

# ADVANCEMENTS

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Montefiore  
Inspired Medicine

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# HOW HER LEGACY LIVES ON

## The Geraldine Richtand Pediatric Marrow & Blood Cell Transplantation Program



### DONORS

Dr. Sara and Mr. Joshua Ross

### FOCUS

Pediatric Marrow & Blood Cell Transplantation

*"...we continue to feel passionate about the strong social mission at Montefiore and hope to contribute to the well-being of children and families who are impacted by life-threatening diseases."*

**-SARA ROSS, MD**

Last year, the Children's Hospital at Montefiore (CHAM) officially named the Geraldine Richtand Pediatric Marrow & Blood Cell Transplantation Program, thanks to a generous gift from Dr. Sara and Mr. Joshua Ross. The program offers traditional and alternative donor options for any child who may benefit from transplantation. These include children with cancers such as leukemia, lymphoma, brain tumors, neuroblastoma and sarcoma, as well as children with genetic diseases such as sickle cell disease, thalassemia, immune deficiencies and metabolic disorders.

"We are proud to name The Geraldine Richtand Pediatric Marrow & Blood Cell Transplantation Program in honor of Josh's grandmother, who was one of the most generous and loving people we have known, and who lived with a chronic form of lymphoma herself," says Sara Ross, MD. "Although we left New York over a year ago we continue to feel passionate about the strong social mission at Montefiore and hope to contribute to the well-being of children and families who are impacted by life-threatening diseases." Dr. Ross was an attending physician in the Division of Pediatric Critical Care Medicine from 2007-2014 and the pediatric residency training director from 2011-2014.

"We are extremely grateful to the Ross family for their generous donation, which provides us, through the purchase of a recently developed device, a transplantation option for patients who previously did not have this as a choice. Even half-matched relatives can now serve as donors," says Kris M. Mahadeo, MD, Director, The Geraldine Richtand Pediatric Marrow & Blood Cell Transplantation Program and Assistant Professor, Department of Pediatrics (Hematology & Oncology), Albert Einstein College of Medicine. "The Ross family's support will also create the additional physical space that will be needed to take care of the increasing numbers of patients who can benefit from these curative therapies and ensure children can undergo their potentially life-saving therapy, safely, right here in the Bronx."

### SUPPORT

To support The Geraldine Richtand Pediatric Marrow & Blood Cell Transplantation Program at Montefiore, please visit [montefiore.org/fightchildhoodcancer](http://montefiore.org/fightchildhoodcancer) or call the Office of Development at 718-920-6656.

# MAKING OUR IMPRINT ON GENETIC MEDICINE

## Caring for Children and Families with Complex Disorders

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The Division of Pediatric Genetic Medicine at the Children’s Hospital at Montefiore (CHAM), one of the earliest and most well respected in the country, has provided family-centered care for infants, children and adults with genetic diseases, birth defects, and congenital malformations since 1968.

Caused by irregularities in the genome, genetic disorders may be hereditary (passed down from the parents’ genes) or caused by new mutations or changes to the DNA. Most genetic disorders are rare and affect one person in every several thousands or millions.

At birth, our genes determine familial traits such as eye color, blood type, and susceptibility to disease. However, mutations in our genetic makeup can disturb normal growth and development, potentially causing

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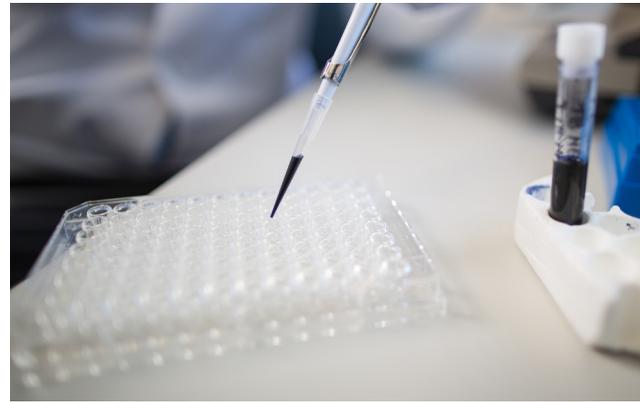
birth defects, developmental delays, growth complications, and other health issues. “Diagnoses of genetic diseases in young children often come as a complete shock, without any known family history,” says Melissa Wasserstein, MD, Chief, Division of Pediatric Genetic Medicine, Montefiore and Associate Professor of Pediatrics, Albert Einstein College of Medicine.



