



10TH ANNUAL

# Sugar Soirée

**Saturday, November 4, 2023**

*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 2023

SATURDAY EVENING – November 4, 2023

### COCKTAIL RECEPTION

### DINNER & PROGRAM

### SILENT AUCTION

### HOST

Cheri Preston

### AWARDEES

- Heather McKnight
- Leo Folsom
- Professor Sarah Flanagan, PhD

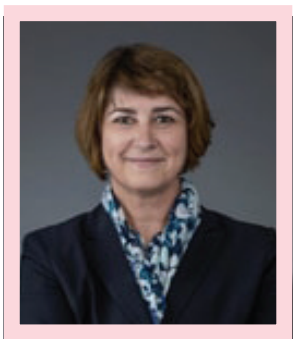
### MUSIC GUESTS

Janna Pelle and Eric Vanderzee

**Please visit the museum galleries during the cocktail hour.**

# MASTER OF CEREMONIES

CHERI PRESTON



Cheri Preston is an Edward R. Murrow and Gracie Allen award-winning broadcaster who currently anchors the top-of-the-hour news and bottom-of-the-hour updates for ABC News Radio. She is writer and host of the weekly ABC Audio newsmagazine "Perspective," which airs nationwide as a radio show and as a podcast. Cheri serves on the National and New York Boards of SAG-AFTRA and is the Chair of the SAG-AFTRA National Broadcast Steering Committee. She has been named four times as

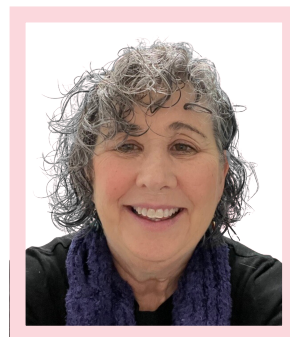
one of Radio Ink's "Most Influential Women in Radio," and she is thrilled to be hosting this year's Sugar Soirée!

# CHAIRPERSON

JULIE SHELDON

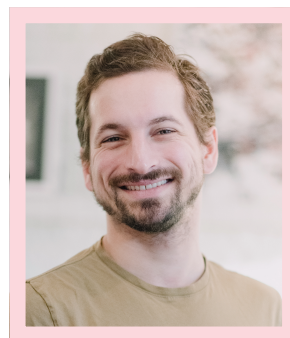


# TONIGHT'S HONOREES



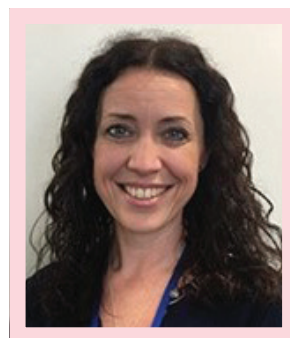
BE MY SUGAR  
EXTRAORDINARY  
NURSE AWARD

HEATHER MCKNIGHT



BE MY SUGAR  
EXTRAORDINARY  
FUNDRAISER AWARD

LEO FOLSOM



BE MY SUGAR  
EXTRAORDINARY  
RESEARCHER AWARD

PROFESSOR SARAH FLANAGAN



# LETTER FROM THE CEO

JULIE RASKIN

Welcome Dear Sugar Soiree Guests,

We are so thrilled you are joining us on the Sweetest Night of the Year to honor our Be My Sugar awardees. We will also celebrate our congenital hyperinsulinism community and raise funds to bring a brighter future to everyone living with hyperinsulinism.

When we had our first Sugar Soiree back in 2014 we had no idea the tradition would flourish and that there would ever be a day when we would celebrate our 10th Sugar Soiree, but it is here! We have a fantastically dedicated group of supporters who come to celebrate with us year in and year out! You veterans are absolutely amazing with your enduring support and dedication to the cause. We are also so grateful to our newest guests.

This is truly a magical year to be awarding deserving leaders in our community.

In addition to being one of the leading rare disease geneticists in the world, Sarah Flanagan has a heart of gold and wants every single person living with HI to understand their genetic report in order to better manage their condition. Sarah's curiosity combined with her knowledge and work ethic have produced many major breakthroughs in the understanding of hyperinsulinism. We are thrilled to be honoring Sarah Flanagan with the Be My Sugar Extraordinary Researcher Award.

