

**Weill Cornell
Medicine**

Children's Health Council

Impact Report

July 2020



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LEADERSHIP

Dear Friends,

In the midst of an unspeakably difficult time, I am deeply proud to thank you for your dedication to Weill Cornell Medicine.

Over the past three months, you have delivered food to our front-line staff; you have facilitated donations of personal protective equipment (PPE); and you, members of the Children's Health Council, have donated more than \$840,000 to support Weill Cornell's COVID-19 emergency response effort. I stand in awe of your commitment and your compassion.

Thanks to your generosity, the world's best physicians and scientists are figuring out how to fight the COVID-19 pandemic and shape New York City's path forward.

We normally spend this time of the year reflecting on everything the Children's Health Council has done to advance pediatric health research. While this year has certainly not been normal, that does not lessen the impact you have made on children and families at Weill Cornell Medicine. I'm excited to celebrate and highlight these achievements in this report.

Since publishing our first Impact Report in April 2019, the Children's Health Council has grown by 14 families, and we have had our most successful fundraising year to date. This year Council members have cumulatively donated more than \$2 million to support pediatric research, education and care at Weill Cornell Medicine. What an incredible feat!

I hope your spirits are lifted as you see how your support is changing lives, and inspires us to look toward a better future. Thank you again for being champions of children's health and of Weill Cornell Medicine.

A handwritten signature in black ink that reads "Christina Truesdale".

Christina Truesdale
Chair, Children's Health Council



From left:
Casey Weiss,
Vice Chair of Programming;
Mara Feil,
Vice Chair of Membership;
Christina Truesdale, Chair;
Lori Freedman,
Vice Chair of Marketing

Children's Health Council By the numbers

Total member households:

59



Total CHC Funds Raised
from 2014-2020:

\$8,321,195



Areas funded:

- Child and adolescent psychiatry
- Newborn medicine
- Pediatric cardiology
- Pediatric endocrinology
- Pediatric gastroenterology and nutrition
- Pediatric hematology/oncology
- Pediatric neurology and neurosurgery
- Pediatric otolaryngology
- Pediatric pulmonology
- Pediatric surgery

Funds Raised Fiscal Year 2019-2020

Children's Health Investigators Fund

\$135,000

Other Children's Health Funds

\$2,205,214

Total Raised

\$2,340,214

CHC members have donated

\$841,750

to support COVID-19 response
at Weill Cornell Medicine



Donor Spotlight: Stephanie and James Kearney

At just two and a half years of age, Stephanie and James Kearney's son, Louis, was diagnosed with epilepsy. By the fall of 2017, he was having up to 20 seizures a day. But for the past two years, Louis has been seizure-free and is thriving, set to start kindergarten this fall. His participation in the Ketogenic Diet Program in the Department of Pediatrics at Weill Cornell Medicine and NewYork-Presbyterian has been life-changing, his parents say.

"Louis is one of the funniest, sweetest people and he's taught us so much about resilience," says Stephanie, who with her husband James, have been members of Weill Cornell's Children's Health Council since October 2019. "He always finds the good in everything."

After his diagnosis, Louis became part of the Pediatric Epilepsy Program, where a team of doctors worked tirelessly to understand his illness through myriad exams, including overnight EEGs, MRIs and genetic testing. After mixed results, including resistance to several medications, treatment through the Ketogenic Diet Program at Weill Cornell Medicine and NewYork-Presbyterian was recommended by his medical team, eventually stopping his seizures altogether.

"We can attest that Weill Cornell is at the forefront of the field, pushing the boundaries in order to accelerate the understanding and treatment of pediatric epilepsy," says James.

Louis' treatment team is led by Dr. Srishti Nangia, an assistant professor of pediatrics with a specialty in neurology and a subspecialty in epilepsy and medical director of the Ketogenic Diet Program, and Mary Montgomery, a registered dietitian specializing in pediatric neurology and epilepsy. The program consists of a special high-fat, low-carbohydrate diet that is first administered in a hospital setting and then a medical team works closely with the family to provide them with meal plans and recipes.

"We have been humbled by Dr. Nangia's involvement in our lives. We will forever be indebted to her," says Stephanie. "The months leading up to Louis' official diagnosis were shrouded by the stress

and fear of the unknown. Dr. Nangia approached Louis' case with confidence based on her deep acumen and experience, and she approached us, as parents, with a compassion that proved invaluable during a difficult time."

"We are also enormously appreciative of Mary Montgomery," says James. "The partnership between Mary and Dr. Nangia has been unbelievable, and a real testament to how Louis' entire medical team works together to manage his care."

