

## Congenital Hyperinsulinism Family Conference Konjenital Hiperinsülinizm Aile Konferansı

7–9 May 2026, Royal Seginus Hotel  
Antalya, Türkiye

**Thursday, 7 May 2026 / 7 Mayıs 2026 Perşembe**

18:00–20:00 **Meet and Greet with Dinner/ Tanışma ve Akşam Yemeği**

**Friday, 8 May 2026 / 8 Mayıs 2026 Cuma**

8:00 **Registration and Breakfast/ Kayıt ve Kahvaltı**

9:00 AM **Opening Remarks – KoHHA-DER and CHI International Introductions**  
**Açılış Konuşmaları – KoHHA-DER ve CHI International Tanıtımları**  
Huseyin Demirebilek, Naz Aksan, Jennifer Schmitt, and Trudy Ward

9:10 AM **Dare to Dream: The History of HI**  
**Hayal Etmeye Cesaret Et: HI Tarihçesi**

- History of congenital hyperinsulinism care: Key Clinical Milestones  
*Konjenital hiperinsülinizm tedavisinin tarihçesi: Klinik Dönüm Noktaları*  
Khalid Hussain
- Patient-powered Research and Advocacy Milestones  
*Hasta Odaklı Araştırma ve Savunuculukta Önemli Gelişmeler*  
(CHI International and KoHHA-DER/CHI-T) Huseyin Demirebilek, Trudy Ward

9:50 AM **Diagnosing HI**  
**HI Tanısı**

- Genetics of CHI: How do we know?  
*KHI Genetiği: Nasıl biliyoruz?*  
Sarah Flanagan
- Guidelines for Detecting and Managing Neonatal Hypoglycemia  
*Yenidoğan Hipoglisemisi Tanı ve Yönetim Rehberi*  
Paul Thornton
- The Diagnostic Odyssey: Perspective in HIGR  
*Tanısal Yolculuk: HIGR Perspektifi*  
Kristen Rohli

10:40 **Networking Break / Kahve Arası**

11:00

## **Surgery and HI**

### ***Cerrahi ve HI***

- Surgical Update in the Treatment of HI  
*HI Cerrahi Tedavisinde Yenilikler*  
Oliver Blankenstein
- What Families Teach Us About Pancreatectomy: Learnings from HIGR & the CHI Research Team  
*Pankreatektomi Hakkında Ailelerden Öğrendiklerimiz: HIGR ve CHI Araştırma Ekibi'nden Kazanımlar*  
Kristen Rohli

11:25

## **Managing and Treating HI**

### ***HI Yönetimi ve Tedavisi***

- Safety Fasts and Cure Fasts  
*Açlık Testleri*  
Diva De León-Crutchlow
- Current Medical Treatment Options, Including Gastrostomy for HI  
*Güncel Medikal Tedavi Seçenekleri (Gastrostomi Dahil)*  
Antonia Dastamani - Virtual
- Glucose Monitoring for HI  
*HI'de Kan Şekeri İzlemi*  
Clare Gilbert
- Caregiver and Patient Perspective on Glucose Monitoring: Learning from HIGR Participants  
*Aileler ve Hastaların Kan Şekeri İzlemine Bakışı: HIGR Katılımcılarından Kazanımlar*  
Kristen Rohli

12:25

## **Ask the Experts**

### ***Uzmanına Sor***

Panel: Huseyin Demirbilek, Diva De León-Crutchlow, Paul Thornton, Oliver Blankenstein, Sonya Galcheva, Nino Kheladze, Khalid Hussain, Sarah Flanagan, Clare Gilbert, Fatih Gurbuz, Ekin Demirbilek, Oğuzhan Kalyon, Atilla Çayır, Erin Okawa, Dogus Vuralli

Possible Question Topics:

*Olası Soru Başlıkları:*

- Transition from Pediatric to Adult Care  
*Pediatriden Yetişkin Takibine Geçiş*
- Challenges to Managing HI in Infants and Toddlers  
*Bebek ve Çocuklarda HI Yönetimindeki Güçlükler*
- HI and Growth and Development  
*HI ile Büyüme ve Gelişme*
- When Hypoglycemia is Still an Issue  
*Hipoglisemi Hâlâ Sorun Olduğunda*
- More on Genetics  
*Genetik Hakkında Daha Fazlası*
- Dealing with Highs and Lows  
*Hipoglisemi ve Hiperlisemi ile Başa Çıkmak*
- When to Consider Surgery?  
*Cerrahi Ne Zaman Düşünülmeli?*
- Issues with Access to Care  
*Sağlık Hizmetlerine Erişimde Yaşanan Sorunlar*
- Rare Disease Advocacy  
*Nadir Hastalık Savunuculuğu*
- Devices  
*Tıbbi Cihazlar*

