



**Ketotic
Hypoglycemia**
INTERNATIONAL

IDIOPATHIC KETOTIC HYPOGLYCEMIA

THIRD ANNUAL HYBRID CONFERENCE

1-2 SEPTEMBER 2023

SCIENTIFIC ADVISORY BOARD



Dr. David Weinstein
Former Director, GSD Program
The University of Connecticut



Dr. Pratik Shah
Pediatric Endocrinologist
The Royal London Children's Hospital



Dr. Terry Derks
Pediatric Metabolic Diseases
Beatrix Children's Hospital



Dr. Paul Thornton
Medical Director
Cook Children's Medical Center



Dr. Mary-Elizabeth Patti
Adult Endocrinologist
Joslin Diabetes Center, Harvard Medical School



Dr. Joseph Wolfsdorf
Clinical Director
Boston Children's Hospital, Harvard Medical School

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ketotichypoglycemia.org/register

WELCOME

We would like to personally welcome each of you to the third annual conference of Ketotic Hypoglycemia International.

This year we are hosting a hybrid conference for the first time, to make sure everyone has a chance to join, regardless of where in the world they live. Our SAB will be joined by an audience live from Copenhagen on Saturday 2nd September.

All of the presentations will be available after the conference for educational purposes on our YouTube channel. Only the live Interviews and question and answer sessions will be available to those registered for the conference so if you can not attend be sure to sign up to not miss out. Please share this conference invitation with whoever could be interested in learning more about idiopathic ketotic hypoglycemia – colleagues, family members, friends, doctors, medical students, schools and childcare provisions and industry partners. Everyone is welcome!

We are beyond excited to have a line-up of presentations made by our scientific advisory board, emerging researchers board and guest speakers, along with patient stories from KHI families from around the world.

Our speakers will be ready to answer questions after the scientific presentations and in the “Meet the Experts” sessions. We will also be interviewing the SAB for the first live at this year's conference.

Do you have a burning question for the experts? If so, please email us at info@ketotichypoglycemia.org.

With gratitude on behalf of the entire staff team,



D. Drachmann

Danielle Drachmann
Founder & CEO



Becky Futers

Becky Futers
Acting CEO



Sara Wilson

Sara Wilson
VP of Administration and Operations

+ Nicklas Rasmussen
Marketing Consultant

AGENDA

04-07	TIME ZONES
08-11	PROGRAM
12-15	SCIENTIFIC ADVISORY BOARD
16-17	WHAT IS KETOTIC HYPOGLYCEMIA?
18-19	EMERGING RESEARCHERS BOARD
20-21	WHAT KHI IS ALL ABOUT
22-23	SCIENTIFIC POSTER
24-25	ACQUISITION INTERNATIONAL ARTICLE
26	SPONSORS

A PERSONAL WELCOME – VISIT:
[**KETOTICHYPOGLYCEMIA.ORG/WELCOME**](https://ketotichypoglycemia.org/welcome)



Time slots listed on the program are in CEST

FRIDAY TIME ZONES

The following timeframes, specify when the conference will be happening in each particular country and zone.

DENMARK (CEST)	02:00PM - 06:00PM
WEST COAST USA (PDT)	05:00AM - 09:00AM
MOUNTAIN ZONE USA (MDT)	06:00AM - 10:00AM
CENTRAL USA (CDT)	07:00AM - 11:00AM
EAST COAST USA (EDT)	08:00AM - 12:00PM
UNITED KINGDOM (BST)	01:00PM - 05:00PM
SOUTH/CENTRAL AFRICA (SAST/CAT)	02:00PM - 06:00PM
MOSCOW, RUSSIA (MSK)	03:00PM - 07:00PM
UNITED ARAB EMIRATES (GST)	04:00PM - 08:00PM
INDIA (IST)	05:30PM - 09:30PM
CHINA (CST)	08:00PM - 11:00PM(+1)
JAPAN (JST)	02:00PM - 00:00AM(+1)
SYDNEY, AUSTRALIA (AEST)	10:00PM - 02:00AM(+1)
NEW ZEALAND (NZDT)	12:00AM(+1) - 04:00AM(+1)





Time slots listed on the program are in CEST





SATURDAY TIME ZONES

The following timeframes, specify when the conference will be happening in each particular country and zone.

