



VIRTUAL
Sugar
Soirée

Saturday, October 24, 2020

In support of people 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.



SUGAR SOIRÉE 2020

6:30 PM EDT VIRTUAL VIP RECEPTION

Tony Dokoupil interviews Dr. David Fajgenbaum, Author of *Chasing my Cure: Turning Hope into Action*

7:00 PM EDT PROGRAM

Tony Dokoupil interviews Julie Raskin, Executive Director, CHI Down and Up

Tai Pasquini and Leighton Sheldon

Tony Dokoupil interviews Dr Diva D. De León-Crutchlow, MD, MSCE and Paul Thornton, MB, BCh, MRCPI

Histories

AWARD PRESENTATIONS

Be My Sugar Awareness Award

Tatjana Milenkovic, MD, PhD

and

Rade Vukovic, MD, PhD

Be My Sugar Extraordinary Volunteer Award

Sunny Chapel

7:45 PM EDT THE AFTER PARTY

Time at Sugar Soirée Virtual Tables

8:30 PM EDT AUCTION CLOSES

MASTER OF CEREMONIES



Tony Dokoupil

Tony Dokoupil is a co-host of *CBS This Morning*. Previously, he was a CBS News correspondent and a CBS Sunday Morning contributor. His reporting has appeared across all CBS News broadcasts and platforms.

Since joining CBS News in 2016, Dokoupil has interviewed a variety of major artists, entertainers and newsmakers, among them First Lady Hillary Clinton, comedy legend Steve Martin, and music superstar Dolly Parton.

As a daily reporter for CBS This Morning and the CBS Evening News, he has written about marijuana legalization, digital privacy and the second amendment. In addition, Dokoupil has served as substitute anchor on CBSN, the *CBS Weekend News*, and *CBS This Morning*.

Dokoupil joined CBS News after three years at NBC News, where most recently he was a correspondent for MSNBC. He was the network's lead reporter on a run of big national stories, including the Paris climate agreement and the Flint water crisis. He also covered the 2016 presidential primaries.

From 2007 to 2013, Dokoupil was a senior writer at Newsweek and The Daily Beast, where his reporting landed him on NBC's *Today*, ABC's *20/20*, and NPR's *Fresh Air* with Terry Gross.

Dokoupil is also the author of the critically acclaimed book, *The Last Pirate: A Father, His Son and the Golden Age of Marijuana* (Doubleday, 2014), a memoir in which he documented his father's exploits smuggling marijuana during the 1970s and 1980s.

FROM THE CHI EXECUTIVE DIRECTOR

If someone had suggested a year ago that we hold the 2020 Sugar Soirée using virtual meeting technology, I would have rejected it out of hand. Why on earth would we not get together? Nothing is better than being with the treasured Sugar Soirée community, in person.

And yet, here we are. Behind a computer wall.

Over the last eight months, many of us have experienced loss and trauma. We have worried about our loved ones, and in many cases, been separated from them; we have also grown and adapted in ways we could have never imagined. We have changed how we work, visit, shop, go to school, vacation, and now, how we donate and support.

The CHI community got a double whammy. In addition to dealing with the global pandemic, we have our “plain old rare disease” to deal with. Congenital hyperinsulinism doesn't stop for Covid-19.

On the other hand, if there was ever a community up to the challenge, it's the CHI community, starting with CHI families who are used to a complicated daily living regime to protect their children from the effects of low blood sugar. We have all seen how our heroic medical professionals have put themselves in harm's way to care for patients, and made themselves available through telemedicine, and made safe protocols for in-person visits. We have seen innovative biotech companies shift their practices to keep their employees safe while keeping their important research on track.

And then there is the Congenital Hyperinsulinism International staff, board of directors, and scientific advisors. Daily, I am amazed by their creativity and ability to pivot to new realities, roll up their sleeves, and continue our unwavering support of hyperinsulinism families.

This year, CHI has grown in so many ways and we are launching important new initiatives thanks to your unwavering support. For the first time in CHI's history, we now have an Associate Director in Jennifer Schmitt. In this role, Jennifer already has many accomplishments and has been instrumental in moving our conferences to the virtual realm, allowing many more people from all over the world to participate, and Jennifer is responsible for creating this beautiful evening for us, and much more. With your support we were able to hire Tai Pasquini, as our Research and Policy Director. Tai is singularly qualified for this position with her background in rare disease and a PhD in public health and policy. Tai's expertise has made it possible for us to take the HI Global Registry to new levels, and to take on new projects that speed up drug development, all while focusing on important access issues. We are just thrilled to announce that the Center of Excellence Designation for congenital hyperinsulinism centers was just launched this week, under Tai's direction. This small but mighty staff has made it possible for us to begin to create the Congenital Hyperinsulinism Collaborative Research Network. Over the next few years, our hope is you will see many new projects that will improve the lives of people living with congenital hyperinsulinism all stemming from this excellent program supported by the Chan Zuckerberg Initiative.