- Sick Days  
*Hastalık Günleri*
- HI Global Registry  
*HI Küresel Kayıt Sistemi*
- CGM use for glucose monitoring in HI  
*HI'de glukoz takibi için sensör (CGM) kullanımı*

13:00 **Lunch and Networking Break / Öğle Yemeği**

14:00 **HI Stories: Sharing Triumphs and Challenges**

**HI-Hikayeleri: Başarılar ve Zorluklar**

Moderator: Yıldız Alaylı Baş and Ulrike Seyfarth

- Tilly Douglas
- Dr. Hakan Guner and Family – Multi-member AD CHI (ABCC8)  
*Dr. Hakan Guner ve Ailesi - Ailevi OD KHI*
- Kerim Görünmez and Family  
*Kerim Görünmez ve Ailesi*
- Hacer Özdemir
- Yasemin Güllü
- Sare Nur Demir
- Mehmet-Merve Demirci

15:00 **Investigational Therapies Under Development**

**Hiperinsülinizm için Geliştirilme Aşamasındaki Yeni Tedaviler**

- Zealand Pharma – Erin Okawa (Phase 3)
- Rezolute – Davelyn Hood (Phase 3) *Virtual*
- Hanmi Pharmaceutical – Speaker TBD (Phase 2) *Virtual*
- The LightCure Project – Sevilay Tokgöz (Pre-clinical)

15:45 **Networking Break and Posters (Yıldız Alaylı Baş, Naz Aksan)**

**Poster Sunumları**

16:05 **Breakout Groups by Type of HI (Individuals with HI and Families)**

**HI Türüne Göre Çalışma Grupları (HI'li Bireyler ve Aileleri)**

- Diazoxide-responsive – Diva De León-Crutchlow, Naz Aksan  
*Diazoksit yanıtı HI tedavisi*
- Diazoxide-unresponsive, Medically Managed – Khalid Hussain, Yıldız Alaylı Baş  
*Diazoksit yanıtı HI' de ilaç tedavisi*
- Diazoxide-unresponsive, Surgically Managed – Paul Thornton, Ekin Demirbilek  
*Diazoksit yanıtı HI ve cerrahi yönetimi*
- Post-pancreatectomy Hyperglycemia/Diabetes – Oliver Blankenstein, İbrahim Doğan, Oguzhan Kalyon  
*Pankreatektomi sonrası Hiperglisemi/Diyabet*
- Breakout Group for Industry – CHI Communication Team -Jennifer Schmitt, Lily Barnett, Huseyin Demirbilek  
*Sektör Temsilcileri Grubu*

16:45 **Breakout Groups by Special Topic**

**Konu Bazlı Çalışma Grupları**

- Feeding and Nutrition – Oliver Blankenstein, Clare Gilbert, Ulaş Baş - Translator  
*Beslenme ve Diyet*
- GI Issues – Sonya Galcheva, Fatih Gurbuz

*Gastrointestinal Sorunlar*

- HI and School – Nino Kheladze, Atilla Çayır, Hüseyin Demirbilek  
*HI ve Okul Hayatı*
- Managing Stress – Ulrike Seyfarth, Yıldız Alaylı  
*Stres Yönetimi*
- Neurodevelopmental Evaluations and Resources – Paul Thornton, Ekin Demirbilek  
*Nörogelişimsel Değerlendirme ve Kaynaklar*
- HI in the Teenage Years – Ulrike Seyfarth, Nisa Duru Özcan  
*Ergenlik Döneminde HI*
- Living with HI as an Adult – Diva De León-Crutchlow, Melis Abikebahşi, Trudy Ward  
*Yetişkin Dönemde HI ile Yaşamak*
- Deep Dive into Genetics – Sarah Flanagan, Dogus Vuralli  
*HI Genetiğe Derinlemesine Bakış,*
- Breakout Group for Industry – Hacer Cirit, Industry representatives, Oguzhan Kalyon  
*Sektör Temsilcileri Grubu*

