



11TH ANNUAL
Sugar
Soirée

Saturday, September 28, 2024

In support of people living with HYPERINSULINISM

OUR MISSION

CHI is the leading organization dedicated to improving the lives of people living with hyperinsulinism (HI). HI is a life-threatening disorder that causes dangerously low blood sugar levels due to the over-production of insulin. Prolonged or severe low blood sugar can cause seizures, brain damage, and even death.

CHI supports research toward better treatments and a cure, tirelessly advocates for timely diagnosis and improved standards of care, and supports children living with HI every step of the way.

Thank you for partnering with us to prevent unnecessary brain damage and death, search for better treatments, and improve the quality of life for all HI patients.



When too little sugar hurts, we help.

SUGAR SOIRÉE 2024

SATURDAY EVENING – September 28, 2024

COCKTAIL RECEPTION

DINNER & PROGRAM

SILENT AUCTION

HOST

Cheri Preston

AWARDEES

- Sally Bliumis-Dunn
- Clare Gilbert
- Mark Sperling

SPECIAL GUEST

Jilani Huffman

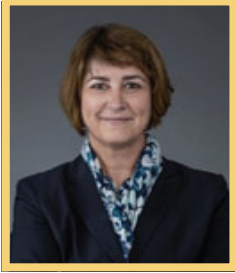
MUSIC GUESTS

Matthew Albeck And Julian Giamio

The museum galleries will be open to our guests during the cocktail hour.

MASTER OF CEREMONIES

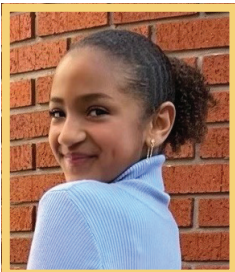
CHERI PRESTON



Our 2024 Sugar Soirée host for the evening is Cheri Preston. Cheri is an award-winning broadcaster who currently anchors Morning Drive ABC News top-and-bottom-of-the-hour updates for radio stations and podcast listeners across the country. A breaking news veteran, Cheri has been behind the microphone for some of the biggest stories of the past several decades, including 9/11, Superstorm Sandy, the capture of the Boston Marathon bombing suspect, the wedding of Prince Harry, the Sandy Hook shootings, and of course, the incredible political and social upheaval of the past eight years. Cheri is the former host of the weekly ABC News podcast and radio news magazine “Perspective,” and has calculated that over the past 23 years, she’s told her listeners what’s happening in the world more than 68,000 times. In addition to her on-air duties, Cheri also serves on the National and New York Boards of SAG-AFTRA -the union representing 160,000 media professionals around the world – and she serves as chair of the SAG-AFTRA National Broadcast Steering Committee. She is thrilled to be hosting the CHI Sugar Soirée for the second year in a row.

SPECIAL GUEST

JILANI HUFFMAN



CHI is honored to welcome Jilani Huffman as our special guest speaker for the evening. Jilani was born in 2013 with diffuse HI. Her treatment included a 98% pancreatectomy (surgical removal of her pancreas), which caused post-pancreatectomy diabetes. At our Family Conference with Children’s Hospital of Philadelphia (CHOP) in 2023, Jilani took to the stage at just ten years old to share her HI and diabetes management story and words of encouragement to other young people with

HI and their families. Jilani’s profound understanding of how HI impacts her life, combined with her active role in managing her medical care, has empowered her to achieve what once seemed impossible without supervision. Now, she bikes to school, spends time with friends, and attends in-person classes independently. Always positive, Jilani encourages us to practice gratitude and look forward to what the future will bring. We are proud to share her invaluable perspective as a young person with HI to our Sugar Soirée guests.

TONIGHT’S HONOREES

BE MY SUGAR SWEETEST SUPPORTER AWARD



SALLY BLIUMIS-DUNN

BE MY SUGAR EXTRAORDINARY NURSE AWARD



CLARE GILBERT

BE MY SUGAR LIFETIME ACHIEVEMENT AWARD



MARK SPERLING, MD



LETTER FROM THE CEO

JULIE RASKIN

Welcome Dear Sugar Soirée Guests,

We are so grateful to you for choosing to support the work of Congenital Hyperinsulinism International by joining us at the Sugar Soirée. We hope you have a fantastic time, get to view some of the superb artwork at the Museum, enjoy the company of all our fascinating guests, learn about our compassionate and brilliant awardees and speakers, and walk away feeling energized to be part of a caring and effective community making improvements in the lives of people with congenital hyperinsulinism.