DENMARK (CEST)	10:00AM - 06:30PM
WEST COAST USA (PDT)	01:00AM - 11:30AM
MOUNTAIN ZONE USA (MDT)	01:00AM - 09:30AM
CENTRAL USA (CDT)	02:00AM - 10:30AM
EAST COAST USA (EDT)	04:00AM - 12:30PM
UNITED KINGDOM (BST)	09:00AM - 05:30PM
SOUTH/CENTRAL AFRICA (SAST/CAT)	10:00AM - 06:30PM
MOSCOW, RUSSIA (MSK)	11:00AM - 07:30PM
UNITED ARAB EMIRATES (GST)	06:00PM - 08:30PM
INDIA (IST)	01:30PM - 10:00PM
CHINA (CST)	04:00PM - 12:30AM(+1)
JAPAN (JST)	05:00PM - 01:30AM(+1)
SYDNEY, AUSTRALIA (AEST)	06:00PM - 02:30AM(+1)
NEW ZEALAND (NZDT)	09:00PM - 05:30AM(+1)





FRIDAY

Duration	Presentation Title	Speaker / Hosts
15 Minutes	Opening session	Danielle Drachmann KHI Founder Becky Futers Acting CEO
5 Minutes	Danielle’s story. Why KHI was established and why we are here – LIVE + VIDEO	 Danielle Drachmann KHI Founder
5 Minutes	Video: Every skill Is viable and can help	 Nick Rasmussen Marketing consultant
15 Minutes	Video: What is Hypoglycemia?	 Dr. Paul Thornton Cook Children’s Hospital, US
15 Minutes	Video: What is <u>Ketotic</u> Hypoglycemia?	 Dr. David Weinstein Rare Disease and Clinical Development Consulting
15 Minutes	What’s new with KHI? – LIVE	Danielle Drachmann KHI Founder Becky Futers Acting CEO
20 Minutes	Interview: Dr. Joseph Wolfsdorf – LIVE	 Dr. Joseph Wolfsdorf Boston Childrens’ Hospital, US
20 Minutes	Video: What are Ketones?	 Dr. Terry Derks Beatrix University Hospital, The Netherlands
20 Minutes	Video: Symptoms and signs of KH	 Dr. Pratik Shah The Royal London Children’s Hospital, UK
20 Minutes	Interview w/ Mary Elizabeth Patti – LIVE	 Dr. Mary-Elizabeth Patti The Hypoglycemia Clinic, Joslyn Diabetes Center, US
5 Minutes	Intro to Munchhausen By Proxy – LIVE	Danielle Drachmann KHI Founder
20 Minutes	Video: Munchausen By Proxy	 Dr. Henrik Thybo Christesen, Odense University Hospital, Denmark
20 Minutes	Video: Family experiences	All FII/MBP families
25 minutes	Video: Munchhausen by Proxy	Anonymous
5 Minutes	A message from Danielle & Becky – LIVE	Danielle Drachmann KHI Founder Becky Futers Acting CEO
20 Minutes	Q&A: Scientific Advisory Board – LIVE	SAB
10 Minutes	Video: Healthy Grocery Shopping	 Kathy Ross
10 Minutes	Video: Sara’s Story	 Sara Wilson
5 Minutes	Wrap-up with Danielle & Becky – LIVE	Danielle Drachmann KHI Founder Becky Futers Acting CEO



