



Helena's CHI story

Congenital Hyperinsulinism
Triumphs and Challenges

Challenges

- born apparently healthy
- **doctors did not recognize the symptoms**
- **It took us too long** and brain was seriously damaged
- medical expertise without experience in HI
- time for parents to take over
- time for **CHI Conference**



CHI Conference



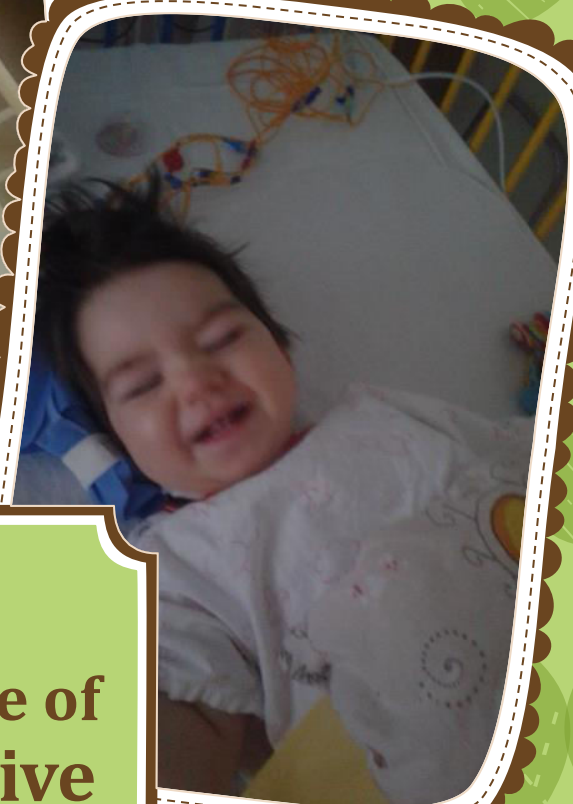
It is lifesaving conference with such an importance for families and medical expertise to meet and share experiences

once CHI family member, always CHI family member

Triumphs

- she is **cured from Focal form of HI in Germany**
- We were able to help other families
- they all had one thing in common, **LACK OF INFORMATION**
- without our CHI community, Helena would still struggle with HI





**The importance of
staying positive**

struggle with consequences

- **Helena can't walk**, has epilepsy and vision defect
- she is special need child
- living in a poor health system
- **excluded from Montessori kindergarten because she can't walk**
- hard to find a nanny





persistent and constant work

- speech therapist
- physical therapies
- psychologists
- sensory integration





Hey, chill out it's
just CHI,
I will be just fine