All these programs are possible because of our brilliant and steadfast board of directors and scientific advisors who make the work of CHI central to their lives and are an equally important engine behind our success. I would like to highlight the work of Davelyn Hood, who is both our board president and the PI of the HI Global Registry. She joins with us on all our important projects to ensure they will be sustained. Turaya Bryant Kamau, also a member of our board of directors, has been instrumental in helping us to produce the Sugar Soirée, year after year, and this year, in the virtual realm, even more so.

Continued ...

Pediatric endocrinologists, Diva De León-Crutchlow and Paul Thornton, are, as always, leaders on our scientific advisory board. This year, they join us in new roles as lead researcher and clinician of our Collaborative Research Initiative, bringing years of experience and content expertise to this important project. We thank them for stepping up to also serve as our honorary chairmen of the 2020 Sugar Soirée, together with their spouses Ricci Thornton and Mike Crutchlow.

I am so thankful for all the individuals, organizations, foundations, universities, companies, and government leaders who work with us in a collaborative way to make the future better for all born with HI. None of this work would be possible without you, not by one iota.

There is something for everyone tonight, from the passionate and caring voices of those who live with congenital hyperinsulinism to the intrepid and superb physicians who care for HI patients. We have original music by the talented Janna Pelle, reality tv stars who happen to be members of our own community, and an incredible awards ceremony! As always, as a centerpiece of the evening, we have our special Sugar Soirée Auction and Live Ask, where we come to you again with a request to further support our important work. Please take a look at our fantastic auction items donated by our incredible community. Keep on bidding!

As always, we have fantastic awardees this year. The Be My Sugar Awareness Award goes to two very deserving pediatric endocrinologists: Tatjana Milenkovic and Rade Vukovic of the Department of Pediatric Endocrinology of Mother and Child Healthcare Institute of Serbia. In the Fall of 2019, Tatjana and Rade, together with colleagues, organized the First Balkan School of Clinical Paediatric Endocrinology in Veliko Gradiste, Serbia. I was so lucky to attend and present at the school, which focused on congenital hyperinsulinism and diabetes. The young pediatric endocrinologists from 15 countries were provided with an opportunity to learn extensively about congenital hyperinsulinism. The young physicians who attended the School now have a good basis for evaluating and diagnosing hyperinsulinism, and they have also developed an interest in hyperinsulinism research. In the 11 months that have passed since the school took place, important connections have been made between students and faculty of the school, leading to new research projects and work helping patients access medication and treatment for HI.


The Be My Sugar Extraordinary Volunteer Award goes to Sunny Chapel, CEO of Ann Arbor Pharmacometrics Group. Davelyn and I had the pleasure of meeting Sunny in the context of her work on the pharmacokinetics of potential hyperinsulinism treatments. Sunny became very interested in our work as well, and selflessly offered to share her expertise and resources with us. We were stunned by her altruism and we give Sunny this award because of her enormous generosity in an area where we desperately needed expertise. Providing pro bono data analytic support for our HI Global Registry, our patient-powered research project, makes it possible to share the patient experience with scientists in a meaningful way that will accelerate treatments and cures. We are really looking forward to continuing to collaborate and want to share with the community how important expertise from A2PG has been.

No matter how we gather, tonight is a very special evening in the CHI calendar. We celebrate the strength of the community as our Sweetest supporters join us to raise funds for CHI Awareness, CHI Research, CHI Support, and we also honor three special members of the CHI Community. Thank you so much.



Julie Raskin
Executive Director
Congenital Hyperinsulinism International

FROM CHI



The CHI Board of Directors and staff congratulate and thank the 2020 Sugar Soirée Benefit Committee and Junior Committee. 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 AWARENESS AWARD



Tatjana Milenkovic, MD, PhD



Rade Vukovic, MD, PhD

BE MY SUGAR EXTRAORDINARY VOLUNTEER AWARD



Sunny Chapel

SPONSORS

PLATINUM SPONSOR

Zealand Pharma

GOLD SPONSORS

Children's Hospital of Philadelphia, Children's Surgical Associates, LTD
Crinetics
Rezolute

SILVER SPONSORS

Children's Hospital of Philadelphia, Hyperinsulinism Center
Cook Children's
Hanmi

BRONZE SPONSORS

Malbrue Industries
Twist Bioscience
Xeris Pharmaceuticals

VIP TABLE SPONSORS

Drs. Davelyn and Bret Hood
Mason Smith

PATRON TABLE SPONSORS

Sheila Bose and Rohit Kaul
Katherine Goldsmith
Turaya Bryant Kamau and
Nicolas Kamau
Dr and Mrs Charles Stanley

VIP TICKETS

Sally Bliumis-Dunn
Joan and David Brown
Kristen Carlberg and Peter Wagner
Daphne Earp
Leo and Alana Folsom
Carla Germanos
Wendy Mikacich
Julie Raskin and Mark Gross
Dr. Lisa States
Dina and Dan Tallis
Elizabeth Van Arsdell

PATRON TICKETS

Amanda Ackermann
Carol Aronoff
Jessica Aronoff
Laurie and Martin Barkman
Ruth Brown Tabak
Jeremy Thomas Brown
Allison Clepper
Christine Eskilson and
Russell Sergeant
Laura Frankel
Amy Graydon and Dan Kaplan
Julie and Greg Graziano
Mary and Matt Hopkins
Liz and Howard Isenstein
Nicole Kofol
Allan and Melissa Malmed
Julie Rowe
Susan Marie Sander
Dr Nelly Silva
Joan and Paul Sher
Helen and Craig Standen
Thais and Marc Stuart
M.L. Wernecke
Lorraine and John Williams
Pam and John Williams

