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NYC HEALTH + HOSPITALS/METROPOLITAN
1901 First Avenue at 97th Street
New York, NY 10029

NYC HEALTH+ HOSPITALS | Metropolitan

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Contents

Our Leadership

At NYC Health + Hospitals/Metropolitan, we take great pride in being a community hospital. We draw strength from the deep ties we have to our patients, their families, and the community we serve.

Among all of the events and commemorations that we host throughout the year, Rare Disease Day has become a personal favorite for me. We join as clinicians, researchers, advocates, community members, and families to learn and to celebrate our patients.

Congratulations to all of the individuals, their families, and caring providers who have come together to create this very special book.

Alina Moran, MPA, FBA
Chief Executive Officer

It is an honor to serve infants, children and adolescents with rare diseases at NYC Health + Hospitals/Metropolitan. Our Genetics Service under the leadership of Maryam Banikazemi, MD, Director of Genetics, has enhanced our understanding of rare diseases, their causes if known, and preventive and treatment strategies available.

This book is a tribute to our patients as they strive to overcome the physical, psychological, social and economic barriers in life. We dedicate the fourth Rare Disease Day celebration at Metropolitan to the children who grace the pages of this book and to their families.

Sarla Inamdar, MD
Chief of Pediatrics

I came to Metropolitan's Genetics Program in 2013, as physician-scientist with over 20 years experience in the field of biochemical genetics, with particular research interests in Fabry disease and lysosomal storage disorders.

I am a strong advocate for a comprehensive, personalized and tailored approach to caring for patients with rare disorders in order to manage different physical and behavioral challenges that these conditions and underlying genetic disorders cause. Each patient's hopes and frustrations need the support of an integrated team of caregivers, and I believe in treating the patient as a whole, not just the genetic disorder.

One of my greatest professional privileges has been joining the Metropolitan hospital community, where everyone shares the same philosophy regarding patient care and the involvement of family and the larger community. Our greatest successes are in joining our patients on their journeys, sharing their joys and sorrows and learning from them.

I want our patients to remember that they are surrounded by friends and supporters, with a fervent belief that as a community we can help them enjoy their lives. This book is an expression of that hope.

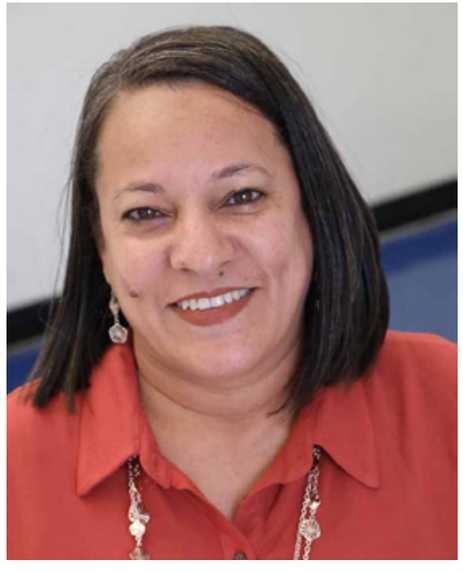
Maryam Banikazemi, MD
Director, Genetics Division

Our Team

Being a genetic counselor allows me the opportunity to change the face of healthcare.

I am grateful to be able to sit with families and individuals and guide them through tough diagnoses and decisions. I'm proud to be able to work with our patients at Metropolitan every day.

Deborah Paul, MS, CGC
Genetic Counselor



I am the first person that our patients see. I receive them with a smile and a 'Good Day', for them it is like lighting up their day. I have been here so many years with them that they know my name and I theirs. We treat each other like family. Working with these children has been one of the best things that has ever happened to me. This book is my dream come true.

Los quiero.

Doris Rojas
Assistant Coordinating Manager

About the Photographer

Rick Guidotti, an award-winning photographer, has spent the past twenty years collaborating internationally with nonprofit organizations, hospitals, medical schools, educational institutions, advocacy groups and communities to promote a more inclusive and compassionate world where ALL differences are understood and celebrated.

