

Congenital Hyperinsulinism Family Conference

Konjenital Hiperinsülinizm Aile Konferansı

Royal Seginus Hotel | Antalya, Turkey
May 7-9, 2026



Congenital Hyperinsulinism in Türkiye

KHHHA-DER
KONJENİTAL HİPERİNSÜLİNİZİMLİ HASTA AİLELERİ DERNEĞİ



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Congenital Hyperinsulinism in Turkiye

Outline

- Frequency of CHI in Turkiye
- Family advocacy (KoHHADER) and its activities
- Future prospects



Congenital Hyperinsulinism in Turkiye

Frequency of CHI in Turkiye

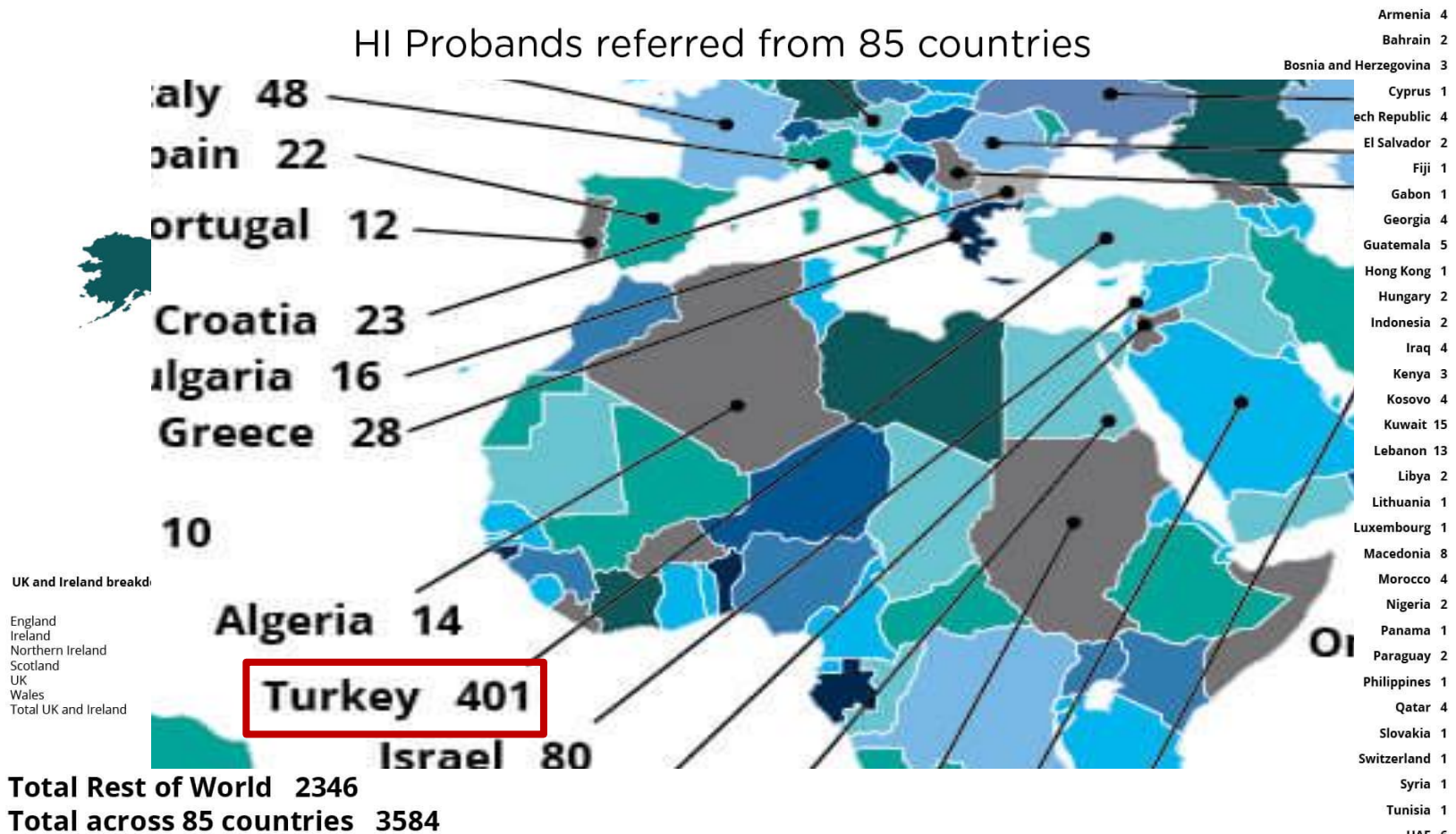
- Population: 85 million
- About 1 million new birth/year
- No formal study
- The estimated incidence: 1 in 20k live birth
- The total number of pt?
 - 500 pts in our database