SATURDAY

PART I

Duration	Presentation Title	Speaker / Hosts
5 Minutes	Opening session - LIVE	Danielle Drachmann KHI Founder Becky Futers Acting CEO
20 Minutes	The Variable Severities of Pathological Ketotic Hypoglycemia and Approach to their Treatment - LIVE	 Dr. Paul Thornton Cook Children's Hospital, US
12 Minutes	Patient story from KHI	A KHI member will share their story.
60 Minutes	Differentiating Physiologic from Pathologic Ketotic Hypoglycemia: Why diagnosis and treatment are critical. - LIVE	 Dr. David Weinstein Rare Disease and Clinical Development Consulting
30 Minutes	Interview: Dr. Paul Thornton - LIVE	 Dr. Paul Thornton Cook Children's Hospital, US
10 Minutes	Video: Normal glucose with elevated ketones	 Elizabeth Rosenfield The Hypoglycemia Clinic, Joslyn Diabetes Center, US
12 Minutes	Patient story from KHI	A KHI member will share their story.
20 Minutes	Q&A 1 - LIVE	
20 Minutes	Impaired hypoglycemia awareness - LIVE	 Dr. Joseph Wolfsdorf Boston Childrens' Hospital, US
30 Minutes	30-minute break	
20 Minutes	Video: Postprandial Hypoglycemia in Children	Rosemary Brungs The Royal London Children's Hospital, UK
20 Minutes	Interview with David Weinstein. - LIVE	 Dr. David Weinstein Rare Disease and Clinical Development Consulting
10 Minutes	Video: Enemy of the state: Ketotic hypoglycemia as a form of catabolic insufficiency	 William Brucker Hasboro Children's Hospital, Providence, US
20 Minutes	Glucose disorders in Children with Syndromic Conditions - LIVE	 Dr. Pratik Shah The Royal London Children's Hospital, UK

SATURDAY

PART II

Duration	Presentation Title	Speaker / Hosts
20 Minutes	Q&A 2 - LIVE	
12 Minutes	Patient story from KHI	A KHI member will share their story.
20 Minutes	Interview with Pratik Shah - LIVE	 Dr. Pratik Shah The Royal London Children's Hospital, UK
10 Minutes	Video: Symptoms in children's language	 Elizabeth Rosenfield The Hypoglycemia Clinic, Joslyn Diabetes Center, US
10 Minutes	Video: Picky Eaters	 Kathy Ross
20 Minutes	Is KH connected with other disorders, diseases, or delays?- LIVE	 Dr. Paul Thornton Cook Children's Hospital, US
20 Minutes	Q&A 3 - LIVE	
20 Minutes	Tips for advocacy in medical settings - LIVE	 Dr. Paul Thornton Cook Children's Hospital, US
12 Minutes	Patient story from KHI	A KHI member will share their story.
10 Minutes	Video: Investigating the molecular basis of Idiopathic Ketotic Hypoglycemia in children	 Dr. Azizun Nessa Queen Mary University of London
10 Minutes	Video: Udderly interesting: Moooooving ketones with corticosteroids	 William Brucker Hasboro Children's Hospital, Providence, US
20 Minutes	Video: PTSD	Elizabeth Nash The Royal London Children's Hospital, UK
15 Minutes	Idiopathic ketotic hypoglycemia in adults	 Dr. Mary-Elizabeth Patti The Hypoglycemia Clinic, Joslyn Diabetes Center, US
45 Minutes	KHI Awards	Danielle Drachmann KHI Founder Becky Futers Acting CEO

IDIOPATHIC KETOTIC HYPOGLYCEMIA

MEET OUR EXPERTS

Ketotic Hypoglycemia International aims to challenge current perceptions and attitudes to expand the recognition that IKH can be more than a normal variation and establish an international platform for future research collaboration. Our mission is supported by leading medical experts within the field of inherited metabolic diseases, pediatric endocrinology, and endocrinology united in our Scientific Advisory Board.



Dr. Paul Thornton
Cook Children’s Hospital, US

Paul Stephen Thornton is a Medical Director, Distinguished Consultant of the Endocrinology/Diabetes Clinic and the Hyperinsulinism Center at Cook Children’s Medical Center, in Fort Worth, Texas. His recent awards include the Cook Children’s Clinical Scholar Award 2012-2014 and recipient of the 2012 Cook Children’s Health Care System Endowed Chair Award.

He has coauthored more than a dozen book chapters and over 50 journal articles. Paul is the lead author of the recent Pediatric Endocrine Society’s Recommendations and Management of Persistent Hypoglycemia in Neonates, Infants, and Children.

Dr. Thornton is also a member of the Pediatric Endocrine Society, Society for Pediatric Research, and The Endocrinology Society.



