

4TH ANNUAL  
**Sugar  
Soirée**

Sunday, November 19, 2017

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.

# FROM OUR 2017 SUGAR SOIRÉE CHAIRMEN

Dear Friends,

If you are reading this letter, thank you for giving your Sunday evening – and so much more—to support the mission of Congenital Hyperinsulinism International (CHI). And, congratulations! If you are here tonight, you are already more aware of hyperinsulinism than most people, including many doctors. This means that you now have the power to save a life, or a brain, by spreading the word. Hyperinsulinism is the leading cause of preventable brain damage in babies.

HI is a condition that most doctors are not trained to identify or treat. Our own child was sent home from a top Manhattan pediatric ER three times in one week with a diagnosis of “colic” before it occurred

to anyone to do a 10-second blood sugar test by pricking her finger, and discover that she was literally crying for her life. So, if you hear of a friend whose child is exhibiting the signs of hypoglycemia, speak up, and ask if anyone has checked that child's blood sugar level.

Eric and I are overcome with gratitude—to all of you who came tonight to support CHI and its mission of awareness, support, and research; to the outstanding doctors, nurses, and researchers who devote their lives to improving the lives of people with hyperinsulinism, and who are working creatively and diligently towards a cure; to Julie Raskin, CHI's visionary and tireless crusader, and the Board members of CHI who worked together to make this event special; to the biotech companies who invest their resources and expertise in working with CHI towards new treatments; to the business leaders who had no previous connection to CHI, but who heard about the brave children living with this disease, and were moved to help; to the artists who gave of themselves to make this event as beautiful as it is meaningful; to our hard-working Junior Committee, who are the future of CHI; to our incredible friends and families, who support us in our journey with hyperinsulinism, not just tonight, but every day; and, most importantly, to our beloved daughter, whose will to live and thrive inspires everything we do.

We begin this season of celebration with many reasons to be full of hope and joy. I see what CHI has accomplished this year. I see a community of HI families who are organized and excited to help progress clinical trials. I see research that is making strides not dreamed possible ten years ago, due to advances in genomics, molecular level understanding of this disease, and innovations in precision medicine. I am excited, and convinced, that we will cure HI. And with your help, soon. Thank you for being with us tonight, and for being part of the cure.

With warm wishes for a happy Thanksgiving from our family to yours,



Pamela Rytter



Eric Rytter

# SUGAR SOIRÉE 2017

## **COCKTAIL RECEPTION AND SILENT AUCTION**

## **DINNER AND PROGRAM**

### **WELCOME**

Conan O'Brien

### **THE CHI STORY**

Pamela and Eric Rytter, 2017 Sugar Soirée Chairmen  
Julie Raskin, Executive Director, CHI

### **CHI VIDEO**

### **MUSIC**

Hamilton Loomis, Musician and HI Parent  
Tenille Arts, Musician

### **LIVE AUCTION**

Lydia Fenet, Auctioneer and Senior Vice President, Christie's

### **AWARD PRESENTATIONS**

Alexandra Fallon  
Dr. Diva D. De León-Crutchlow

# MASTER OF CEREMONIES



## CONAN O'BRIEN

Conan Christopher O'Brien was born in Brookline, Massachusetts, and he started his path in comedy when he served twice as the president of The Harvard Lampoon. Conan went on to become a writer and producer on several television shows, including "Saturday Night Live" and "The Simpsons," until 1993, when NBC tapped him to take over as host of "Late Night." Since then, Conan has hosted two Emmy Awards, the MTV Movie Awards, performed a 32-city live comedy tour, was the subject of a documentary titled "Conan O'Brien Can't Stop," and performed at the White House Correspondents' Dinner for two presidents. He's won three Emmy Awards and six Writers Guild Awards for comedy writing, the People's Choice Award for "Favorite Television Host," and is currently helming the show "Conan," now in its eighth season on TBS. With the retirement of David Letterman in 2015, Conan became the longest-working current late-night talk show host in the U.S., at 24 years. Conan currently lives in Los Angeles with his wife, Liza, and two children.

# FROM THE CHI EXECUTIVE DIRECTOR

I have had the great honor to know and work with this year's Be My Sugar honorees for a long time.