Tonight we are celebrating the 10-year anniversary of our very first Sugar Soirée. The progress CHI has made as a result of this steadfast support over 10 years has made enduring advancement possible. Since that day in November in the year 2014, CHI has launched a global patient-powered research project that now has over 500 participants, inaugurated the Open Hyperinsulinism Gene Project that has provided free genetic testing to over 900 people with a congenital hyperinsulinism medical diagnosis, built the Collaborative Research Network uniting over 50 global hyperinsulinism medical experts and leading patients advocates to solve the most difficult research questions and advocate together for access to timely diagnosis and appropriate care options. CHI has designated eight congenital hyperinsulinism centers of excellence and developed a robust awareness program to inform the general public, medical community, and decision makers about congenital hyperinsulinism with the goal of providing care in a timely manner to end preventable brain injuries and death from the condition. Your steadfast support over 10 years is responsible for these advancements for the CHI community.

Tonight we also honor individuals with the Be My Sugar awards for their remarkable contributions to science, clinical care, and support to the organization.

For the second year we are honoring an individual with the CHI *Be My Sugar Extraordinary Nurse Award*. Clare Gilbert, a clinical nurse specialist from the Great Ormond Street Hospital. Since I first met Clare in 2013 in Milan, Italy, I knew she was an extraordinary nurse. It was the first year we held a hyperinsulinism family conference in Europe and Clare became extremely involved in the planning process offering to cover a wide range of topics. This commitment to patient care and support has only expanded over the years as Clare has presented at CHI conferences year after year and participated as a leader in collaborative research and advocacy projects, all of that on top of her day job caring for children with congenital hyperinsulinism at GOSH. Clare is a leading advocate for early diagnosis of congenital hyperinsulinism.

We are also honored to be giving a lifetime achievement award to Dr. Mark Sperling, one of our esteemed scientific advisors. Dr. Sperling's career spans decades and his work on neonatal hypoglycemia is important to our understanding of the transition from fetal development to a newborn's independent control of blood glucose levels. This work is a cornerstone of CHI's advocacy efforts for newborn screening for all babies. Dr. Sperling leads the editorial board of the *Sperling Pediatric Endocrinology Book*. Read by endocrinologists and pediatricians, this book covers important topics in the science and clinical practice of pediatric endocrinology. Dr. Sperling is also one of the authors of the seminal PES 2015 hypoglycemia guidelines. These guidelines are designed to increase early detection and management of hyperinsulinism in newborns. Dr. Sperling has also been a fantastic contributor to our Collaborative Research Network as a member of the nomenclature group.

Our final award of the evening goes to Sally Blumis-Dunn. Sally and I developed a deep friendship when we were undergraduates studying Russian literature at the University of California. As luck would have it we both settled in the New York area and have been friends living in proximity to each other for over 40 years. Sally is a creative person who has had a brilliant career as a poet and writing teacher, she has been an extraordinary help mate to me and to all of CHI as the organization grown and developed. Her history as an extraordinary supporter of HI patient advocacy predates the CHI organization. In 2003 when Randy Hart and I worked with CHOP on the first CHI family conference, Sally led two fantastic days of poetry writing with the children attendees. She also made it possible for me to produce a documentary film based on the conference. When the CHI organization was established, through her involvement in a family foundation, Sally made possible a yearly grant that has enabled a tremendous expansion of CHI's work. Sally's support to CHI is enduring and essential!

A soirée would never be complete without a spotlight on an amazing survivor of the condition. At this year's Soirée, Jilani Huffman will take the stage. Jilani is a true inspiration to all who meet her. Her positivity and energy in the face of challenges is incredible. She is wise beyond her tween years and gives great comfort to parents of younger children with congenital hyperinsulinism. Through her words and actions, she transfers hope to those parents who worry about the future. And so I end this message on a note of hope and gratitude. We are so grateful to you for joining us tonight and more generally as supporters of our cause to advocate for people living with the consequences of congenital hyperinsulinism.

The CHI Community is strong because of our devoted board of trustees, scientific, medical, and patient advisors, associate board, amazing supporters, and incredible staff. I cannot thank our sponsors and supporters enough for their unswerving support for our cause. "When too little sugar hurts, you help."

Julie Raskin



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VIP TICKETS

Sally Blumis-Dunn and John Dunn
Kristen Carlberg and Peter Wagner
Judy Fletcher and John Rathé
Phil & Beth E. Kruse
Julie Raskin and Mark Gross
Beth Ryan and Michael Hanna

PATRON TICKETS

Dr. Lisa States and Michael Hamel
Ewa Hamel



You or someone you love could be part of developing new therapies for congenital hyperinsulinism !