17:30 **From my family story to global advocacy**  
***Aile hikayemden küresel savunuculuğa***  
Julie Raskin - virtual

17:45 **Conference First Day Wrap-Up and Adjourn**  
***Birinci Gün Değerlendirmesi ve Kapanış***

19:00–22:00 **CHI Reception and Dinner at Royal Seginus Hotel (MedRock Concert)**  
***CHI Resepsiyonu ve Akşam Yemeği – Royal Seginus Otel (MedRock Konseri)***

**Saturday, 9 May 2026 / 9 Mayıs 2026 Cumartesi**

8:30 **HI Advocacy and Awareness Updates**  
***HI Savunuculuğu ve Farkındalık Çalışmalarındaki Gelişmeler***  
Jennifer Schmitt, CHI International and KoHHADER/CHI-TBD

9:00 **HI Life Hacks**  
***HI ile Yaşama Rehberi***  
Lily Barnett and Yıldız Alaylı Baş

9:30 **HI Stories – Family Presentations – Moderator: Ekin Demirbilek and Kerim Görünmez**  
***HI Hikayeleri – Aile Sunumları***

- Spontaneous decreasing severity of CHI at age 8 – Naz Aksan  
*Büyüdükçe Kendiliğinden Hafifleyen HI: 8 Yaşında Tam Düzelmeye – Naz Aksan*
- Change of lifestyle and quality of life after focal CHI surgery – Ece Alan  
*Fokal HI'de Ameliyat Sonrası Yaşam Tarzı ve Kalitesindeki Değişim – Ece Alan*
- A whole life with HI: From childhood to adulthood - Melis Abikebahşi  
*Yaşam boyu HI: Çocukluktan yetişkinliğe HI serüveni - Melis Abikebahşi*
- Raising an HI Child in Türkiye – Before and After KoHHADER- Nisa Duru Ozcan & Family, Sergen & Merve Özkan  
*Türkiye'de HI'lı Bir Çocuk Büyütmek: KoHHADER'den Önce ve Sonra- Nisa Duru Ozcan ve Ailesi- Sergen & Merve Özkan )*
- Protein sensitive HI: Tuğba Aykaç  
*Protein Duyarlı HI: Tuğba Aykaç*

10:10	<b>HI Bulgaria and Georgia</b> <b><i>Bulgaristan ve Gürcistan'da HI</i></b> Sonya Galcheva, Nino Kheladze
10:45	<b>Coffee Break / <i>Kahve Arası</i></b>
10:55	<b>Outcomes Reports from Turkey</b> <b><i>Türkiye'den Güncel Raporlar</i></b> Huseyin Demirbilek, Naz Aksan, Ekin Demirbilek
11:40	<b>Your Voice Has Power: How Research Helps Tell the HI Story (Quality of Life)</b> <b><i>Sesinizin Gücü: Araştırmaların Yaşam Kalitesine ve HI Hikayesine Katkısı</i></b> Kristen Rohli
12:00	<b>Conference Highlights Recap / <i>Konferanstan Satır Başları</i></b>
12:10	<b>Lunch and Close of Conference / <i>Öğle Yemeği ve Kapanış</i></b>

## 2026 Family Conference Sponsors

### *Sweetest Sponsors*



### *Platinum Sponsor*



### *Bronze Sponsor*



## Confirmed Panelists, Presenters and Moderators

### **Melis Abikebahşi**

HI Patient  
Co-Founder and Supervisory Board  
Member, KoHHA-DER, Ankara, Turkiye

### **Naz Aksan**

HI Parent  
Co-Founder and Vice President,  
KoHHA-DER, Ankara, Turkiye

### **Ece Alan**

HI Parent  
İzmir, Turkiye

### **Tuğba Aykaç**

HI Parent  
Co-Founder and Board Member,  
KoHHA-DER, Ankara, Turkiye

### **Lily Barnett**

Communications Associate, CHI  
Brooklyn, NY, United States

### **Yıldız Alaylı Baş**

HI parent  
Istanbul, Turkiye

### **Ulaş Baş**

HI parent  
Istanbul, Turkiye

### **Oliver Blankenstein, MD**

Pediatric Endocrinologist, Medical  
Director, Charité–Universitätsmedizin  
Berlin, Germany

### **Atilla Çayır, MD**

Consultant Pediatric Endocrinologist at  
Atatürk University Research Hospital  
Faculty of Medicine, Erzurum, Turkiye