Guidotti's work has been published in newspapers, magazines and journals as diverse as Elle, GQ, People, the American Journal of Medical Genetics, The Lancet, Spirituality and Health, the Washington Post, New York Times, Atlantic Monthly and LIFE Magazine. Rick is the founder and director of POSITIVE EXPOSURE, an innovative arts, advocacy, and education organization which utilizes the visual arts to celebrate human diversity. (www.positiveexposure.org)

Photo by Deborah Paul

Photo by Dr. Banikazemi

Freddy, 15

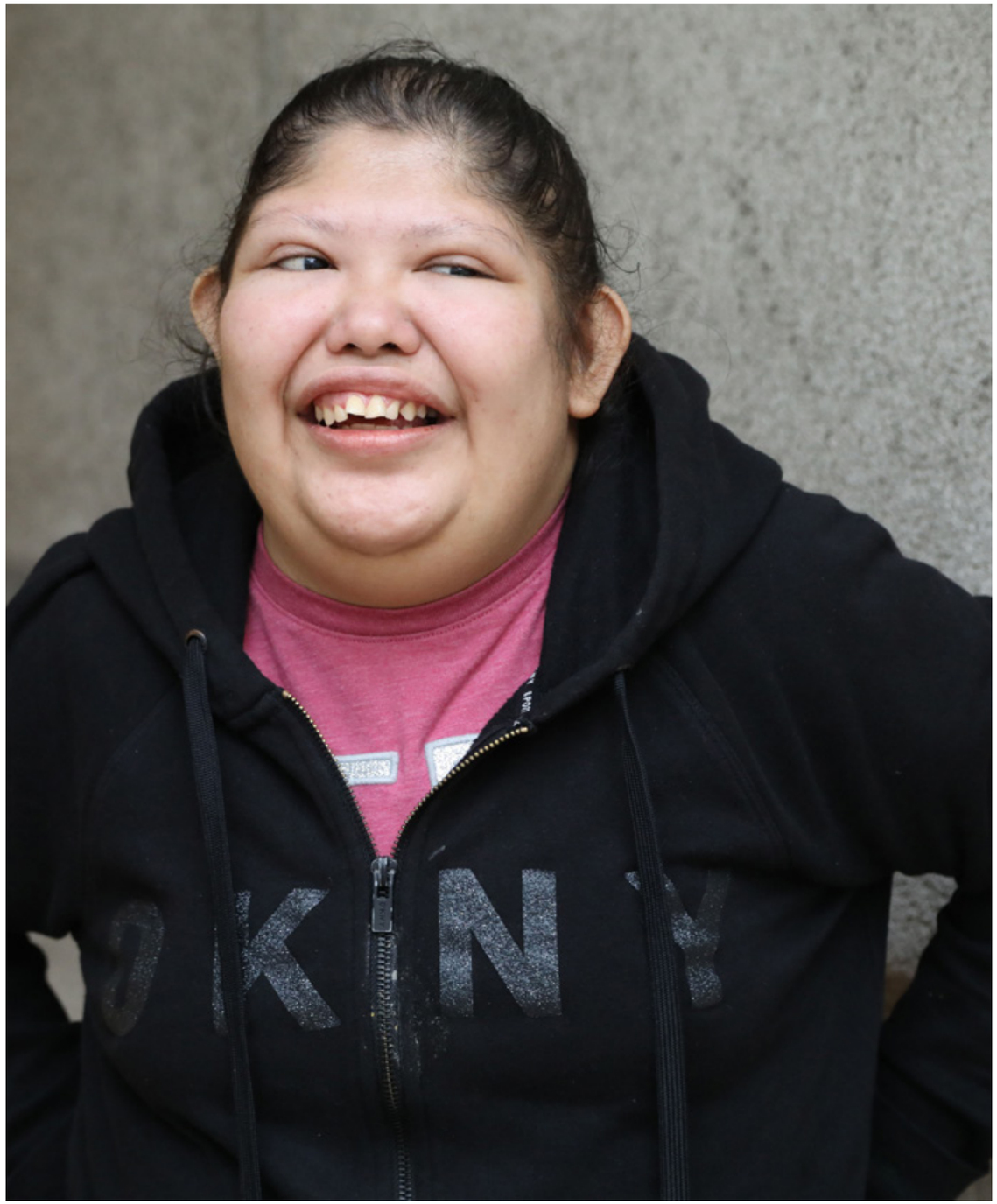
Mexican-American
Diagnosis: Bardet-Biedl syndrome
Favorite Things: Art, soccer, camp, the pool. He is happy with his friends and playing ball. He also likes dogs.