**Melissa P. Wasserstein, MD**

### Clinical Care

Recognizing the challenges families face in organizing care for children with complex medical needs, CHAM has a strong history of coordinating patient visits with multiple medical providers and clinics, facilitating greater communication amongst medical



subspecialists. The Division of Pediatric Genetic Medicine is dedicated to providing diagnostic and clinical services; performing clinical and basic science research; and training the next generation of leaders in the field. The Division is also home to the Center for Inherited Metabolic Disorders, a New York State-approved newborn screening referral program. “Every child and family is managed based on their specific psychological, medical and genetic needs,” says Robert Marion, MD, Chief Emeritus, Division of Genetics, CHAM and Professor, Pediatrics, Obstetrics, Gynecology and Women’s Health, Einstein. “In terms of both diagnosis and management, this is cutting-edge, personalized medicine.”

### Newborn Screening

Newborn screening (NBS) is a public health program created to test infants shortly after birth for a list of disorders that are treatable, but not clinically apparent in newborns. Established in the early 1960’s, NBS is intended to identify infants with treatable conditions before they suffer irreversible damage. Most newborn screening tests are done by measuring metabolites and enzyme activity in blood samples. Infants who screen positive undergo further testing to determine if they

are truly affected with a disease or if the test result was a false positive. Follow-up testing is typically coordinated between geneticists and the infant’s pediatrician or primary care physician.

NBS has expanded worldwide with different testing menus in each country. Initially possessing the ability to test for only one disease, NBS can now test for over 50 increasingly complicated disorders, some of which are not treatable or may not have clinical manifestations until adulthood. Despite these challenges, many physicians and scientists agree that genomic screening at birth will become widespread in the near future, raising important ethical and practical concerns.

### Subspecialty: Williams Syndrome

Williams syndrome (WS) is a rare genetic condition affecting growth, physical health, and learning abilities. It is caused by a deletion of approximately 25 genes on chromosome seven. This deletion randomly occurs before birth, affecting roughly one out of every 10,000 newborns. WS affects both males and females, in every culture across the globe.

People with WS may have some common facial features, slow growth, and multiple medical problems. These individuals experience developmental delays, and mild to moderate intellectual disabilities. Additionally, they often have strong verbal abilities, social personalities, and a high affinity for music. Children with WS need ongoing learning assistance and physical therapy. As adults, many live in assisted housing and volunteer or work with extra supervision.

The WS program at CHAM is one of only 10 centers nationally recognized by the Williams Syndrome Association for multidisciplinary care. Available on the first Friday of each month, our specialists work together to see children and adults with WS, with visits supplemented by social services,

*continued...*

## PEDIATRIC GENETIC MEDICINE

music and other therapy. “CHAM is well known for taking care of children with WS,” says Dr. Wasserstein. “It’s one of the best known centers in the country. Dr. Marion has a particular interest in WS and set up an impressive multi-disciplinary clinic where patients with complex medical needs can come and their families medical needs and arrange to see several physicians in one day, coordinate laboratory testing and ultrasounds as needed, and manage different aspects of the disease. Because of the ability to offer these services under one roof, patients come to us from all over the country.”

To address some of these issues in an efficient, high yield manner, Dr. Wasserstein is currently conducting an NIH-funded pilot NBS program in New York City. The goals of the study are to evaluate how NBS works for complex diseases with variable phenotypes, to pilot the use of disease registries that can be shared with the rare disease research community; to develop guidelines about when to initiate treatment in presymptomatic children; and to evaluate the ethical, legal, and social issues associated with this type of screening. To date, this one-of-a-kind pilot program has enrolled and screened more than 45,000 infants across New York City.