Congenital Hyperinsulinism in Turkiye

Frequency of CHI in Turkiye

HI Probands referred from 85 countries





Congenital Hyperinsulinism in Turkiye

Recent Developments

- Family organization (KoHHA Organizasyonu)
- Family meetings (Online & in person)
- Family Association (KoHHA-DER)
- A nationwide study on clinical and genetic characteristics of CHI
- 18-F-DOPA-PET/CT imaging
- Surgery of focal disease
- Contribution to the clinical trials

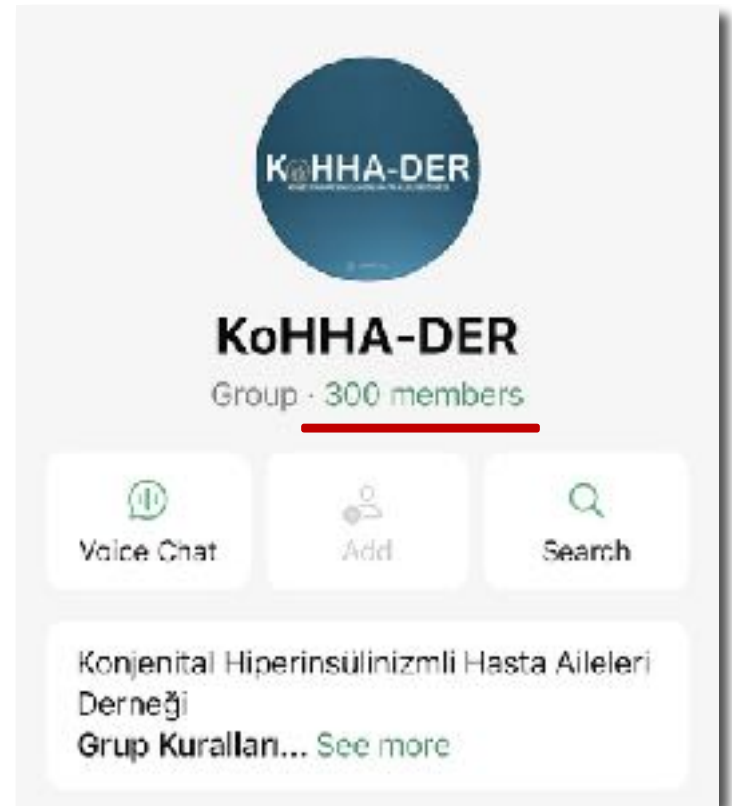
History

First step: On February 6, 2020 CHI Turkiye (KOHHA) founded



Our logo was designed by Naz Aksan, who is the most active member of our organization and leader of the social media team.