Mexicoamericano
Diagnóstico: síndrome de Bardet-Biedl
Cosas Favoritas: Arte, fútbol, campamento, la piscina. Está feliz con sus amigos, jugando pelota, y también le gustan los perros.

Karla, 24

Mexican
Diagnosis: PRMT7 disorder
Favorite Things: She is happy when she is in her program and with her family. She likes to eat everything. Books are a favorite of hers.

Mexicana
Diagnóstico: desorden de PRMT7
Cosas Favoritas: Le hace feliz estar en su programa y con su familia. Y le gusta comer de todo. Lo favorito de Karla son los libros.



Ibrahim

Ghanaian-American
Diagnosis: TRIO-related disorder
Favorite Things: Enjoys rice and chicken. He likes to spend time with his mom and family. He likes to play games on his tablet and listen to happy music.

Ghaneseamericano
Diagnóstico: desorden de TRIO
Cosas Favoritas: Le gusta el pollo y arroz. Le gusta pasar tiempo con su mamá y la familia. Le gusta jugar juegos en su tableta y escuchar música la hace feliz.

Melanie, 13

Mexican-American
Diagnosis: 22q11.2 deletion syndrome
Favorite Things: Painting, drawing and listening to music makes her happy and chatting with her friends.

Mexicoamericana
Diagnóstico: síndrome delección 22q11.2
Cosas Favoritas: Pintar, dibujar y escuchar música la hace feliz. Platicar con sus amigas también.

Rasheeda, 19

African-American
Diagnosis: BRPF1-related disorder
Favorite Things: I like to watch television, color, and listen to music. My favorite things are being around my brother and sister. What makes me happy is having fun.

Africanamericana
Diagnóstico: desorden de BRPF1
Cosas Favoritas: Me gusta ver la tele, dibujar, y escuchar música. Mis cosas favoritas son estar con mi hermano y hermana. Lo que me hace feliz es divertirme.

Anthony, 3

Mexican-American
Diagnosis: Down syndrome
Favorite Things: Anthony likes balls and cars, music, all musical instruments, dancing, and blocks.

Mexicoamericano
Diagnóstico: síndrome de Down
Cosas Favoritas: Anthony le gustan las pelotas, los carritos, la música, todos los instrumentos musicales, bailar, y los bloques.

Lourdes, 12

Mexican-American
Diagnosis: Rubinstein Taybi syndrome
Favorite Things: She likes dolls and toys. She likes to eat fruit. Dancing and music make her happy.

Mexicoamericana
Diagnóstico: síndrome de Rubinstein Taybi
Cosas Favoritas: Le gustan las muñecas y juguetes. Le gustan las frutas. Le hace feliz bailar y la música.

Jesus, 10

Mexican-American
Diagnosis: Ataxia Telangiectasia
Favorite Things: Jesus likes to watch cartoons on his phone and he also likes to play with Thomas the Train.

Mexicoamericano
Diagnóstico: Ataxia Telangiectasia
Cosas Favoritas: Jesus le gusta mirar caricaturas en el teléfono y también le gusta jugar con los trenecitos de Thomas.

Nico, 8 months

Mexican-American
Diagnosis: Achondroplasia
Favorite Things: Nico loves tummy time and playing with his big sister, Sofia. His favorite food is applesauce and he loves smiling.

Mexicoamericano
Diagnóstico: Acondroplasia
Cosas Favoritas: Nico le encanta jugar boca abajo y jugar con su hermana mayor, Sofia. Su comida favorita es puré de manzana y le encanta sonreír.

Gamal, 33

Jamaican-American
Diagnosis: Fabry disease
Favorite Things: Basketball, nightlife, mechanics. I like being physical. It's not only a pastime but tones the body. Dogs, movies, videogames, traveling, festivals, and surfing (just starting).