When, in 2005, Dr. Charles A. Stanley suggested I contact Alex Fallon about getting involved in planning CHI's first international congenital hyperinsulinism (HI) conference, I gave her a call and we set up a time to meet. At the time, Alex was weeks away from giving birth to her third child, but she didn't hesitate to invite me up to her apartment for coffee and a chat. Being two HI moms, we had an instant bond. Little did I know at that first meeting that Alex would become such an important helpmate to CHI.

Alex Fallon is one of New York's most talented graphic artists. The company she co-founded with her husband, Dan Fallon, The Prendel Company, serves many companies, organizations, and individuals, helping them all to develop strong and cohesive visual identities.

A strong visual message is very important to a rare disease organization on a mission to share the unfamiliar signs and symptoms of a deadly disease in the service of saving lives and preventing brain damage. With that in mind, I was overjoyed Alex offered to do all the design work for our major fundraiser, the Sugar Soirée, in 2014. And she hasn't stopped since. I think we can all agree that our Sugar Soirée logo and materials are a thing of beauty. Alex's design work has made it possible for CHI to raise hundreds of thousands of dollars to support HI families, fund research and raise awareness of the condition to prevent death and brain damage. Working with CHI is not always easy. We are a small organization aiming to help everyone we can who has HI. This means taking advantage of last-minute opportunities that often alter a well-planned work schedule. Alex has never complained about last-minute additions to invitations or programs, even when she is juggling big projects at work and being there for her three children. I cannot thank Alex enough for her service.

When we announced on our Facebook page Conan O'Brien would be the host of the 2017 Sugar Soirée, we were not surprised by the number of likes we received. He is a big star and it was a record. Then we announced Dr. Diva D. De León-Crutchlow, Director of the Congenital Hyperinsulinism Center at CHOP would receive this year's Be My Sugar Award for Medical Excellence, and she broke another record. In the HI world, Dr. De León-Crutchlow is a rock star, held in the highest esteem by patients and peers all over the world. Dr. De León-Crutchlow provides her patients, newborns to young adults, with an unusual combination of expertise and care. Always a good listener, she understands that each of her patients is a full person with a unique and complex set of health issues that need to be addressed.

When I first met Dr. De León-Crutchlow many years ago, I was struck by what a humble, understated person she is. I knew she was very ambitious and was the author of many important research papers, as well as being one of the leading HI doctors in the world. I wasn't prepared for how unassuming she is. It is known in the HI world that Dr. De León-Crutchlow is a brilliant doctor who runs a leading international HI Center at one of the world's premier children's hospitals. It may not be so well known that Dr. De León-Crutchlow works tirelessly for every baby with HI anywhere in the world. She goes out of her way to assist wherever she is needed on the planet, and many babies around the world literally owe their lives to her. And there is more to come. The world will see many more big things from this giant of a doctor.

It is an honor and a joy for CHI to be presenting these outstanding people with CHI Be My Sugar awards.

A handwritten signature in black ink that reads "Julie Raskin". The signature is fluid and cursive, with a long horizontal line extending to the right from the end of the name.

Julie Raskin  
Executive Director  
Congenital Hyperinsulinism International

# FROM CHI

The **CHI Board of Directors** and staff congratulate and thank the 2017 Sugar Soirée Committee, led by the remarkable Chairmen **Pamela and Eric Rytter** and our Honorary Chairmen **Liza and Conan O'Brien** and **Mario Carbone**. They have made this a truly memorable and successful event. They have shared their time, energy and talents to make this the **#SweetestGala** ever!

# TONIGHT'S HONOREES



## **BE MY SUGAR AWARD FOR MEDICAL EXCELLENCE**

**Dr. Diva D. De León-Crutchlow**

Director, Congenital Hyperinsulinism Center  
Children's Hospital of Philadelphia

Dr. De León-Crutchlow is at the forefront of HI clinical care and research. She personally treats hundreds of children with the condition, and is the physician-scientist directing an NIH-funded translational research program with the goal of identifying new treatments and cures. She is an ardent supporter of all babies born with HI, as well as their families, and is known all over the world for her compassion, groundbreaking research projects, and cutting-edge care.