This compassionate and comprehensive care prompted Stephanie and James to make a generous gift to the Ketogenic Diet Program, in order to assist other families whose children will benefit from this regimen. Implementing the diet can be costly, due to the specialized foods needed, including frozen premade meals.

"We wanted to make sure that Louis' success can be paid forward to be shared with others," says Stephanie. "This

program requires so much diligence and the cost can be prohibitive. It can be an incredibly overwhelming thing to commit to, and we wanted to help with that. We wanted to promote the diet and also make it much more accessible for families and individuals."

Their gift has already made it possible for several families to begin the program. When the COVID-19 pandemic hit and some families were affected financially, the Kearneys' generosity allowed multiple families to receive specific Ketogenic Diet Program foods at no cost.

"To see a child who was seizing multiple times a day to actually thriving is very gratifying. That's why I wanted to specialize in epilepsy – to have an impact, improve quality of life, and help kids be seizure-free," says Dr. Nangia. "The Kearney family has been wonderful and supportive of other families in the program. They've made a tremendous contribution."

The program also provides nutrition education, notes Dr. Nangia. It requires families to learn exactly what types of food are needed and the correct portions to feed their child in order to get the best results and minimize side effects. And who administers the diet is critical to its success.



Dr. Srishti Nangia



James, Louis and Stephanie Kearney

"This diet program is a medical treatment and it's so important that it is followed by trained professionals and nutritionists," says Dr. Nangia. "The program requires expertise and guidance by a dietitian to make sure that patients are getting the appropriate amount of protein, vitamins and minerals for their growth."

Dr. Nangia introduced the Kearneys to the Children's Health Council when they asked how they could get more involved.

"We joined the Children's Health Council as a way to express our appreciation for everything that has been done for Louis," says James. "The Council is a phenomenal opportunity to feel

connected and also a great conduit to ensure that support is directed to high priority pediatric research."

While discovering the diagnosis and treatment for Louis' condition has been challenging, the Kearneys say they're grateful for the support the program has provided.

"An epilepsy diagnosis can be extremely overwhelming for a parent, and it can be lonely as well," says Stephanie. "We felt pretty scared until we were introduced to resources, and then we realized there was a support system, which made all the difference. Seeing the selflessness of others in action – doctors, nurses, volunteers and other families – has served as an inspiration to us, and will positively impact our family forever."

Children's Health Investigators Fund Recipients

The Children's Health Investigators Fund is a vital source of support for early-career scientists, providing the funds needed for our pediatric investigators to establish promising preliminary results and then qualify for large-scale federal grants. In July 2019, \$203,000 from the Investigators Fund was distributed to support these three exciting research projects.

Cori M. Green, MD, MSc

Associate Professor of Clinical Pediatrics
Director, Behavioral Health and Integration in Pediatrics



In her role as director of Behavioral Health Education and Integration in Pediatrics, Dr. Cori Green is building an integrated behavioral and mental health program in the Department of Pediatrics. Weill Cornell Medicine has one of the few pediatric residency programs studying educational interventions around mental health.

The new program, for those training to be general pediatricians, is expected to have three components: putting clinical systems into place to integrate mental health into the practice; a three-year longitudinal curriculum for pediatric trainees; and a research component, exploring the impact of educational interventions on pediatric trainees' competence and practices around mental health care. Dr. Green's prior research documented the gap in mental health training in pediatrics and

created a framework for how training programs need to evolve in order to best train future pediatricians.

Funding from the Children's Health Council has enabled Dr. Green to build a large data repository in advance of the program start in order to position the work for maximum impact. The data repository will allow for a rigorous evaluation of the program and educational initiatives. This data can help to inform national initiatives for all training programs, a top priority of both the American Board of Pediatrics and the American Academy of Pediatrics.

The mental health impact of the COVID-19 pandemic has only motivated Dr. Green further to implement the curriculum and research. The CHC funding will help her team to proactively improve the lives of children and families.

Matthew Scult, PhD

Postdoctoral Associate of Psychology in Psychiatry



This year, Dr. Matthew Scult completed a pilot study with youth diagnosed with anxiety disorders as they used the Maya App, developed by investigators at Weill Cornell Medicine and previously supported by the CHC.

The Maya App guides participants through an interactive six-week program focusing on managing anxiety symptoms through exercises based in cognitive behavioral therapy (CBT). Study findings showed that 72 percent of participants used the app for six weeks and completed all core exercises. Youth who used the app had a 40 percent reduction in general anxiety and 50 percent reduction in social anxiety symptoms.