KoHHA Whatsapp Group



300 members, patient families, doctors

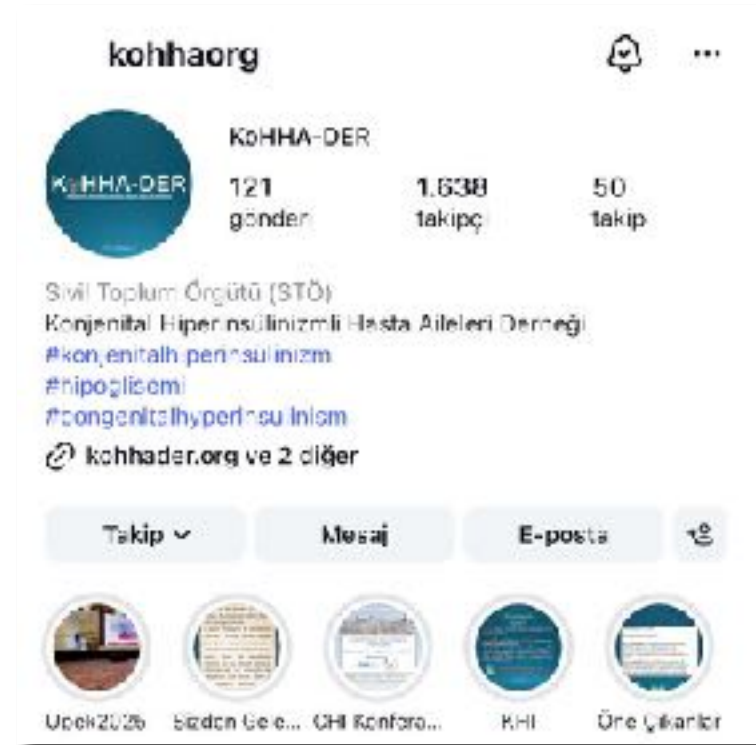
KoHHA on X - April 6, 2022



KoHHA on Instagram - June 13,2021



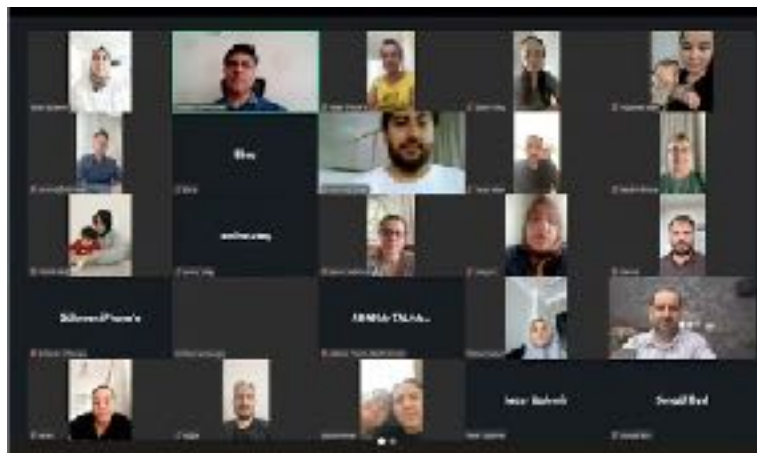
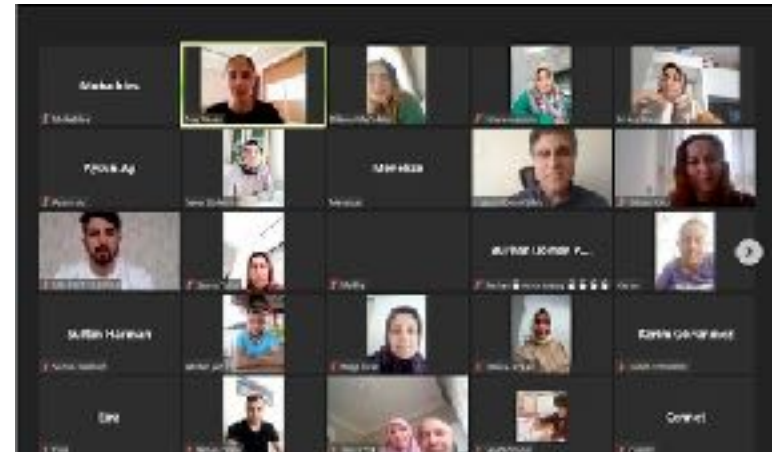
@KOHHAORG



10 Family Meetings



10 Family Meetings



KoHHA-DER founded on June 13, 2023



63 registered member as of March 2026

KOHHA-DER Founders



Prof. Dr. Hüseyin
Demirbilek
President



Naz Aksan
Vice President



Dr. Ekin Demirbilek



Gülten Çıfci



Kerim Görünmez



Melis Abikebahşi



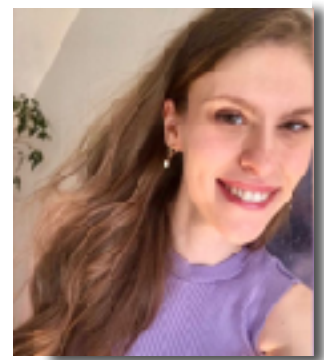
İ. Can Doğan



Tuğba Aykaç



Tuğba Ekinci



Doğa Zelal Tunç

KoHHA-DER Board Of Directors (Current)