Jamaquino-americano
Diagnóstico: enfermedad de Fabry
Cosas Favoritas: Baloncesto, la vida nocturna, la mecánica. Me gusta ser físico. No es solo un pasatiempo, sino que tonifica el cuerpo. Perros, películas, juegos de video, viajar, festivales, y el surf (apenas comenzando).

Sonia, 70

Jamaica
Diagnosis: Fabry disease
Favorite Things: Socializing with friends and family, eating, travelling, TV, music, and going to church.

Jamaica
Diagnóstico: enfermedad de Fabry
Cosas Favoritas: Socializar con amigos y familiares, comer, viajar, tele, música, e ir a la iglesia.

Yolani, 10

Honduran-American
Diagnosis: Autism
Favorite Things: She likes math, music, dancing, drawing, and reading. What makes her happy is being with her family and playing with her brothers.

Hondureña-estadounidense
Diagnóstico: autismo
Cosas Favoritas: Le gusta la matemática, la música, bailar, dibujar, y leer. La hace feliz estar con la familia y jugar con sus hermanos.

Jessica, 13

Mexican-American
Diagnosis: Dyskeratosis congenita
Favorite Things: I like BTS K-pop group and drawing.

Mexicoamericana
Diagnóstico: Disqueratosis congénita
Cosas Favoritas: Me gusta el grupo de K-pop BTS y dibujar.

Abdulrahman, 11

Yemenese
Diagnosis: DPH1-related disorder
Favorite Things: Abdulrahman is a clean boy. He likes to watch TV and play on his iPad. He can also eat by himself.

قل لنا من فضلك قليلاً عن نفسك/طفلك
الإسم
بلد المنشأ/الخلفية العرقية
التشخيص
اوصف ما تحب القيام به، ما يجعلك سعيداً، الأشياء المفضلة لك ... الخ

Andrea, 31

Mexican
Diagnosis: 5q deletion syndrome
Favorite Things: She likes to talk a lot, dance, and being with her nieces and nephews makes her happy. Her favorite things are eating, going to the park, and sleeping. She likes to cut her own hair and polish her nails.

Mexicana
Diagnóstico: síndrome delección de 5q
Cosas Favoritas: Le gusta hablar mucho, bailar, y estar con sus sobrinos le hace feliz. Sus cosas favoritas son comer, ir al parque, y dormir. Le gusta cortarse el pelo y pintarse las uñas.

Stephanie, 23

United States
Diagnosis: Fabry disease
Favorite Things: Snowboarding and spending time with friends and family.

Americana
Diagnóstico: enfermedad de Fabry
Cosas Favoritas: Tirarse en la tabla de nieve, pasando tiempo con amigos y familia.

Kailee, 2

Mexican-American
Diagnosis: Prader-Willi syndrome
Favorite Things: She is happy when she is with her family. She really likes to dance and look at books. She likes to eat fruits; bananas, plums, strawberries, and blueberries.

Mexicoamericana
Diagnóstico: síndrome de Prader-Willi
Cosas Favoritas: Ella está feliz cuando está con su familia. Le gusta mucho bailar y mirar los libros. Le gusta comer frutas; plátanos, ciruelas, fresas y arándanos.

Hector, 23

Mexican-American
Diagnosis: Moebius syndrome
Favorite Things: I like to dance. I play basketball and I like pizza. I'm happy when I'm with my family.

Mexicoamericano
Diagnóstico: síndrome de Moebius
Cosas Favoritas: Me gusta bailar. Jugar baloncesto. Me gusta comer pizza. Estoy feliz cuando estoy con mi familia.

Axel, 18

Mexican-American
Diagnosis: CDG Type 1t
Favorite Things: I like to meet new people. I like to cook new foods from different countries. I like to do new things that I would not expect.

Mexicoamericano
Diagnóstico: CDG tipo 1t
Cosas Favoritas: Me gusta conocer nuevas personas. Me gusta cocinar comidas nuevas como de diferente paises. Me gusta hacer nuevas cosas que no lo he experimentado.

Alex, 11

Mexican-American
Diagnosis: Learning disabilities
Favorite Things: Playing ball, videogames, and listening to music.
What makes him happy is spending time and being with his family.