Most important, study participants reported that the app helped them to get through difficulties in their day, and that they planned to continue using the strategies they learned.

In light of COVID-19, Dr. Scult's team is adjusting the app to better teach skills relevant to coping with the pandemic. They also plan to freely distribute the app to Weill Cornell Medicine graduate students, to help them through this difficult time. The global pandemic highlights the need for widely available, high-quality mental health interventions like the Maya App, and Dr. Scult is immensely appreciative that the CHC is helping make this a reality.

Matthew Smith-Raska, MD, PhD

Assistant Professor of Pediatrics
Friedman Family Foundation Clinical Scholar in Newborn Medicine



Dr. Smith-Raska studies how life experiences and exposures affect the risk of disease in our children and grandchildren by changing the epigenetic molecules found in our sperm and eggs.

As a baby develops in the womb, epigenetic molecules turn genes on or off in various combinations, determining cell specialization (whether cells become skin cells, blood cells, liver cells, etc.) and other inheritable traits (eye color or hair color, for example). When these epigenetic factors are abnormal in eggs and sperm, the fetus is predisposed to abnormal development and conditions like autism, cancer or congenital heart disease.

New discoveries have revealed that the epigenetic "signature" of molecules

in sperm and eggs is determined by a person's life experiences and environmental exposures, such as nutrition, exercise and stress, as well as exposure to various medications and toxins. Therefore, we know that an ancestor's life experiences can influence the risk of disease in descendants, but it is still a mystery how this form of inheritance works at the cellular level.

With CHC support, Dr. Smith-Raska developed a mouse model that enables him to study two genes he believes are critical to explaining how, at the molecular level, environmental signals cause inheritable modifications in sperm and eggs. This work has important implications for our prevention and treatment of many common pediatric diseases.

Children's Health Council 2019-2020



Dr. Gerald M. Loughlin, Vice Chairs Mara Feil, Casey Weiss, Lori Freedman, Chair Christina Truesdale and Dr. Virginia Pascual at the 2019 New Member Welcome Reception.



Dr. Melody Zeng, Dr. Amy Tsou, Executive Committee members Courtney Nataraj and M. Steven Silbermann enjoy the 2019 New Member Welcome Reception.



Executive Committee member Erika Feil-Lincoln, Julie Barer and Janet Krauthamer attend the 2019 Discovery Panel.



Overseer Nancy Paduano and Chair Christina Truesdale attend the 2019 CHC 5th Anniversary Celebration.



Breanna and John Khoury with Dr. Francis S. Lee at the 2019 New Member Welcome Reception.

Jack Cross, age 11, enjoys Family Science Day 2020.



Dr. Matthew Smith-Raska and Kenix Cheng attend Family Science Day 2020 with Charleston, age 3, and Samuel, 9 months.



Amy and Michael Fang join a toast at the 2019 CHC 5th Anniversary Celebration.

Children's Health Council Members

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Vice Chairs

Mara Feil

Lori Freedman

Casey S. Weiss

Executive Committee

Alison Bernstein

Gail Cohen

Erika Feil-Lincoln

Barbara B. Friedman

Debra Gelband

Lynne Hammerschlag

Robert J. Katz

Ronay Menschel

Courtney Nataraj

Nancy Paduano

Sal Piscopo

M. Steven Silbermann

Council Members

Anonymous (2)

Mackenzie and Stephen Bartlett

Alexandra and Michael Bassik

Jay Bernstein

Natalia Bulgari

Kate and Matthew Burke

David Cohen

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Christina and Christopher Crampton

Jamie and Michael Crespi

Lauren and Christopher Dawson

Rebecca and Loïc de Kertanguy

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Michael Gelband

Tara and Drew Gabel

Mark Hammerschlag

Todd Hollander

Stephanie and James Kearney

Breanna and John Khoury

Galina and Igor Kirman

Jamie and Shaun Kolnick

Michelle and David Kroin

Rekha Kumar, MD and Vinay Kumar

Kim and Jonathan Kushner

Kate Leitch and Terence Kooyker

Charlotte and Jed Lenzner

Arline Mann

Fara and Matthew Marcus

Richard Menschel

Stephanie and Jonathan More

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Naveen Nataraj

Alicia Nevarez-Bunnell and Mitchell Bunnell

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Jill Swid Rosen and Eric Rosen

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Noah N. Weiss

Cricket Whitton and Nick Hammerschlag

Carolyn Seely Wiener

Julia and John Zito

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Biology in Psychiatry

Gerald M. Loughlin, MD, MS

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Nancy C. Paduano Professor

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Institute for Children's Health

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