

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
Antonia Dastamani - Virtual
- Current Medical Treatment Options, Including Gastrostomy for HI
Güncel Medikal Tedavi Seçenekleri (Gastrostomi Dahil)
Diva De León-Crutchlow
- 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	HI Bulgaria and Georgia <i>Bulgaristan ve Gürcistan'da HI</i> Sonya Galcheva, Nino Kheladze
10:45	Coffee Break / <i>Kahve Arası</i>
10:55	Outcomes Reports from Turkey <i>Türkiye'den Güncel Raporlar</i> Huseyin Demirbilek, Naz Aksan, Ekin Demirbilek
11:40	Your Voice Has Power: How Research Helps Tell the HI Story (Quality of Life) <i>Sesinizin Gücü: Araştırmaların Yaşam Kalitesine ve HI Hikayesine Katkısı</i> Kristen Rohli
12:00	Conference Highlights Recap / <i>Konferanstan Satır Başları</i>
12:10	Lunch and Close of Conference / <i>Öğle Yemeği ve Kapanış</i>

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Confirmed Panelists, Presenters and Moderators

Melis Abikebahşı

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
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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.