect to see new precision medicine targets soon from this database, the promise that these efforts will help our diverse population is extremely exciting and promising! To learn more about the *All of Us* research program, you can visit <https://allofus.nih.gov/>



Our program is growing! Pictured above are our first- and second-year students at the fall Human Genetics Association of New Jersey meeting



Some of our students participated in the Huntington Disease Society of NJ's HOPE walk this fall. They had a great time walking for this important cause!

Contact Information

Jessica Rispoli Joines, MGC, CGC
Program Director
joines@dls.rutgers.edu
Phone: (848) 445-9637

Christy Seymour, MS, CGC
Assistant Program Director
seymour@dls.rutgers.edu
Phone: (848) 445-9547

Sherry Pernice
Administrative Assistant
pernice@dls.rutgers.edu
Phone: (848) 445-9636

Rutgers, The State University of New Jersey
Department of Genetics
Life Sciences Building
145 Bevier Road
Piscataway, NJ 08854

Special thanks to Jessalyn Gerber for her work in putting together this newsletter