Dr. David Weinstein
Rare Disease and Clinical Developmental Consulting , US

Following his graduation from Trinity College (CT) and Harvard Medical School, Dr. Weinstein did a residency, chief residency, and fellowship in pediatric endocrinology at Boston Children’s Hospital. He subsequently obtained a Masters in Clinical Investigation from Harvard and MIT, and became Director of the Glycogen Storage Disease Program at Boston Children’s. In 2005, Dr. Weinstein moved to the University of Florida where he directed the Glycogen Storage Disease Program and became a tenured professor.

He and his team moved to the University of Connecticut and Connecticut Children’s Medical Center in 2017 to perform gene therapy for GSD. In August 2020, he left the academic world to serve as the medical lead for the GM1 gangliosidosis gene therapy trial at Passage Bio.

Donations are now welcome.

proceed to ketotichypoglycemia.org/donate to learn more



Dr. Terry Derks
Beatrix Children’s Hospital, NL

Terry Derks has been certified as consultant pediatric metabolic diseases and he is appointed as associate professor at the University Medical Center Groningen, University of Groningen, the Netherlands.

Since his PhD thesis defense in 2007 (title: “MCAD deficiency: clinical and laboratory studies”), he developed a special interest, both clinically and scientifically, in inherited disorders of glycogen metabolism (i.e. hepatic glycogen storage diseases) and fatty acid oxidation disorders.

Dr. Derks has more than 60 international publications, 2 book chapters and is a SSIEM Advisory Council Member.

In MetabERN Dr. Derks is a Medical Executive Board member and the Work package leader for the “Virtual Counseling Framework”.



Dr. Pratik Shah
The Royal London Children’s Hospital, UK

Pratik Shah is a Consultant in Pediatric Endocrinology/Diabetes and Honorary Senior Lecturer at The Royal London Children’s Hospital (Barts Health NHS Trust) and Queen Mary University of London (QMUL), London.

He did his PhD in the field of Congenital Hyperinsulinism and specializes in children with all forms of glucose disorders and has led the highly specialized service for Congenital Hyperinsulinism.

His main research includes understanding molecular basis various forms of non-diabetic hypoglycemia in children and identifying novel therapies in hypoglycemia/hyperinsulinism.

He has been a speaker at various international and national meetings and has been primary investigator for various investigational studies and clinical trials.

IDIOPATHIC KETOTIC HYPOGLYCEMIA



Dr. Mary-Elizabeth Patti
Joslin Diabetes Center, Harvard Medical School, Boston, US

Dr. Mary-Elizabeth Patti is a physician-scientist, serving as a Principal Investigator at Joslin Diabetes Center, Director of the Hypoglycemia Clinic, Co-Director of the Molecular Phenotyping Core, and Associate Professor of Medicine at Harvard Medical School.

Dr. Patti’s NIH-funded lab focuses on identification of molecular/epigenetic mechanisms by which nutritional exposures during early life increase diabetes risk in subsequent generations.

Translational studies are focused on mechanisms contributing to diabetes resolution and hypoglycemia after bariatric surgery.

Dr. Patti received her MD from Jefferson Medical College magna cum laude, internal medicine residency at the University of Pittsburgh, and endocrinology fellowship at Harvard. She is board-certified in endocrinology and metabolism.

Dr. Patti has held numerous leadership roles in the diabetes scientific community, including service as organizer of a diabetes-focused Keystone Symposium and chair of the American Diabetes Association Scientific Sessions Planning Committee.

She was elected to the American Society of Clinical Investigation in 2009 and to Fellowship in both the American College of Physicians and Obesity Society in 2014.



Dr. Joseph Wolfsdorf
Boston’s Children’s Hospital, Harvard Medical School, Boston, US

Professor of Pediatrics at Harvard Medical School and the first incumbent of the Boston Children’s Hospital Chair in Endocrinology. He served as the Director of the Diabetes Program at Boston Children’s Hospital for 35 years until June 2018.