### Clinical and Translational Research

The Division, through its close work with investigators at Albert Einstein College of Medicine, particularly the team at the Rose F. Kennedy Intellectual and Developmental Disabilities Research Center (IDDRC), is in an extraordinary position to impact the lives of children with inherited disorders. The IDDRC, now entering its sixth decade, focuses on unraveling the mysteries of normal and abnormal brain development in children. There are critical translational collaborations linking basic science expertise at Einstein with CHAM’s clinical programs, including Rett and Williams syndromes, Niemann-Pick and other lysosomal diseases, inborn errors of metabolism, neurocutaneous disorders, infantile and childhood seizures, and others. Through these and other initiatives, and with the support of donors and supporters, we hope to advance understanding of the causes and consequences of neurodevelopmental disorders and to enhance translational studies designed to bring bench research discoveries to the bedside in the form of new and innovative therapies.

#### SUPPORT

To support Pediatric Genetic Medicine at Montefiore, visit [montefiore.org/supportgeneticmedicine](https://montefiore.org/supportgeneticmedicine) or contact the Office of Development at 718-920-6656.



# EMERGENCY HEALTHCARE IN A TIME OF NEED

## Stroke Diagnosis & Treatment with Dr. Allan Brook

### DOCTOR

Dr. Allan Brook, Director,  
Interventional Neuroradiology,  
Montefiore

**What are strokes and what cause them?** A stroke is a "brain attack" and can happen to anyone at any time. Strokes occur when poor blood flow to the brain results in cell death, typically caused by a blockage of a blood vessel from a clot, or bleeding either directly into the brain or into the space surrounding the brain. Either way, they both result in part of the brain not functioning properly.

### What symptoms do people display if they are having a stroke?

Patients typically experience an inability to feel or move on one side of the body, difficulty understanding or speaking words, dizziness, and/or loss of vision. Symptoms often appear very soon after the stroke has occurred. The more extensive the area of brain affected, the more functions that are likely to be lost. Strokes can be devastating because they typically start suddenly, and can cause permanent physical and/or brain damage as well as death.

### Who is at risk for having a stroke?

Overall, two thirds of strokes in the United States occur in people over 65 of age. The main risk factor for stroke is high blood pressure. Other risk factors include tobacco use, obesity, high cholesterol, and diabetes.

**How are strokes treated at Montefiore?** We frequently perform a minimally invasive emergency surgical procedure called a thrombectomy, utilizing the latest clot-retriever technology. It is typically a catheterization through the groin, where a catheter is threaded through the heart up to the artery of the brain that has the clot. We then use a suction device or a stent to remove the clot.

**What is unique to the work that is being done at The Stern Stroke Center at Montefiore?** The Stern Stroke Center is a recognized leader in stroke services, treating more than 1,200 acute stroke patients each year, making it the second busiest stroke center in the State of New York. Designated by the New York State Department of Health as a primary stroke center, the Stern Stroke Center offers advanced acute and long-term management and preventative care, treating victims of stroke rapidly and efficiently.

Our inpatient team of doctors, nurses, rehabilitation specialists and social workers identify the patient's stroke risk factors, maximize patient safety and ensure a smooth transition to outpatient rehabilitation and stroke prevention. Care starts in the emergency department and continues after the patient leaves the hospital. At the Stern Stroke Center outpatient office, we collaborate with patients, their physicians, and rehabilitation specialists to improve their quality

of life and reduce the chance of recurrent stroke.

**What developments are you excited about that are taking place here at Montefiore in neuroradiology and stroke treatment?** The advances taking place in the field of diagnostic neuroradiology at Montefiore are simply incredible. State of the art diagnostic imaging is a huge priority for us right now and will allow us to better diagnose strokes going forward. Currently, we do not know for certain if a patient has had a stroke without performing a CT scan or an MRI. With the rapid advances taking place using cutting edge medical technology, we are positioning ourselves front and center at being able to better diagnose and treat strokes. Right now, we hypothetically know where the stroke is coming from in a patient, based on seeing an arm or leg that is weak or unresponsive. We will know theoretically what side of the brain it is on, but to actually see how big a clot could be, what artery is causing it, and then target our therapy using advanced imaging is absolutely fantastic and will benefit our patients going forward.