The ACHIEVE clinical trial is evaluating an investigational drug for congenital hyperinsulinism with once-weekly dosing

What is the study drug?

- Our study drug, called efpegerglucagon, is an injectable medication that mimics glucagon to maintain blood sugar levels.
- Efpegerglucagon has good stability and an long half-life allowing for once-weekly dosing.

What is our program?

- The purpose of this study is to assess the tolerability (how well the body reacts) and safety of efpegerglucagon.
- This study will help determine if efpegerglucagon is effective for the treatment of congenital hyperinsulinism (CHI).

Who would be eligible?

- Aged over 2 years* subjects diagnosed with CHI
- Be having 3 or more hypoglycemia events per week
- Be on therapy for congenital hyperinsulinism
- Not have type 1 or type 2 diabetes

** Minimum age may vary based on where you live. Please ask your doctor first for scheduling.*

Investigational sites

- United States (2)
- United Kingdom (2)
- Germany (2)
- Israel (1)
- Korea (1)

Study information

- NCT 04732416
- EudraCT No. 2021-000508-39
- EUCT No. 2024-515290-98-00
- For more information, please visit our study website:
www.achieve.study

REZOLUTE



We are caregivers, loved ones, and patients. The spectrum of our humanity informs and inspires everything that we do in our mission to develop therapies that will make a difference.



sunRIZE
RZ358-301

**Enrolling in the
United States Soon!**

Rezolute whole-heartedly thanks the entire HI community for their unwavering support as we continue our global Phase 3 study of RZ358.



**Zealand Pharma is proud
to sponsor CHI's
11th Annual Sugar Soirée**

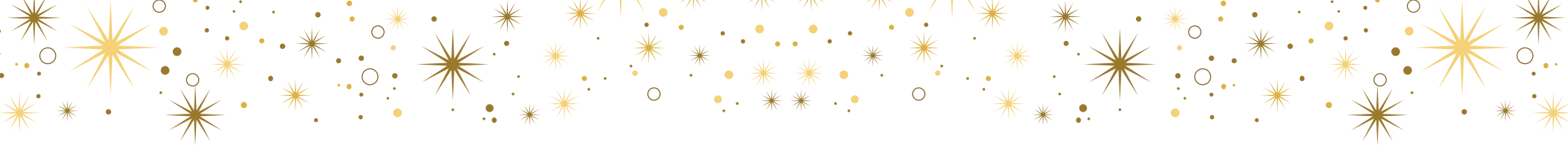


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Our purpose is to make a difference in the lives of people living with significant unmet medical needs.

For more information, visit us at
www.zealandpharma.com.



THANK YOU

We greatly appreciate the generous contributions of all who have purchased tickets or donated to the event. We extend an enormous thank you to the Benefit Committee Members who made this event possible.

BENEFIT COMMITTEE

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|---|--|
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MORE KUDOS

Thank you to the following people, organizations, and companies for making this year's Sugar Soirée stupendous:

- Alex Fallon and The Prendel Company
- Angelbeck's
- Holly Felber
- Kristen Carlberg Flower Design

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| Lolly Kruse | Hunter Standen |



PROUD TO SUPPORT THE SWEETEST CAUSE

As the largest and most active program in the world dedicated to congenital hyperinsulinism (HI), we know how important it is to support patients and families and advocate for advances in diagnosis and treatment. We are proud to be part of the strong community you've cultivated and promise to continue making breakthroughs for sweet kids like Grace.

Visit chop.edu/hyperinsulinism for more information.



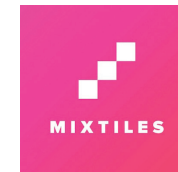
Children's Hospital of Philadelphia
Breakthroughs. Every day.

25GTF24T6UD/PDF/8-24



Grace, 9, HI patient, with her mother, Turaya

THANK YOU TO OUR SILENT AUCTION DONORS



WORLD-CLASS, COMPASSIONATE CARE

Our Congenital Hyperinsulinism Center, recognized as a Center of Excellence by Congenital Hyperinsulinism International, cares for more children than any other center in the world. We're here with compassionate, patient-first care, from diagnosis to treatment and beyond.

Children's Hospital of Philadelphia
Congenital Hyperinsulinism Center

Grace, 9, HI patient



CookChildren's
Choose our Hyperinsulinism Center

The Highest level of care



Let's connect!

#sayhitoHI

#WeHaveHIHopes

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Questions? Please contact jraskin@congenitalhi.org