From 1986-1997 he was also Chief of Pediatrics at Joslin Diabetes Center and Medical Director of the Pediatric Diabetes Treatment Unit of the New England Deaconess Hospital. Was a member of the Joslin Diabetes Center DCCT research team from 1984-1993. Served as Clinical Chief of the Division of Endocrinology, Boston Children’s Hospital from 1994-1998 and from 2006-2016. Dr. Wolfsdorf continues to be active in the practice of pediatric endocrinology. He has a special interest in disorders of carbohydrate metabolism (hypoglycemia disorders in children, glycogen storage disease) and, especially, the care of children, adolescents and young adults with diabetes mellitus. Professor Wolfsdorf is an author of more than 250 publications and has edited and contributed to 5 monographs and textbooks. He serves on the editorial board of Diabetes Care and Pediatric Diabetes, is an Associate Editor for Hormone Research in Pediatrics, and is the pediatric endocrinology section editor for all topics related to diabetes mellitus and hypoglycemia in UpToDate.

Dr. Wolfsdorf is the immediate Past President of the International Society of Pediatric and Adolescent Diabetes (ISPAD) for the period 2016-2018 and currently chairs the ISPAD eLearning committee.

Donations are now welcome.

proceed to ketotichypoglycemia.org/donate to learn more





What is ketotic hypoglycemia?

“Ketotic hypoglycemia may be unexplained, or idiopathic (IKH). This is a challenge and should urge for more research”

For the patients

In a normal person, fuel for the brain and the general cell metabolism primarily comes from the burning of sugar deposits (glycogen). When the glycogen stores are depleted, the body will switch to burn fat deposits. The fat burn lead to two fuels for the brain, both glucose (sugar) and ketone bodies. However, ketones in the blood will lead to nausea and eventually vomiting. This will lead to a vicious circle, where you cannot eat or drink sugar-rich items, which again leads to further fat burn and production of ketone bodies.

In a KH-patient, the glycogen stores are somehow insufficient. This leads to decreased fasting tolerance with earlier onset of fat burn and hence ketone bodies. In most patients, the hypoglycemia is relatively mild, and the ketone bodies help to provide fuel to the brain, which prevents loss of consciousness and convulsions. However, in relatively few patients, the condition is more severe, but still without an identified cause despite intense investigations in hormones and cell metabolism. Such patients are said to have “idiopathic” KH, or IKH, which simply means KH without any known cause.

Source: Professor Henrik Christesen, Odense University Hospital, Chair of the Scientific Advisory Board in KHI, Denmark



Illustration by Illulines

For the doctors

Ketotic hypoglycemia can be seen in children because of growth hormone deficiency, cortisol deficiency, metabolic diseases with intact fatty acid consumption, including glycogen storage diseases (glycogenosis; GSD) type 0, III, VI, and IX, or disturbances in transport or metabolism of ketone bodies. When these diagnoses are excluded, ketotic hypoglycemia can be categorized as unexplained or idiopathic (IKH), otherwise known as accelerated starvation.

The primary treatment is dietary prevention with long carbohydrates (e.g. uncooked cornstarch) and frequent meals. In some more severely affected patients, continuous feeding may be needed through a gastrostomy tube.

Emergency treatment constitutes of oral or i.v. glucose, eventually i.m. glucagon, to raise the plasma glucose, which will prevent further lipolysis. However, the ketones can take hours to be eliminated. In more severely affected patients, the ketone production can be significant before hypoglycemia occurs, why recognition of increased ketones above approximately 1.5 mol/L is important, sometimes already when the glucose concentration goes below 3.9 mmol/L (70 mg/dL).

Source: Professor Henrik Christesen, Odense University Hospital, DK

IDIOPATHIC KETOTIC HYPOGLYCEMIA

EMERGING RESEARCHER'S BOARD

The emerging researchers board contains researchers from around the globe who are the next generation in complex hypoglycemia. They have a particular interest in ketotic hypoglycemia and work closely with our staff team and the Scientific Advisory Board.



Alessandro Rossi, MD

Beatrix University Hospital,
Groningen, The Netherlands



Anne Benner, MD

H.C Andersens Children Hospital,
Odense University Hospital, Denmark



Monika Williams, MD

University of North Carolina



Komal Parmar, MD

Tennessee Children's Hospital, US



Elizabeth Rosenfeld, MD

Childrens Hospital of Philadelphia,
Philadelphia, US



Erin Okawa, MD

UCLA



Azizun Nessa, MD

Royal London Children's Hospital,
London, UK



William (Bill) Brucker, MD

Hasboro Children's Hospital,
Providence, US



Annieke Venema, MD

Beatrix University Hospital,
Groningen, The Netherlands

**Donations are
now welcome.**

ketotichypoglycemia.org/donate

What is this organization about?