Mexicoamericano
Diagnóstico: discapacidades de aprendizaje
Cosas Favoritas: Jugar pelota, juegos de video, escuchar música.
Le hace feliz pasear y estar con familia.

Bryan, 8

Mexican-American
Diagnosis: Alternating hemiplegia of childhood
Favorite Things: Bryan likes music, dancing, and singing. He likes to play and he loves clowns.

Mexicoamericano
Diagnóstico: hemiplejía alternante de la infancia
Cosas Favoritas: A Bryan le gusta la música, bailar, y cantar. Le gusta jugar y los payasos le encantan.

Ameer, 4

Dominican-American/Colombian-American
Diagnosis: Angelman syndrome
Favorite Things: Toys with music and instruments like the recorder.
He loves to eat everything, especially bananas.

Dominicano-americano / colombiano-americano
Diagnóstico: síndrome de Angelman
Cosas Favoritas: Juguetes con música e instrumentos musicales como la flauta. Le gusta comer todo, especialmente los plátanos.

Isis, 14

Mexican-American
Diagnosis: Arthrogryposis
Favorite Things: Baking and watching Netflix.

Mexicoamericana
Diagnóstico: artrogriposis
Cosas Favoritas: Hornear y mirar Netflix.

Jenny, 4

Mexican-American
Diagnosis: Angelman syndrome
Favorite Things: She likes to play with and tease her dad. She likes toys and eats everything. She's happy when she's playing with her dad. Jenny smiles with all people.

Mexicoamericana
Diagnóstico: síndrome de Angelman
Cosas Favoritas: Le gusta jugar con su papá y hacerle maldades a su papá. Le gusta los juguetes. Jenny le gusta comer de todo. La hace feliz estar con su papá jugando. Jenny es muy sonriente con todas las personas.

Jennifer, 13

Mexican-American
Diagnosis: Learning disabilities
Favorite Things: She likes to sing, dance, and eat all kinds of foods. She loves to watch the movie Frozen, make friends, go to the park, go shopping, and she likes to read books.

Mexicoamericana
Diagnóstico: discapacidades de aprendizaje
Cosas Favoritas: A Jennifer le gusta cantar, bailar, y comer todo tipo de comidas. Le encanta ver la película Frozen, hacer amigos, ir al parque, ir de compras, y le gusta leer libros.

Julio, 12

Dominican Republic
Diagnosis: Charcot-Marie-Tooth disease type 4D
Favorite Things: I like my cell phone and games like PUBG mobile and 8 ball pool. My favorite thing is listening to trap and my favorite singer is Bad Bunny. What makes me happy is being with family and travelling to the Dominican Republic.

República Dominicana
Diagnóstico: enfermedad de Charcot-Marie-Tooth 4D
Cosas Favoritas: A mi me gusta el cellular y los juegos como PUBG mobile y 8 ball pool. Mi cosa favorita es escuchar trap y mi cantante favorite es Bad Bunny. Lo que me hace feliz es estar con la familia y viajar a la República Dominicana.

Maria, 45

Ecuador
Diagnosis: Fabry disease
Favorite Things: Working, cooking. It makes me happy to be playing with my daughter. I like pears and peaches.

Ecuatoriana
Diagnóstico: enfermedad de Fabry
Cosas Favoritas: Trabajar y cocinar. Me hace feliz jugar con mi hija. Me gusta la pera y durazno.

Johnathan, 8

Mexican-American
Diagnosis: Autism spectrum disorder, Charcot-Marie-Tooth type-1A
Favorite Things: He likes to play with his friends and sister. His favorite thing at school is math. Being with his sister makes him happy.

Mexicoamericano
Diagnóstico: autismo, Charcot-Marie-Tooth 1A
Cosas Favoritas: Le gusta jugar con sus amigos y su hermana. Su cosa favorita en la escuela es matemáticas. Le hace feliz estar con su hermana.

Yaneth, 24

Mexican-American
Diagnosis: Joubert syndrome
Favorite Things: Music, fruit juices, everything makes her happy.

Mexicoamericana
Diagnóstico: síndrome de Joubert
Cosas Favoritas: La música, jugo de fruta, todo le hace feliz.