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



ZEALAND PHARMA

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



REZOLUTE

A Metabolic and Orphan Disease Company

*Advancing targeted therapies for metabolic
diseases with serious unmet needs*



**Children's Hospital
of Philadelphia®**

Department of Surgery



Crinetics

Pharmaceuticals

Proudly Supports



www.Crinetics.com



WE KNOW HI

Children's Hospital of Philadelphia has unmatched expertise and experience treating children with congenital hyperinsulinism. Our researchers are closing in on better treatments and, one day, a cure.

LEARN MORE:
chop.edu/hyperinsulinism



 Hanmi Pharm.

Creation and Challenge

- Focus on Metabolic Disease Area.
- Drug development focusing on patients suffering from rare disease.



**Choose Cook Children's
Hyperinsulinism Center:
The Highest level of care**

cookchildrenshyperinsulinism.org

CookChildren's.




Malbrue
INDUSTRIES

 **T W I S T**
BIOPHARMA

 **xeris**
PHARMACEUTICALS

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

HONORARY CHAIRMEN

Diva D. De León-Crutchlow, MD, MSCE and Michael Crutchlow, MD
Ricci Thornton, RN and Paul Thornton, MB, BCh, MRCPI

SPECIAL GUESTS

Tony Dokoupil
Dr. David Fajgenbaum

BENEFIT COMMITTEE

Dr. N. Scott Adzick
Jessica Aronoff
Sheila Bose and Rohit Kaul
Leo Brown and Alana Folsom
Kristen Carlberg and Peter Wagner
Diva D. De León-Crutchlow and Michael Crutchlow
Alex and Dan Fallon
Katherine Goldsmith
Drs. Davelyn and Bret Hood
Mary and Matthew Hopkins
Turaya Bryant Kamau and Nicholas Kamau
Julie and Christopher Krcmaric
Margaret Maher
Julie Raskin and Mark Gross
Jennifer and Jim Schmitt
Julie and Leighton Sheldon
Mason Smith and Gordon Green
Dr. and Mrs. Charles Stanley
Dina and Dan Tallis
Ricci and Paul Thornton
Dr. Lisa States and Kevin Hamel
Pam and John Williams



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
Leo and Alana Folsom
Turaya Kamau
Leighton Sheldon

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

JUNIOR COMMITTEE

Hannah Albertaine
Megan Freeman
Katie Frohling
Phillip Gomez
Ryan Hiatt
Emma Hinchliffe
Patricia Kilbride
Elizabeth Kölln
David Maher
Elif Mamak
Grace O'Grady
Amy Patterson
Janna Pelle
Ben Raskin-Gross
Hannah Raskin-Gross
Kim Rogers
Madeline Schmitt
Jordan Siff
Hunter Standen
Divya Talwar
Devin Williams
Andrew Williamson
Rianna Williamson



SCIENTIFIC ADVISORS

- Dr. Jean-Baptiste Arnoux, Necker Children's Hospital, Paris, France
Dr. Indi Banerjee, University of Manchester, Manchester, UK
Dr. Oliver Blankenstein, Charite Hospital, Berlin, Germany
Dr. Henrik Christesen, Odense University Hospital, Odense, Denmark
Dr. Louise Conwell, University of Queensland, Brisbane, Australia
Dr. Diva De León-Crutchlow, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, US
Dr. Pascale De Lonlay, Necker Children's Hospital, Paris, France
Dr. Mark Dunne, University of Manchester, Manchester, UK
Dr. Sarah Flanagan, University of Exeter Medical School, Exeter, UK
Dr. Morey Haymond, Texas Children's Hospital, Houston, Texas, US
Dr. Khalid Hussain, Sidra Medical and Research Center, Doha, Qatar
Dr. Klaus Mohnike, Otto von Guericke University, Magdeburg, Germany
Dr. Andrew Palladino, Pfizer, New York, New York, US
Dr. Pratik Shah, Great Ormond Street Hospital, London, UK
Dr. Mark Sperling, Mount Sinai Hospital, New York, NY, US
Dr. Senthil Senniappan, Alder Hey Hospital, Liverpool, UK
Dr. Charles Stanley, Children's Hospital of Philadelphia, Philadelphia, Pennsylvania, US
Dr. Paul Thornton, Cook Children's, Fort Worth, Texas, US
Dr. David Zangen, Hadassah Medical Center, Jerusalem, Israel





Sharing Yesterday's Memories Today



#sayhitoHI

#WeHaveHIHopes

#StopTheLows

#BeMySugar

#RaringToGoForCHI

#SugarSoiree2020

#Sweetest Cause



Congenital Hyperinsulinism International
P.O. Box 135, Glen Ridge, NJ 07028
973.544.8372

www.congenitalhi.org

Questions? Please contact jraskin@congenitalhi.org