Ketotic Hypoglycemia International (KHI) is a global reaching family organization, uniting more than 1500 families from all over the world affected by idiopathic ketotic hypoglycemia. KHI aims to globally unite leading hypoglycemia experts with patients, caregivers, and healthcare providers, and to establish a greater understanding of IKH in the hopes to facilitate improved treatment options and greater quality of life for individuals suffering from IKH. The organization aims to challenge current perceptions and attitudes to expand the recognition that IKH is more than a normal variation and establish an international platform for future research collaboration. We are committed to supporting and advocating for those in the KH community through our international KHI Parents Support Group by utilizing the contributions of general medical guidance made by our scientific advisory board, supporting research on the general well-being of KH-families, and furthering research into KH etiology, diagnosis, and management

KHI have published 2 scientific papers, presented and won a poster prize at the Engaging Citizen Science Conference in Århus, Denmark. The publications can be found below, and you'll see the poster on the next page.

We have also been honoured to receive the Most Pioneering Hypoglycemia Patient Organization 2023 from Acquisition International. A copy of our article can be found on page 24.

Article 1

 BMC Part of Springer Nature

 Orphanet Journal of Rare Diseases

Published: 13 April 2021 | <https://ojrd.biomedcentral.com/articles/10.1186/s13023-021-01797-2>

“Towards enhanced understanding of idiopathic ketotic hypoglycemia: a literature review and introduction of the patient organization, Ketotic Hypoglycemia International”

[Danielle Drachmann](#), [Erica Hoffmann](#), [Austin Carrigg](#), [Beccie Davis-Yates](#), [Valerie Weaver](#), [Paul Thornton](#), [David A. Weinstein](#), [Jacob S. Petersen](#), [Pratik Shah](#) & [Henrik Thybo Christesen](#)



Article 2

 JIMD REPORTS

 SSiEM

Published: 28 July 2021 | <https://doi.org/10.1002/jmd2.12241>

“Ketotic hypoglycemia in patients with Down syndrome”

[Danielle Drachmann](#), [Austin Carrigg](#), [David A. Weinstein](#), [Jacob Sten Petersen](#), [Henrik Thybo Christesen](#)



Where to find us

Our families are united through a variety of social media channels. Ketotic Hypoglycemia International are active on LinkedIn, YouTube, Instagram, Twitter, and Facebook. The Facebook Support Group is where the families are most active, and where we are sharing experiences and support each other to navigate the everyday-IKH-rollercoaster ride.

Ketotic hypoglycemia in patients with Down syndrome

Danielle Drachmann^{1,2,3}, Austin Carrigg¹, David A. Weinstein^{1,4}, Jacob Sten Petersen^{1,5}, Astrid Janssens^{2,3,6}, Henrik Thybo Christesen^{1,7,8}

1. Ketotic Hypoglycemia International, Skanderborg, Denmark | 2. University of Southern Denmark, Unit of User Perspectives, Odense, Denmark | 3. Center for Research in Partnership with Patients and Relatives, Odense University Hospital, Odense, Denmark | 4. University of Connecticut, Connecticut, United States | 5. Novo Nordisk A/S, Bagsvaerd, Denmark | 6. University of Exeter Medical School, United Kingdom | 7. Department of Clinical Research, University of Southern Denmark, Odense, Denmark | 8. Hans Christian Andersen Children's Hospital and Steno Diabetes Centre Odense, Odense University Hospital, Odense, Denmark

Conclusion

We present a case of co-created and family-organization driven research in the family organization Ketotic Hypoglycemia International, from the establishment of the organization to the scientific publication. This is the first demonstration of a possible high prevalence of ketotic hypoglycemia (KH) in Down syndrome (DS). Even though this finding needs to be confirmed in other research settings, identification of KH in DS could have a dramatic impact, as simple treatments with cornstarch, protein and frequent meals may prevent KH attacks and, analogous to other conditions with KH, improve growth, stamina and prevent overeating and obesity. GYG2 deletion may contribute to KH in DS, resembling glycogen storage disease type 0. Our research is an example of a family-run patient organization driven and co-produced research, where novel observations may arise, not firstly caught by the health care system. This story can inspire others to adopt this approach to health research within research and patient groups.