### SUPPORT

To support The Stern Stroke Center at Montefiore, visit [montefiore.org/supportstrokecenter](http://montefiore.org/supportstrokecenter) or contact the Office of Development at 718-920-6656.

# PROTECTING THE HEALTH OF THE JEWISH COMMUNITY AND ITS FUTURE GENERATIONS

Jewish men and women from many different backgrounds and beliefs are faced with specific genetic concerns that are successfully being addressed through the use of new medical knowledge and technology. By screening for conditions that can affect offspring, the research focus has expanded towards diseases such as cancer and adult-onset disorders.

Breast cancer affects one in eight women in the United States, with hereditary breast cancer accounting for approximately five to ten percent of documented cases. Additionally, ovarian cancer affects about one in 70 women with hereditary ovarian cancer accounting for 10-15 percent of documented cases. Although there is no identifiable cause for most breast and ovarian cancers, a large proportion of hereditary breast and ovarian cancer can be linked to mutations in the BRCA genes.

Of particular interest to researchers are the BRCA1 and BRCA2 genes. These genes are typically expressed in the cells of breast and other tissue, where they are involved in the repair of chromosomal damage. If BRCA1 or BRCA2 itself is damaged by a mutation, damaged DNA is not repaired properly and the risk for developing breast cancer increases. The BRCA1 and BRCA2 genes are normal; it is their mutation that is abnormal.

Individuals of Ashkenazi Jewish descent (families with origins in Central or Eastern Europe) are 10 times more likely to be carriers of cancer-predisposing mutations in the BRCA genes than individuals in the general population. "BRCA mutations can run in families and be inherited by children," says Nicole Schreiber-Agus, PhD, Director of the Program for Jewish Genetic Health. "However, women and men who are shown by genetic testing to carry BRCA gene mutations have options to reduce and manage their cancer risks."

Established in 2010, the Program for Jewish Genetic Health seeks to prevent cancer by educating the Jewish community and its leadership about the risks of hereditary cancer, providing counseling and

testing for hereditary cancer predisposition for at-risk Ashkenazi Jews, and conducting research about how and when to best implement Ashkenazi Jewish population-wide BRCA screening.

In 2015, the Program for Jewish Genetic Health launched "The BRCAcommunity Initiative" to provide a mechanism for Ashkenazi Jews to gain access to BRCA genetic testing, especially in cases when their health insurance would not cover such testing. In its pilot year, the initiative attracted more than 400 interested Ashkenazi participants from 19 states. Two-thirds of these people were classified based on their family cancer history to have an even higher risk to be a BRCA carrier than the typical Ashkenazi individual, whose chance is one in 40. Two hundred participants were tested and have been provided with genetic counseling. More than 50 percent of these patients did not meet criteria for their insurance to cover testing, and benefited greatly from the subsidized test provided through the initiative.

Carriers who were identified through their testing are pursuing medical management and reproductive options, and have also notified their at risk blood relatives. The participants include couples seeking testing to prevent transmission of the BRCA mutations to their children, and families without a complete family medical history due to truncation of family lines in the Holocaust. Going forward, the Program for Jewish Genetic Health hopes to provide testing for more patients, and to collaborate with interested distant cities with large Jewish populations.

The program is affiliated with Albert Einstein College of Medicine and Montefiore Medical Center, but does not receive financial support from either institution, relying exclusively on the generosity of donors to support and expand these critical services for the Jewish community.

## SUPPORT

To support The Program for Jewish Genetic Health, visit [montefiore.org/pjgh](http://montefiore.org/pjgh) or contact Alexis Eggleton at 718-920-6786 or [aeggleto@montefiore.org](mailto:aeggleto@montefiore.org).