Vanessa, 25

Mexican-American
Diagnosis: Joubert syndrome
Favorite Things: Dancing, music, and singing. It makes me happy to be with family.

Mexicoamericana
Diagnóstico: síndrome de Joubert
Cosas Favoritas: Bailar, música, cantar. Me hace feliz estar con la familia.

Leonydes, 10

Dominican American
Diagnosis: Witteveen Kolk syndrome
Favorite Things: Riding my bicycle and going to the park, listening to music, going on train rides, and watching TV.

Dominicano-americano
Diagnóstico: síndrome de Witteveen Kolk
Cosas Favoritas: Montar en bicicleta, ir al parque, escuchar música, montar en tren, mirar la tele.

About Metropolitan

NYC Health + Hospitals/Metropolitan is the community hospital of choice for residents of East Harlem, northern Manhattan, and neighboring communities.

We provide culturally-sensitive primary and specialized medical care to patients of all ages regardless of national origin, immigration status, or ability to pay.

Our mission is to deliver high quality health services with compassion, dignity and respect to all, without exception.

Since our founding in 1875, the hospital has been affiliated with New York Medical College, representing the oldest partnership between a hospital and a private medical school in the United States. Previously located on what is now Roosevelt Island, Metropolitan has been in its present location in East Harlem since 1955.

Metropolitan is part of NYC Health + Hospitals, the largest public health care system in the nation.

About Our Program

Metropolitan's Genetics clinic provides comprehensive care for patients with, or at risk of, conditions with a genetic basis.

This includes diagnostic services for pediatric, adult, preconception, prenatal and high risk cancer patients. We focus on communicating comprehensive information to patients and families in ways that they can understand the condition and how it affects them. Sessions are one-on-one, focused on individual patient needs, with referrals to specialty clinics, resources, and follow up care as needed.

We have a proactive community outreach with awareness programs that extend to providers and policymakers. We have not forgotten to echo the Patient's Voice, and we take pride in our deep level of support within the provider community. One example is the annual celebration of Rare Disease Day, a program established by the European Organization for Rare Diseases in 2008, and now shared with our community for the past 4 years. A rare disease is one that affects fewer than 200,000 Americans at any given time. According to the National Institutes of Health, there are between 6,000 and 7,000 rare diseases affecting 25 to 30 million Americans - and more than half of them are children. It is estimated that at least 80% have identified genetic origins.

Rare Disease Day aims to raise awareness about rare diseases and their impact on patients' lives. Photos from previous celebrations are on the pages that follow.

Rare Disease Day 2017

Every year, Metropolitan's Genetics Division commemorates Rare Disease Day, held on the last day in February to raise awareness about rare diseases and their impact on patients' lives. Activities include informational tabling, presentations by advocates, and a joyful celebration for patients and their families. Photos by Damien Kim and Eugene Song.

Rare Disease Day 2018

Rare Disease Day 2019

This book is dedicated to our patients and their families. You are our inspiration every day!

Wholehearted thanks to Rick Guidotti, our wonderful photographer. Many of our patients only met him once, but his heart and mind was open and invited them to express themselves. Rick has devoted his life to making sure everyone sees how amazing, fearless, and beautiful you all are.

The Metropolitan family is large and full of love. Behind the scenes, there are so many staff and departments that help make our work possible on Rare Disease Day and throughout the year.

For this book project we are especially grateful for the beautiful design by Eugene Song, editorial support from Claudia Duarte and Noel Alicea in Public Affairs, and production from Michell Bisette and the Metropolitan Print Shop.

Metropolitan leadership has been unwavering in their dedication to the Genetics program. Chief Executive Officer Alina Moran has led by example. We will always be grateful for her support of our program.

I have had the privilege of leading this amazing Genetics team of Doris Rojas and Deborah Paul, whose dedication and compassion motivates me and provides such comfort and support to our patients. Along with our previous Genetics counselors, including Karina Acrich, Monica Erazo and Miriam Maik, this team has been there for our patients and their families, hearing their concerns and challenges to figure out how we can help them through difficult times.

You are all extraordinary!

Dr. Banikazemi

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