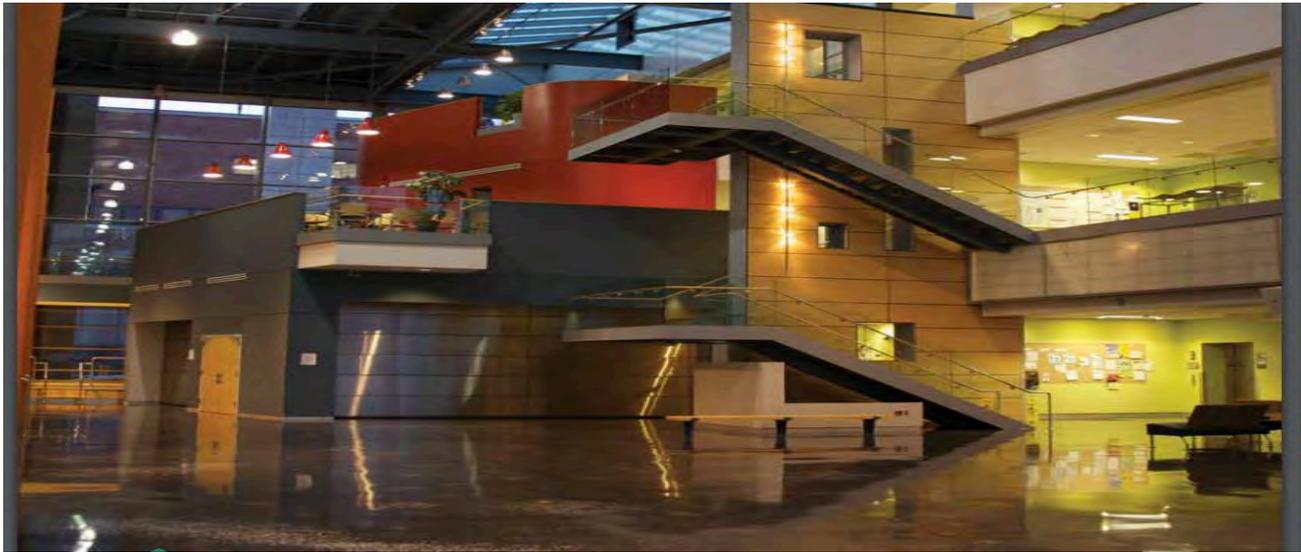


# Rutgers University

## Genetic Counseling Program



Our inaugural class has been busy over the past two semesters. They have taken on summer rotations locally and nationally, continued to learn about the complexities of metabolic genetics, deepened their thinking and discussion with classmates about the psychosocial aspects of their cases, and spent time learning about important and emerging topics in the field of genetic counseling. They've also recently attended the annual NSGC conference to learn and network with genetic counselors from

around the country. Two students even had the opportunity to present their case study posters. Students also had the pleasure of welcoming a new class to Rutgers! The first year class has been off to a great start with their classes, support groups, tumor board meetings, and lab rotations. We are excited to see them take on their first six-week rotations in the coming semester. We know they'll be cheering our second year class on as they prepare to present their theses and enter the workforce!

### Directors Note

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

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### Student Highlights

Get to know our new class and hear what the second year class was up to over the summer

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### Faculty Spotlight

Shama Khan is a clinical and thesis supervisor for some of our students. Hear about her role and how she got there.

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## A word from the Director

By Jessica 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.

Happy Holidays!

Another semester has flown by! I continue to be grateful for all of the year's accomplishments and the hard work of our faculty and students.

Since our last newsletter, our program has more than doubled in size through the addition of the eight amazing young women who make up the Class of 2020! These students were selected from an applicant pool of over 150 applicants! They also were the first class to participate in the genetic counseling match process administered by National Match Services (NMS). This process, adapted by all accredited genetic counseling programs, is comparable to the match algorithm that medical students participate in for residency. Although change can be challenging for all involved parties, we were certainly very pleased with the results. Once again, we have recruited a strong, motivated group of future leaders.

A big highlight this past semester was bringing our 2<sup>nd</sup> year students to Atlanta for the NSGC annual conference. It was clear that they all enjoyed being in such a professional and invigorating environment. We had the pleasure of spending time with a few Rutgers alums from the 1970s at our own mini reunion. We look forward to the size of our reunion growing quickly over the next few years.