# THE WIRE

## The Latest News from Montefiore

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### Montefiore Einstein Center for Transplantation and St. John's Riverside Hospital Announce new Venture in Yonkers

Montefiore Health System has established a new program with its partner St. John's Riverside Hospital. This program offers patients suffering from kidney, pancreas or liver disease the option to be evaluated for transplantation at St. John's Riverside Hospital by specialists from the Montefiore Einstein Center for Transplantation. This collaboration is designed to increase continuity of care for patients and their families between their local healthcare providers and Montefiore transplant experts. Montefiore Einstein Center for Transplantation reports that Montefiore adult patient survival rates consistently rank higher than the national average, with a 95.09 percent liver transplant one-year survival rate compared to a 90.89 percent national liver transplant one-year survival rate, according to the Centers for Medicaid and Medicare Services.

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### Montefiore Launches New "Doing More" Brand Campaign

Montefiore Health System has launched "Doing More," a new advertising campaign featuring Montefiore's history of firsts in medicine, its Centers of Excellence, breadth of medical research, and expanding footprint in Westchester, the Hudson Valley, and the Bronx. The campaign highlights that Montefiore now brings its scientific breakthroughs, comprehensive high quality clinical care and research excellence directly to more local communities than ever before, making it possible for people to receive outstanding care in their own neighborhoods. This multi-media campaign is rolling out over a variety of platforms including TV, radio, outdoor, print, digital and social media. Discover more about Montefiore's history of firsts at [doingmoremontefiore.org](http://doingmoremontefiore.org).

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### The Arthur D. Emil Caregiver Support Center Celebrates 5 Year Anniversary

Five years ago, Montefiore Health System opened The Arthur D. Emil Caregiver Support Center, the only center of its kind in New York City, that provides caregivers with emotional support, practical assistance and a quiet, private place to relax while their loved one is in the hospital. The Center has recruited 30 volunteers, many of whom are former Montefiore patients or individuals who had loved ones cared for at Montefiore and have firsthand experience with the center. As Montefiore has continued to grow, it opened its second Caregiver Support Center at the Jack D. Weiler campus in 2014. Our vision is that eventually each campus at Montefiore will have its own Caregiver Support Center to provide these services to families and caregivers.

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### Investigators from Montefiore and Einstein Presented Data at American Society of Clinical Oncology Annual Meeting

Investigators from the Montefiore Einstein Center for Cancer Care and the NCI-designated Albert Einstein Cancer Center in New York presented several abstracts at the 52nd Annual Meeting of the American Society of Clinical Oncology (ASCO), held June 3 - 7. Presentations included the evaluation of biomarkers for neuroendocrine therapies; revealed the benefits of an immunotherapy for African American men with prostate cancer; outlined the phase II trial results of a combined modality therapy for squamous cell carcinoma of the rectum; and the evaluation of therapies for patients with advanced solid tumors.

#### SUPPORT

Ensure Montefiore has funding for more of these innovative initiatives by visiting [montefiore.org/donate](http://montefiore.org/donate) or contact the Office of Development at 718-920-6656.

# SUPERHEROES FIGHTING CHILDHOOD CANCER

April 8, 2016

Raised more than \$92,000 to benefit pediatric oncology treatment and research at the Children's Hospital at Montefiore



# 18<sup>TH</sup> ANNUAL GOLF TOURNAMENT AND DINNER

June 13, 2016

Raised over \$850,000 to benefit important programs and services at the Children's Hospital at Montefiore



# Montefiore

Inspired Medicine

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## OFFICE OF DEVELOPMENT

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# LOOKING AHEAD

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## FALL WINE TASTING

Thursday, September 22, 2016



Find out more details by visiting  
[montefiore.org/winertasting](https://montefiore.org/winertasting).

## CELEBRATE MONTEFIORE GALA

Wednesday, October 26, 2016



Find out more details by visiting  
[montefiore.org/gala](https://montefiore.org/gala).