### **Hacer Cirit, MSci**

Clinical Research Coordinator  
(SunRIZE358-301), Monitor CRO  
Ankara, Turkiye

### **Antonia Dastamani, MD, PhD (Virtual)**

Pediatric Endocrinologist, Lead, Congenital  
Hyperinsulinism Service, Great Ormond  
Street Hospital for Children (GOSH)  
London, United Kingdom

### **Diva D. De León-Crutchlow, MD MSCE**

Pediatric Endocrinologist, Chief of the  
Division of Endocrinology and Diabetes  
Director of the Congenital Hyperinsulinism  
Center, Children's Hospital of Philadelphia  
(CHOP), Philadelphia, PA, United States

### **Hüseyin Demirbilek, MD**

Consultant Pediatric Endocrinologist at  
Hacettepe University Ihsan Dogramaci  
Children's Hospital  
Founder and President, KoHHA-DER,  
Ankara, Turkiye

### **Ekin Demirbilek, MD**

Co-Founder and Board Member,  
KoHHA-DER, Ankara, Turkiye

### **İbrahim Doğan**

HI Patient  
Co-Founder, KoHHA-DER  
Ankara, Turkiye

### **Sarah Flanagan, PhD**

Professor of Genomic Medicine and Sir  
Henry Dale Fellow at University of Exeter  
Medical School, Exeter, United Kingdom

### **Sonya Galcheva, MD, PhD**

Pediatric Endocrinologist, Medical  
University of Varna, Bulgaria

### **Clare Gilbert, RN**

Pediatric Endocrinology Advanced Nurse,  
GOSH, London, United Kingdom

### **Kerim Görünmez**

HI Parent  
Co-Founder and Board Member,  
KoHHA-DER, İzmir, Turkiye

**Fatih Gurbuz, MD**

Consultant Pediatric Endocrinologist at  
Ankara Yıldırım Beyazıt University Faculty  
of Medicine, Ankara, Türkiye

**Davelyn Hood, MD MBA (Virtual)**

HI Parent  
Director of Scientific & Patient  
Affairs, Rezolute  
Brownwood, TX, United States

**Khalid Hussain, MBChB MD MRCP  
MRCPCH MSc**

Division Chief of Pediatric Endocrinology,  
Sidra Medical & Research Center  
Doha, Qatar

**Oguzhan Kalyon, PhD**

Postdoctoral Research Fellow in Genetics  
and Bioinformatics, University of Exeter  
Medical School, Exeter, United Kingdom

**Nino Kheladze, MD**

Pediatric Endocrinologist, M. Iashvili  
Children's Central Hospital. Evex Medical  
Corporation, Tbilisi, Georgia

**Erin Okawa, MD**

Senior Medical Science Liaison  
Zealand Pharma  
Los Angeles, CA, United States

**Julie Raskin, MA (Virtual)**

HI Parent  
Chief Executive Officer, CHI  
Glen Ridge, NJ, United States

**Kristen Rohli, PhD**

Research Manager, CHI  
Chattanooga, TN, United States

**Jennifer Schmitt**

Chief Operating Officer, CHI  
Glen Ridge, NJ, United States

**Ulrike Seyfarth**

HI Parent and Sibling  
Radiology Specialist, Charité  
President, Kongenitaler Hyperinsulinismus  
e.V. Berlin, Germany

**Sevilay Tokgöz**

PhD candidate, Radboud University  
Medical Center, Nijmegen, Netherlands

**Paul Thornton MB BCh MRCPi DCh**

Pediatric Endocrinologist, Medical Director  
of the Congenital Hyperinsulinism Center,  
Endocrine and Diabetes Program, Cook  
Children's Medical Center  
Fort Worth, TX, United States

**Dogus Vuralli, MD**

Pediatric Endocrinologist at Hacettepe  
University Ihsan Dogramaci Children's  
Hospital, Ankara, Türkiye

**Trudy Ward, QN MSc RNC RNA**

HI parent  
Board member, CHI  
Brighton, United Kingdom

**Additional HI family speakers include:**

Tilly Douglas, Dr. Hakan Guner and Family, Hacer Özdemir, Yasemin Güllü, Sare Nur  
Demir, Mehmet-Merve Demirci, Ece Alan, Nedim Özcan, Aylin Özcan, Nisa Duru Özcan,  
Muharrem Özkan, Merve Özkan, and Sergen Özkan.