Thank you for your contributions to our program's success in both big ways and small. We hope you enjoy reading more about our students and their current activities. Again, best wishes for a healthy and happy holiday season.

Warm regards,

*Jessica Joines*  
Jessica R. Joines



From left: Sarah Belsky, Jill Tokarczyk, Julia Weston, Erin Swartz, Kendall Snyder, Jessalyn Gerber, Deirdre Sumski, Emily Chien

## Get to know the Incoming Class of 2020

**Sarah** graduated from Montclair State University in 2016 with a degree in Psychology and a minor in Biology. During her undergraduate experience, she interned in a therapist's office and spent time volunteering with her sorority. Since graduating, Sarah has worked in a mental health clinic, volunteered to assistant teach an art class for adults with disabilities. She loves to paint in her free time and is currently work in a nursing home, which has been a wonderful experience! Sarah is very excited to be part of the GCMP, and is looking forward to all the valuable experience and knowledge she will gain this year.

**Jillian** was raised in North Tonawanda, NY a suburb between Niagara Falls and Buffalo. She attended Hamilton College in Upstate NY, where she majored in Biology and played Division III ice hockey. For the past 3 years, she has been teaching Biology to high school students. This previous year, she taught at Forman School in Connecticut. This experience was especially meaningful as the school is exclusively for students diagnosed with learning disorders. Jillian dedicated time to working with children through Camp Good Days and Special Times at their annual camp. She looks forward to transition back to life as a student and exploring her new surroundings in New Brunswick, NJ.

**Julia** is from Roanoke, VA and graduated from Virginia Tech in January of 2018 with a Bachelor's of Science in Biology. As an undergraduate, she pursued her interest in genetics while working in her Genetics professor's lab. Julia volunteered for two years as a supervisor for RAFT Crisis Hotline, the community crisis line in the Blacksburg, VA area, where she helped callers experiencing crisis. She was able to advocate for breast cancer education and awareness through her sorority's philanthropic events, where her interest in genetics also prospered. This year, Julia is most excited to see all different sides of genetic counseling through rotations and shadowing, specifically non-traditional roles.

**Erin** got her undergraduate degree in Biology with minors in Public Health and Statistics, from American University in May 2018. She played division I volleyball during her time at American, where they won the Patriot League, their conference, all four years she was a part of the team. While at American Erin also enjoyed exploring DC and the many museums and interesting places around the city. She is really excited to begin grad school and her genetic counseling education at Rutgers this year; Erin is most looking forward to clinical rotations and getting to meet and work with many different genetic counselors throughout New Jersey.

**Kendall** is from Torrington, Connecticut and graduated from Rutgers University in 2016 with a Bachelor's degree in Genetics. Following graduation, Kendall worked as a Clinical Specialist and Genetic Counseling Coordinator for CooperGenomics, where she was introduced to carrier screening. Kendall also volunteers with the NJ Chapter of the Huntington's Disease Society of America and holds board positions as Executive Secretary and Chairman of the Youth Outreach committee. Through her volunteer work Kendall has facilitated a connection with the local HD youth organizations, incorporated youth breakout sessions into the chapter's education events and is in the process of planning a virtual Q&A to discuss topics such as genetic testing with at-risk youth. Kendall is interested in neurodegenerative and neuromuscular genetic diseases, and looks forward to exploring those specialties while in school.

**Jessalyn** is from Teaneck, New Jersey, and graduated from The College of New Jersey in 2018, where she majored in Biology and minored in Psychology within the Honors College. As an undergraduate, she was a member of Alpha Phi Omega, the National Service Fraternity, as well as a biology peer mentor. She also worked as a lab tech in the genetics teaching lab, where she cared for fruit flies. Jessalyn is looking forward to developing the skills necessary to counsel the diverse patient population that New Jersey has to offer, as well as getting to know her new classmates and the faculty of the Genetic Counseling Master's Program

**Deirdre** is from Cornwall, NY. In May of 2017 she graduated with a BSc specializing in genetics from the University College of Dublin in Ireland. While pursuing her undergraduate degree she interned with Pinto Labs at the Icahn School of Medicine at Mount Sinai where she contributed to the International Autism research project. Her experience at Camp Sunshine inspired her to become a genetic counselor and use her degree to help families navigate genetic testing and diseases. Deirdre then interned under the supervision of genetic counselors at the Northern Westchester Hospital, Cancer Treatment and Wellness Center. She is eager to begin her master's in genetic counseling at Rutgers University, and she is passionate about working in a field that allows her to use knowledge and compassion to help people every day.