## **BE MY SUGAR AWARD FOR EXTRAORDINARY SERVICE**

**Alexandra Fallon**

Co-Founder, Creative Director  
The Prendel Company  
HI Parent

Ms. Fallon has shared her graphic design talent with CHI and has spent countless hours volunteering her time. Ms. Fallon is an award-winning advertising art director and graphic designer. She has worked at many top agencies including Young & Rubicam and Ogilvy & Mather where she directed work on campaigns for consumer products such as American Express, Hershey Foods, Kimberly-Clark, Miller Lite, and Jolly Rancher, which won two ADDY awards. Alex and her husband, Dan Fallon, co-founded The Prendel Company, where they serve global clients in many sectors including General Electric, AIG and WPP.

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**CONAN**



**Supports CHI.**

**Congratulations to  
Be My Sugar Honorees  
Dr. Diva De León-Crutchlow  
and Alexandra Fallon!**

We are so pleased to announce  
the creation of the HIHA Research  
Fund at CHI.

*-Conan & Liza*

To life.  
Healthier.  
Happier.  
Sweeter.

We are proud to support the  
Congenital Hyperinsulinism International  
4th Annual Sugar Soiree.

Best Wishes from  
your friends at

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PRG-40008 October 2017

# EXPERTISE. INNOVATION. DETERMINATION.

Our Congenital Hyperinsulinism Center team, led by Diva D. De León-Crutchlow, MD, MSCE, isn't content with providing unparalleled care to children with HI. We won't rest until we find a cure.



# SWEET RELIEF

At Children's Hospital of Philadelphia's Congenital Hyperinsulinism Center, we are committed to improving the quality of life for children with HI. Our surgical team is the most experienced in the world, caring for two-thirds of children in the U.S. who require surgery for HI, and our researchers are working tirelessly toward a cure. We are proud to support this year's Sugar Soiree and families in need of care.



©2017 The Children's Hospital of Philadelphia

*Olive Yoon Stuart  
April 26, 2017- September 13, 2017*



Our darling Olive,

Before you were born we had never heard of HI; rare diseases were abstract. But we know more now, and we need others to know too.

We will honor you, our beautiful baby girl, as we help to best serve this wonderful community of CHI babies and CHI families.

Olive Yoon Stuart, you are and always will be the greatest gift we could ever wish for.

Love, Mommy and Daddy



**ZEALAND PHARMA**

Zealand Pharma A/S is a biotechnology company focused on the discovery, design and development of innovative medicines.

We intend to be a leader in specialty medicines focusing on metabolic and gastrointestinal diseases and other specialty disease areas. Proud to support Congenital Hyperinsulinism International's Annual Sugar Soirée.

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

We are proud to support CHI!

**-Katie McGrath & J.J. Abrams  
Family Foundation**

CHI is grateful to the  
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for its generous support  
of the CHI cause.

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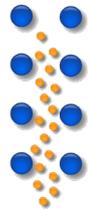
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# THANK YOU

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 Honorary Chairmen, Chairmen, and Sugar Soirée Committee Members who made this event possible.

## HONORARY CHAIRMEN

Liza and Conan O'Brien  
Mario Carbone & Major Food Group

## CHAIRMEN

Pamela and Eric Rytter

## BENEFIT COMMITTEE

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# MORE KUDOS

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

SJ and Kevin Abrams  
Susan Alter  
Tenille Arts  
Christian Oth Studios  
CONACO  
Dorsey & Whitney Foundation  
Lydia Fenet, Christie's  
T. Powell Hedley and Hedley Entertainment  
Andrew Joblon  
Kristen Carlberg Flower Design  
Hamilton Loomis  
Elif Mamak  
Jennifer Schmitt  
The Prendel Company

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

## **JUNIOR COMMITTEE**

Hannah Albertine	Elizabeth Kölln
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## HI GLOBAL REGISTRY

*The HI Global Registry is a resource to better understand how the whole community of HI patients is affected by the condition.*

### THE REGISTRY WILL:



**Generate new insights into HI**



**Drive new research for treatments and cures**



**Support the success of HI clinical trials**



**Study and guide standards of care**



**Improve the lives of all those affected by HI**

**Please join us to advance HI research and find a cure!**

[www.congenitalhi.org/donate](http://www.congenitalhi.org/donate)

The HI Global Registry has many global partners and is sponsored by



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