Heather Mcknight is the inaugural recipient of our Be My Sugar Extraordinary Nurse Award. Hyperinsulinism is one of those conditions where nurses and nursing really matter. From the moment our babies wind up in the NICU to the all-important outpatient clinic appointments, the ins and outs of daily management require the close attention of a dedicated nurse specialist. Heather is the ideal nurse in her attention to detail and her thoughtfulness. As a nurse practitioner Heather has become one of the world's leading hyperinsulinism clinicians bringing her attention to the details of daily life to her practice.

Leo Brown is the Be My Sugar Extraordinary Fundraiser Awardee. Leo is not only a survivor of hyperinsulinism. He is a thriver. From the moment he joined our community about ten years ago, he has been making an impact. He was a dedicated captain of our Million Dollar Bike Ride Team, helping us to raise hundreds of thousands of dollars for hyperinsulinism medical research. He also has shared the cause with so many of his friends and family members to raise even more unrestricted funds to support CHI's awareness and support programs, in addition to research.

All three of our awardees are treasured members of our Collaborative Research Network that is increasing collaboration across institutions and organizations to break new ground in research and advocacy leading to new treatments, better diagnostics, while increasing access to expertise and treatments where it has not been available.

Finally ten years ago, a lovely young expectant mother with the same name as I called me up to share she was going to give birth to a child with hyperinsulinism. I knew from that first call she would be an amazing mother. What I didn't know at the time was Julie Sheldon would become an essential helpmate in the growth and development of CHI, that she would make it possible for CHI to become a leader in patient-powered hyperinsulinism research. As a lawyer, and an HI parent with a gigantic heart and a nuanced and brilliant mind, Julie has contributed so much to CHI as our Board of Trustees Vice President. Julie has also shared her strong, witty, and whip smart son Crosby with the CHI community, and he is an absolute delight.

The CHI Community is strong because of our devoted board of trustees, scientific, medical, and patient advisors, junior Committee, 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*

# SPONSORS

## PLATINUM

Crinetics  
Hanmi – waiting for ad  
Rezolute  
Zealand Pharma

## GOLD

Childrens Hospital of Philadelphia Surgical Associates

## SILVER

Amidebio  
Children's Hospital of Philadelphia Hyperinsulinism Center  
Cook Children's Medical Center

## PATRON TABLES

Dr. Charles and Mrs. Christian Stanley  
Alanna and Leo Folsom

## VIP TICKETS

Sally Bliumis-Dunn and John Dunn  
Julie Raskin and Mark Gross  
Dr Lisa States

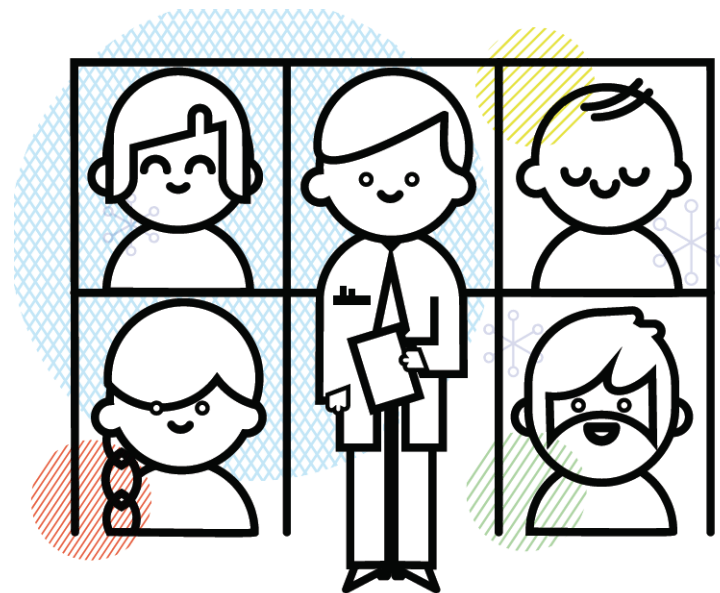
## PATRON TICKETS

Amy Graydon and Dan Kaplan  
David Landis  
Michael States



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

**The long-acting medication acts like a glucagon in the body to maintain blood sugar levels**



You or someone you love could be part of developing new therapies for HI

**For more information, please visit our study website:**

[www.achieve.study](http://www.achieve.study)



Rezolute wishes to thank to the entire HI community for their continued support as we prepare for the global launch of our RZ358 Phase 3 study.