**Emily** is from Wellesley, Massachusetts. She graduated from University of California, Los Angeles in 2016 with a Bachelor of Science in Molecular, Cell, and Developmental Biology. As an undergraduate, Emily participated in research involving the study of epigenetics in *Arabidopsis thaliana* and held an internship at a biomedical research company. She also had the opportunity to volunteer at health fairs that offered screenings to underinsured residents in the greater Los Angeles area. After graduation, she served as a Crisis Counselor for Crisis Text Line and worked as a research coordinator assistant in clinical genetics at University of California, Irvine. In her free time, she enjoys photography, writing, and learning languages. She looks forward to contributing to a relatively new program as a member of its second incoming class and is eager to learn more about the ever-evolving field of genetics.



Some of the first year class headed out to a Rutgers Football game!

## Faculty Spotlight



Shama Khan, MPH, MS, LGC

**Q: So you have an MPH in addition to your genetic counseling degree, tell me about how your path went.**

**A:** When I moved to New Orleans post – Katrina to attend Tulane’s School of Public Health and Tropical Medicine, I attended an Epidemiology conference in Seattle. That was where I discovered the field of public health genetics. This initial spark of curiosity led me to the decision to pursue a career in genetics, and so I enrolled in Tulane University’s Masters of Human Genetics Program, which led me to the field of genetic counseling. I will never forget my first clinical experience, a patient presenting with Marfan’s Syndrome. The purpose of his visit was to get tested because he was concerned about the possibility of his newborn baby inheriting his condition. Both the physician and genetic counselor went in together to educate the patient and advocate for his genetic testing. I was truly inspired by the environment in the clinic of everyone working together as a team. To me, this embodies the essence of public health,

which I am so passionate about, as well as my love for genetics. After this experience I was hooked, and knew that the field of genetic counseling is where I belong.

**Q: What sparked your interest in doing research?**

**A:** Having a degree in epidemiology, I really enjoy being involved in the design of research studies and using my background in statistics. My interest in genetic counselors working in research developed during my initial rotation at the Children’s Hospital of Philadelphia in Cardiology Research where I observed the responsibilities of research genetic counselors. I had the unique opportunity of experiencing genetic counselors utilizing their background and skills in a meaningful way to communicate the complexity of the research study in a language that patients can understand and fully provide informed consent.

**Q: What is your role here at Robert Wood Johnson and within the program at Rutgers?**

**A:** As a genetic counselor here at Rutgers-Robert Wood Johnson Medical School, my primary role is as study coordinator for the division of maternal fetal medicine and section of perinatal genetics. I do have the opportunity to see patients, but the majority of my time is working on clinical trials, industry sponsored, and departmental studies. I also have a strong interest in supervising all the diverse students that rotate here and making sure they each have

a meaningful experience with us. I'm also truly invested in supporting the thesis projects of the graduate students within the program. Since I have a lot of experience and familiarity working with the IRB, I feel fortunate to provide that guidance and feedback to the students as their committee member and mentor.

**Q: What are some of the research projects that you've worked on that you are most excited about?**

**A:** I think one of the perinatal genetics projects I'm most excited about is the work we are doing to evaluate the performance and expansion of the utility of the noninvasive prenatal screening test. We were involved in the initial studies examining NIPT in the clinical setting when screening for aneuploidies such as Trisomy 21, 13, 18 and the sex chromosomes. As technology has advanced, we're able to contribute to studies that will hopefully benefit pregnant women in the future in a more expanded capacity, and that is something that is really exciting for me. I am also enthusiastic about working closely with the students on their individual projects, specifically with topics such as advanced paternal age and expanded carrier screening.

