

HI Global Registry

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Hayden

2015 Highlights

Research:

- Raring to Go for CHI Research Award

Advocate for Early Detection:

- Guidelines Participation
- Video
- Sugar Soiree, Sugar Shindig

Support HI Families:

- International Parents' Forum
- Direct Patient Interaction
- Host Barcelona Conference
- Created 1st Family Fund

CHI'S THREE-PART MISSION



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Support research
for better treatments
and a cure

HI Global Registry

Advocate for early
HI detection and
improved care

Support those
with HI and their
families

HI Global Registry

- Partnership:
 - NORD (National Organization of Rare Diseases)
 - CHI
 - CHI Scientific Advisory Group
 - Worldwide Patient Groups
- Life-long, Natural History Information
- Patient/Parent Contributed Data
- Interactive Format (for Patient/Parents)
- De-identified Sharing of Trends
- Just beginning to customize for HI
- Go-Live Goal = Fall 2016





PhotoCandy