*Imagining a life where days are defined by special moments and balance is restored to the lives of patients and their families.*



**sunRIZE**  
RZ358-301



Zealand Pharma is proud to sponsor  
CHI's Annual Sugar Soirée.



Zealand Pharma is a biotechnology company focused on the discovery, design and development of innovative peptide-based medicines.

We intend to be a leader in specialty medicines focusing on metabolic and gastrointestinal diseases and other rare disease areas with significant unmet medical needs.

Please visit us at [www.zealandpharma.com](http://www.zealandpharma.com)

## SWEETNESS BEYOND MEASURE.



We're proud to support this year's Sugar Soiree and thrilled to call the recipient of CHI's inaugural *Be My Sugar Extraordinary Nurse Award* one of our own. We are grateful to **Pediatric Nurse Practitioner Heather McKnight-Menci, MSN, BSN, BA, CRNP**, and all the members of our Congenital Hyperinsulinism Center team for their dedication to patients like Jilani and their families.

[chop.edu/hyperinsulinism](http://chop.edu/hyperinsulinism)

*Jilani, 9, HI surgical patient*



## THANK YOU

### BENEFIT COMMITTEE

Sandy and N. Scott Adzick, MD  
Jessica Aronoff  
Sheila Bose and Rohit Kaul  
Alana and Leo Folsom  
Kristen Carlberg and Peter Wagner  
Diva D. De León-Crutchlow, MD and Michael Crutchlow, MD  
Alex and Dan Fallon  
Holly and Don Felber  
Katherine Goldsmith  
Turaya Bryant Kamau

Julie and Christopher Krcmaric  
Nomi and Michael Plaut, DMD  
Julie Raskin and Mark Gross  
Jennifer and Jim Schmitt  
Julie Sheldon  
Mason Smith and Gordon Green  
Dr. and Mrs. Charles Stanley  
Laura and Jeff Sullivan  
Ricci and Paul Thornton, MD  
Lisa States, MD and Kevin Hamel  
Pam and John Williams

## INCOMPARABLE CARE



Our Congenital Hyperinsulinism Center cares for more children than any other center in the world.

*Asher, 7, HI patient*

We're here for you from before diagnosis, through treatment and beyond.



We are grateful to have such an active and enthusiastic group of young people supporting our cause.

### JUNIOR COMMITTEE

Hannah Albertine  
Tyler Clevenger  
Brendan Goldenberg  
Phillip Gomez  
Ryan Hiatt  
Emma Hinchliffe  
Justin Hunt  
Elizabeth Kölln  
Dane Lamendola  
Jon LeBoutillier  
Elif Mamak  
Catharine Parker

Amy Patterson  
Chloé Powell  
Benjamin Raskin-Gross  
Hannah Raskin-Gross  
Talia Rubnitz  
Jordan Sanders  
Madeline Schmitt  
Jordan Siff  
Hunter Standen  
Divya Talwar  
Devin Williams



Choose our  
Hyperinsulinism Center

The Highest level of care



Let's connect!

## 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  
Holly Felber  
Angelbeck's

AMIDEBIO

## THANK YOU TO OUR SILENT AUCTION DONORS





#sayhitoHI

#WeHaveHIHopes

#StopTheLows

#BeMySugar

#RaringToGoForCHI

#SugarSoiree2023

#SweetestCause

**Congenital Hyperinsulinism International**

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*Questions? Please contact [jraskin@congenitalhi.org](mailto:jraskin@congenitalhi.org)*