**Q: Tell me about some of your outreach projects.**

**A:** I have a personal interest in educating the community on the importance of examining your family health history. This evolved from a New York Mid-

Atlantic Consortium for Genetic and Newborn Screening Services Family Health History Mini – Award that I received to “Promote Family Health History Awareness in the Muslim Community”. This led to other opportunities such as speaking at a Women's Health Forum on Health History and Genetics and participating annually since 2014 in Rutgers Day with a Genetics and Family Health History Program, which now includes the participation of the graduate students.

**Q: Do you have any advice for students who are looking into genetic counseling?**

**A:** I encourage having as much exposure as possible to the diverse roles of genetic counselors beyond just pediatric, prenatal and cancer positions. I think it's really important to learn about the more non-traditional roles such as genetic counselors working in industry, laboratories, and research. I think if students were more aware of the ability to function in different capacities such as working remotely or having the opportunity to travel, they would appreciate the versatility and diversity of this career. I would also encourage students to go the NSGC website and see which counselors are welcoming to accept students to shadow. Also, doing volunteer work with different crisis hotlines or other counseling organizations can give you an exposure to what it's like to be involved in difficult psychosocial situations. It's not only helpful in preparation for your application, but it also provides insight that you are going to be involved in sensitive situations where there are difficult decisions and a sense of how you would handle that is an important part of the job as well.

## The Rise of Industry Genetic Counseling

When you think of genetic counselors you may picture someone sitting in an exam room educating a family on a genetic condition, or in a small office space discussing testing options for hereditary cancer syndromes. Maybe you think of them talking to expecting parents or educating future genetic counselors. While these are still primary roles of a genetic counselor, there has been a recent expansion into the world of industry.

While this expansion is seen a more positive light today, that was not always the case. This most likely stemmed from a misunderstanding of the intentions and motivations of genetic companies and labs. This divide has lessened over time, especially as the opportunities for genetic counselors in industry have expanded over the past few years. The core skills of genetic counselors identified by an NSGC task force are clearly utilized by industry genetic counselors. These include; a deep and broad knowledge of genetics, the ability to tailor, translate, and communicate complex information in a simple relevant way for a broad range of audiences; strong interpersonal skills, emotional intelligence, and self awareness; the ability to dissect and analyze a complex problem; research skills; and an in-depth knowledge of health-care delivery. These skills encompass a wide range of abilities showing that there is a place for counselors in industry as well as

traditional clinics.

Because of this broad skillset, the term “industry genetic counselor” can mean a lot of different things. These counselors can work for biotechnology firms, pharmaceutical companies, start-up companies, internet companies, commercial labs, telegenetic companies, etc. According to the NSGC’s 2018 PSS Work Environment report, 25.5% of respondents work in an industry role. This percentage has been steadily rising since the early 2000’s. Even just two years ago, in 2016, around 20% of genetic counselors worked in industry roles. Many of the counselors filling these roles transitioned from clinical roles.

The new challenge will be for genetic counseling programs to somehow incorporate this growing field into their training. Clinical rotations have always been a hallmark of these programs, but even these have evolved over time to include new specialties like cancer genetics. As of 2018, few programs offer rotations in an industry setting. With over 20% of genetic counselors working in an industry role, programs cannot ignore this growing trend. Rutgers has embraced this change by offering students the opportunity to do a non-clinical rotation in their final semester. Students will be able to rotate with genetic counselors working with laboratories, marketing, telegenetics, preimplantation genetic diagnosis, and patient advocacy. This placement allows students to get a glimpse into an industry role and get invaluable experience before entering the workforce.

## Second Year Student News

Catch up on what the inaugural class has been up to as they round the corner into their last semester!

**Audrey Morrissette-** This summer she rotated at the Dartmouth Hitchcock's Norris Cotton Cancer Center in Lebanon, New Hampshire. She pursued this rotation because she wanted the opportunity to network with genetic counselors in her home state. Additionally, she wanted to rotate at an NCI-designated facility and be closer to family. There was a lot to gain from this rotation including the opportunity to see many diverse cases, attend numerous tumor boards, get exposure to clinical trials, and participate in innovative approaches to care like telegenetics. Audrey would absolutely recommend other students consider travelling for their summer rotation. She believes that the opportunity to rotate outside of NJ can be helpful for those who wish to move from NJ upon graduating. Meeting the GCs at Dartmouth opened doors for her that may not have been possible if she had not gone to NH for my summer rotation, so she encourage students to be strategic in their clinical placements, in order to make the most of the opportunity.