CO-PRODUCED RESEARCH

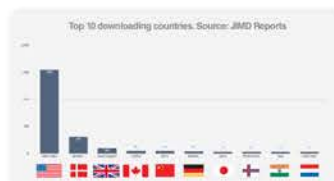
10 steps that shaped a scientific discovery

9. The Dissemination

Worldwide press attention for our findings.

2617 downloads in the first 6 months (average annual downloads for JIMD Reports: 441).

2nd most downloaded article in JIMD Reports in 2021



1. The Beginning

Danielle Drachmann and her two kids, Noah and Savannah: Diagnosed with low blood glucose and high ketones, without any known genetic cause: idiopathic ketotic hypoglycemia (IKH).



2. The Organization

Danielle established Ketotic Hypoglycemia International (KHI), established a scientific advisory board (SAB) with leading medical experts from all over the world - expanded with many IKH-families united in KHI rapidly.



3. The Discovery

Melanie is a girl with DS who got diagnosed with KH. Her mother entered the support group and contacted Danielle with suspicion about a correlation between DS and KH after seeing posts in the online support group on social media.



4. The Survey

No association between DS and KH was ever reported in the literature - SAB members supported Austin and Danielle to draft out a survey. SAB consulted on survey draft.



5. The Data

A survey was sent to DS organisations and families worldwide.



6. The Findings

The results indicated an association. Want to know about the findings? Scan QR code 2 below.



7. The Mice Study

A SAB member found a mice study (1), giving a medical explanation (2) for why patients with DS could have KH. Want to know more about the mice-study? Scan QR code 1 below.



8. The Publication

Scientific paper written by Austin, Danielle and medical experts in the SAB is published alongside a video abstract (3).



1. Mice Study
Hippocampal cell study in the trisomy 21 mice model htk.



2. Paper
Ketotic hypoglycemia in patients with Down syndrome.



3. Video Abstract
Extending the reach and visibility of our research, we published a video abstract.

Most Pioneering Hypoglycemia Patient Organization 2023

Founded in 2020, Ketotic Hypoglycemia International (KHI) is a worldwide organization for families affected by Idiopathic Ketotic Hypoglycemia, aiming to enhance understanding of the disorder for the benefit of the children, parents, and families affected by it. Here, we take a look at the work the organization has done and how it continues to help families across the world.

Hypoglycemia occurs when the glycogen stores are depleted, the body will switch to burn fat deposits. The fat burn lead to two fuels for the brain, both glucose and ketone bodies. However, ketones in the blood will lead to nausea and eventually vomiting. This will lead to a vicious circle, where you cannot eat or drink sugar-rich items, which again leads to further fat burn and production of ketone bodies. In a KH-patient, the glycogen stores are somehow insufficient. This leads to decreased fasting tolerance with earlier onset of fat burn and hence ketone bodies. In most patients, the hypoglycemia is relatively mild, and the ketone bodies helps to provide fuel to the brain, which prevents loss of consciousness and convulsions. However, in relatively few patients, the condition is more severe, but still without an identified cause despite intense investigations in hormones and cell metabolism. Such patients are said having "idiopathic" KH, or IKH, which simply means KH without any known cause.

When Danielle Drachmann and her children were diagnosed with pathological idiopathic ketotic hypoglycemia, she was inspired to found Ketotic Hypoglycemia International (KHI) to raise awareness about the condition and support families who were in a similar position. Danielle was supported by Dr Henrik T. Christesen and Dr Jacob Sten Petersen in founding and running KHI and navigating the new medical advocacy world she found herself in. Dr Jacob Sten Petersen continues to be a supporter of the work of KHI and is currently the chairman of the board. Danielle had no background knowledge of ketotic hypoglycemia and no previous experience in the medical field, which meant that she had to learn a whole new language of medical terminology and formalities. This was a huge challenge for her, which she faced alongside raising her children, but she was determined to accomplish it.