Prof. Dr. Hüseyin
Demirbilek
President



Naz Aksan
Vice President



Gülten Çıfci



Hacer Özdemir



Kerim Görünmez



Merve Özkan



Tuğba Aykaç



Tuğba Ekinci



Ekin Demirbilek



Şerife Sude Ölker

KoHHA-DER Supervisory Board



Kenan Demir



Melis Abikebahşı



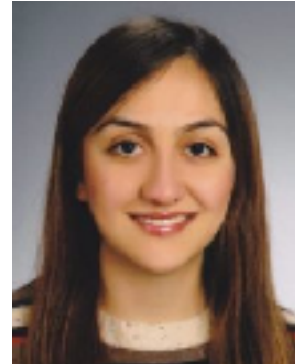
Emine Ateş



Aylin Özcan



Ayşe Görünmez



Duygu Özhan

General Meetings



Annual General Meeting
April 26, 2025

First General Meeting
December 24, 2023



Family Visits



2025 National Pediatric Endocrinology Congress (UPEK2025)



2025 National Pediatric Endocrinology Congress (UPEK2025)



National TV Channels



TRT TURK Sağlık olsun
May 25,2025

TRT AVAZ Sağlıklı Günler
March 26, 2022



Magic Number

+905433705491

7/24



Congenital Hyperinsulinism in Turkiye

- F-DOPA-PET/CT imaging
 - Was not available until recently
 - Now there are 3 centers
 - Once indicated we perform F-DOPA PET/CT





Congenital Hyperinsulinism in Turkiye

- Once the focal disease is confirmed we do their surgery
- 13 cases with focal disease
 - 5 in the body and tail...cured with surgery
 - 8 in the head and neck
 - 1 cured
 - 5 surgery+medical treatment
 - 2 treated medically....no surgery due to localization, inadequate surgeon experience and families unwillingness
- Surgical success rate
 - Overall: 6/11 (%55)
 - 1/6 (16,6%) head-neck
- Surgical success was not satisfactory due to
 - Localization of the lesion
 - Inadeqaute experience of surgeons/lack of experienced pancreas surgeons



Congenital Hyperinsulinism in Turkiye

- Contribution to the clinical trials on CHI
- An outstanding experience with the Rezolute Inc. for Phase 2 (RIZE) study (Recruited 7 patients)
- One of largest contributors to Phase 3 (SunRIZE) study (10 pts)
- In contact for collaboration with other pharmaceutical companies
 - To contribute to developing the best treatment option(s) for CHI patients
 - Improve the quality of life of all patients and families from around the globe



Congenital Hyperinsulinism in Turkiye



So, no hypos, no injection after that



Who is the most sweetest ?



Congenital Hyperinsulinism in Turkiye

Happy END!!!!



Most
proudly
look ever



Congenital Hyperinsulinism in Turkiye

Our Motivation





Congenital Hyperinsulinism in Turkiye

Our Motivation





Congenital Hyperinsulinism in Turkiye

Our Motivation

My life-saver
keeping my sugar
up!



If I eat
enough
my sugar
would not
drop





Congenital Hyperinsulinism in Turkiye

Future prospect

- Expanding and improving the KOHHA-DER
- Collaborate with CHI and other family advocacy groups
- Negotiate with Turkish SSI for covering the 18F-DOPA PET/CT fee
- Provide faster detection and surgery of focal cases
- Educating our pancreas surgeons and collecting all focal patients at a single center
- **Establishing a Center of Excellence!!!!**



Congenital Hyperinsulinism in Turkiye

Thanks!!!!

- Families and clinicians who contribute to KoHHA-DER
- Leading team of KoHHA-DER
- Clinicians who refer their patients and are in collaboration with us
- Our nuclear medicine and pediatric surgery team
- CHI International
- Exeter University Molecular Genetics Unit Team
- Rezolute and all pharmaceutical companies who work on developing the best treatment options for our patients