**Laurie Simone-** This past November at NSGC, Laurie had a poster presentation of a case report. Her case involved a 2q12.2q13 microdeletion segregation in a family with agenesis of the corpus callosum. Individuals with balanced chromosome rearrangement are often told that they are benign, aside from the associated reproductive risks. However, this particular case highlights a family in which the patient's partner (FOB) and the fetus were found to have an inversion on chromosome 2, which was reported to be a benign polymorphism. Fetal MRI confirmed agenesis of the corpus callosum and upon microarray testing of both parents and the fetus, it was discovered that there was a deletion at a breakpoint of the inversion, present in both the FOB and fetus. MRI scans of the FOB revealed he also has agenesis of the corpus callosum. This case not only presents a need to determine if any genes within the deletion may be associated with agenesis of the corpus callosum but also that array testing may be a recommendation for those with reported balanced chromosome rearrangements to determine if there are any deletions or duplications detected at breakpoints.

**Caitlin O'Brien-** This summer she spent three weeks at Geisinger in Danville, PA working on her thesis project. Caitlin's project utilizes data from their MyCode project, a biobank offered to all of their patients, which has recently expanded to start returning actionable genetic results. She is mostly focusing on how and why patients share that information with their relatives. While she was out there, she also had the opportunity to shadow some of their counselors who split their time between research and clinical work, and attend tumor boards, grand rounds and genetics research meetings. In between doing her research and taking advantage of clinical opportunities, Caitlin enjoyed getting to know the other students who were staying in Geisinger's Genome House, which houses all of their visiting student researchers and clinical students. Danville may be a small town, but it had a lot to offer.

**Amanda Roth-** She had the opportunity to spend four days at Myriad in Salt Lake City, Utah after winning their essay contest! She was able to observe laboratory genetic counselors on the Medical Information Liaison team and with with physicians, patients and other genetic counselors via telegenetics. While she was there, she was able to tour Myriad Genetics labs, meet members of their staff along with other genetic counseling students, and explore Salt Lake City. She thought it was great to be able to see all the different roles genetic counselors can have in an industry setting. They are key to making sure tests are appropriately ordered and patients are counseled appropriately. In addition, they are vital members of sales and marketing teams due to their ability to effectively communicate genetics information to a variety of audiences. She was amazed by the diversity of roles genetic counselors can have!

**Taylor Reeve-** Her thesis is aiming to assess the uptake rate as well as the barriers to a novel technology called Vistara, which is a test offered to pregnant women whose reproductive partner is of advanced paternal age (45 and older). There is a push for women to become pregnant by a certain age as their “biological clock” will prevent them from having children once they reach menopause. Women over the age of 35 are termed “advanced maternal age”. Men on the other hand can continue to conceive children for as long as they want, yet there is minimal awareness to the risks they can pose to a pregnancy. Research has proven that there are multiple genetic conditions that can affect a pregnancy when conceived with a man who is 45-years and older. Understanding the barriers for utilizing this novel technology can help to make it more accessible, and assist genetic counselors in discussing the importance of this test with their patients. Taylor has always had a very strong interest becoming a prenatal genetic counselor. Having RWJ in your backyard is one of the many great things that Rutgers has to offer. RWJ has a diverse group of patients and a very busy perinatal genetics program within maternal fetal medicine. This team is invested into giving their patients the best care and they are motivated to participate in research projects that can help to better understand the access, barriers and motivation for patients to have the best genetic testing.

**Franki Spinosi-** She attended Biotechnology High School in Freehold, NJ where the curriculum and culture are STEM-focused. When her former teacher asked our program to give a talk about genetic counseling, she jumped at the opportunity. She was first exposed to genetic counseling during her sophomore year there so she understood the utility in finding your profession at a young age. Having this knowledge helped shape her entire undergraduate experience and helped her prepare for applying to graduate school. Biotech also has a strong alumni network that often visits the high school and gives advice to the current student. As a high school student she always appreciated the input of alumni and wanted to extend that same courtesy to the current students. She thought it was interesting to hear back from the students about their opinions on the ethical issues. After getting their initial thoughts, she challenged them to think psychosocially about the scenarios. This fostered a great discussion regarding the ethics and decision making involved in genetic counseling.

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