Danielle has now co-authored research papers, won patient advocacy awards, and worked hard to grow KHI into what it is today. Now, the organization serves 1900 families globally through its patient support group, social media, and website, offering them advocacy, support, guidance, and a place to share their experiences.

KHI is currently headed by acting CEO Becky Futers, who is supported by a dedicated team of parents who have children with ketotic hypoglycemia: Tiffany Palms, Sara Wilson, Austin Carrigg, Yvette Ollada Lavery and Nicole Bøttger Jensen. The team works alongside leading experts in complex hypoglycemia across the

globe, including Dr. Paul Thornton, Dr. David Weinstein, Dr. Partik Shah, Dr. Joseph Wolfsdorf, Dr. Terry Derks, and Dr. Mary-Elizabeth Patti.

By uniting medical experts with affected families, KHI brings the latest research directly to those who need it. Annually, KHI hosts a conference for families and healthcare professionals, where the latest research, patient stories, and understanding of living with ketotic hypoglycemia are presented. The organization is fortunate to have been supported by various sponsors, who have assisted greatly in realizing its mission and yearly conferences.

KHI is incredibly grateful for the hard work and dedication of its volunteers, which include both parents and medical professionals. Its team of staff consists entirely of parents with children who have ketotic hypoglycemia. On top of tackling regular parenting responsibilities, they also navigate the rare disease world, not only for themselves but also for the other children and families who are striving to make a difference. Often, they participate in meetings from the hospital bedside, between medical appointments, or on the side of their full working day. Additionally, KHI's medical expert volunteers generously offer their free time where they can. In order to continue to support its families and improve the assistance it provides, the organization is hoping to grow enough to allow for at least one full-time member of staff in the future.

When KHI recruits new volunteers, it seeks individuals who share its values and are committed to the rare disease community. The organization is proud to be run for patients and their families by patients and their families, which sets it apart from other organizations. No one knows the difficulties and battles of living with ketotic hypoglycemia better than those who face them every day.

The organization is looking forward to carrying out more focused fundraising to support its families. Fundraising brought into KHI goes directly to the costs of its annual conference, support its families and research projects. Currently the staff team is working towards its first organised get moving challenge which will be launched later this year. Earlier this year, KHI ran its first annual ketotic hypoglycemia awareness day on 18th of February. It was a huge success; both its families and volunteers thoroughly enjoyed it. The KHI mascots were out in full force, helping to spread the word of ketotic hypoglycemia and bring fun to younger members.

Original found
at Acquisition
International
Magazine

acquisition-international.com



In the coming year, KHI is planning its upcoming annual conference, which is scheduled for 1st to 3rd September 2023. For the first time, the conference will be a hybrid event, featuring the usual online content as well as a live audience in Copenhagen on 2nd September 2023. The event is free, but attendees are invited to voluntarily donate in order to support the organization's vital research. A link to sign up and obtain a ticket can be found on its website.

The KHI team is working closely with medical professionals as they continue to carry out these important research projects. The organization provides regular updates and the latest information across all of its platforms. With its Emerging Researchers Board, KHI hopes to continue to support these projects and broaden its scope of work. In the future, the organization also hopes to bring a specific scientific community portal to its families, providing them with more dedicated access to the resources and support that they would usually access on the KHI website.

As a result of the amazing work, Ketotic Hypoglycemia International (KHI) has been awarded Most Pioneering Hypoglycemia Patient Organization in the Non-Profit Organization Awards 2023. With big plans for the future, there is no doubt that KHI will continue to help patients and families living with ketotic hypoglycemia by raising awareness of the disorder and providing them with resources, information, and support.

Contact: Becky Futers and Danielle Drachmann at info@ketotichypoglycemia.org Company: Ketotic Hypoglycemia International Web Address: <http://ketotichypoglycemia.org/>

SPONSORED BY



See you at the conference!



D. Drachmann

Danielle Drachmann
Founder & CEO



Becky Futers

Becky Futers
Acting CEO



Sara Wilson

Sara Wilson
VP of Administration and Operations