



# Barcelona 2015

## **Project PEAK**

Participation and Empowerment of Kids  
with Congenital Hyperinsulinism

# **Congenital Hyperinsulinism Family Conference**

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# overview

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- About us
- Aims of the association
- What we do
- Project „PEAK“
- Partnerships
- Outlook



# About us

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- association was founded in 2011 at Rare Diseases Day, Berlin
- 61 members 2015
- 45 affected children and their families
- Countries: Germany, Austria, Switzerland, Sweden, Slovakia and Portugal



# aims

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- Support children and their families living with congenital hyperinsulinism
- exchange and networking among the association members in order to offer support to patients and their families
- information platform (nutrition, diagnostic, therapy, medications, problems in everyday life)



# What we do

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- Summer family conference in Berlin
- Regional meetings
- Help for newly affected families
- Increase awareness of CHI
- Alone we are powerless. Together we are strong



# Project „PEAK“

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## PEAK

**Participation and Empowerment  
of Affected Kids  
with congenital hyperinsulinism**

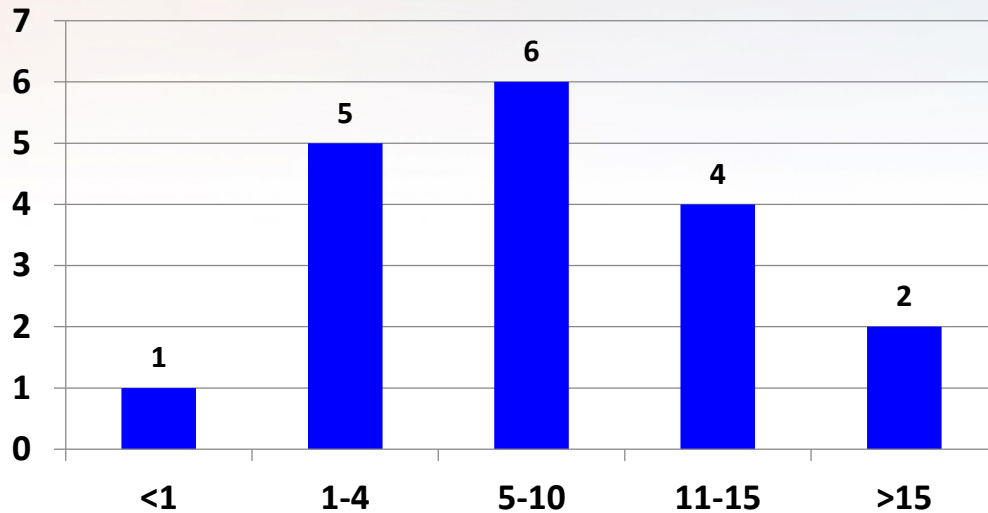


# CHI International

## Gender



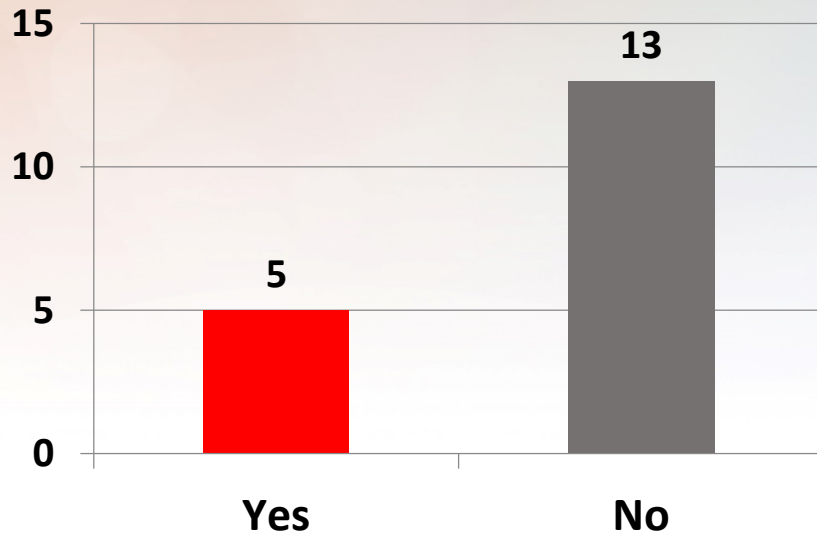
## Kids/age brackets



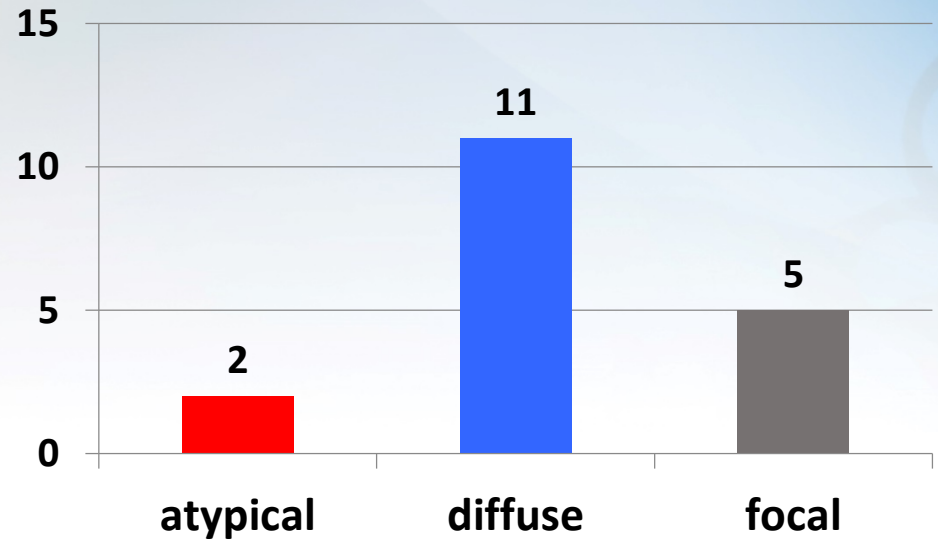


# CHI International

## Other cases in the family



## HI-Phenotype

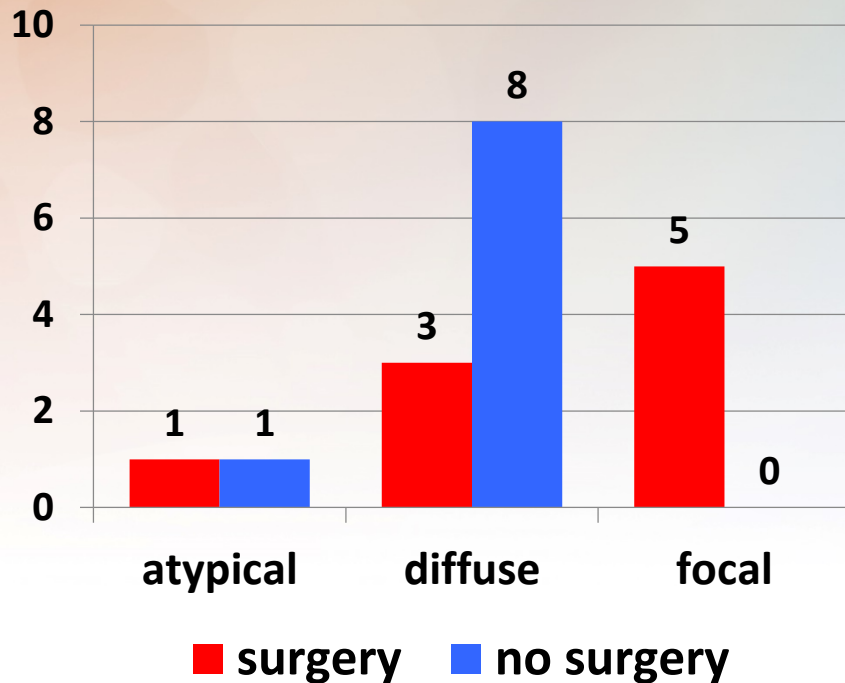




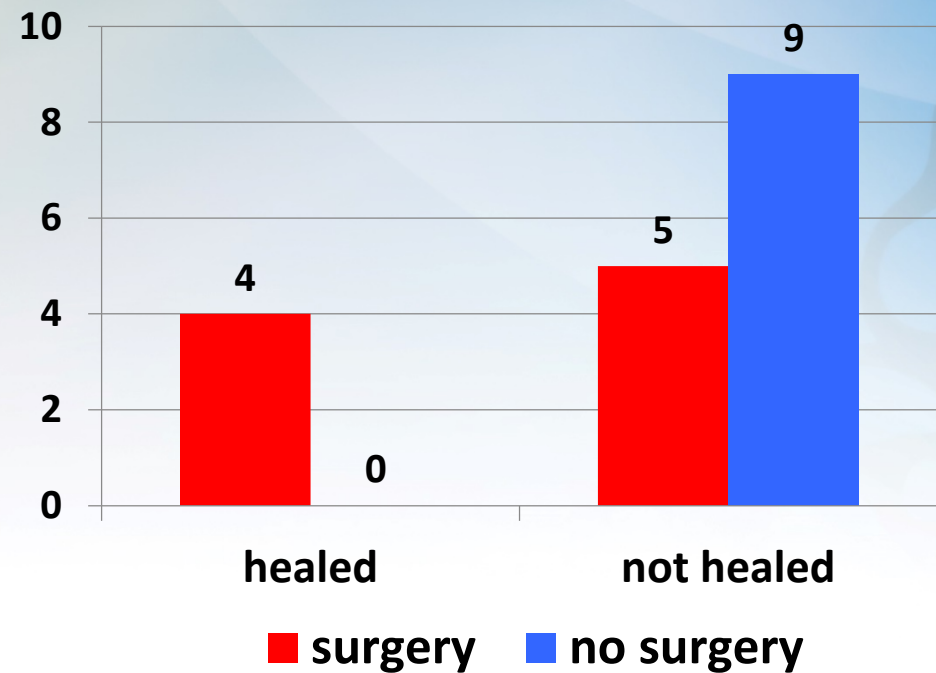


# CHI International

## Surgery / Phenotype



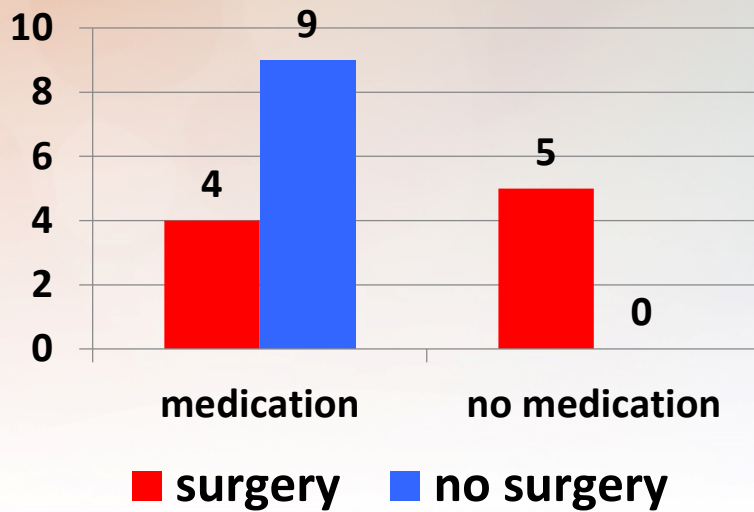
## Surgery/ healing



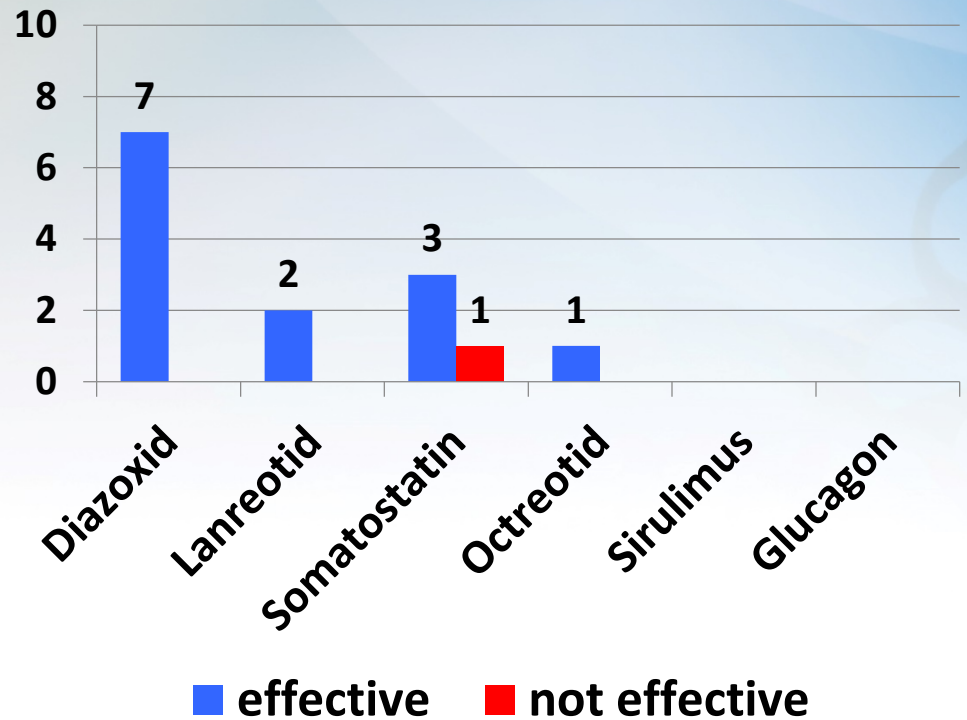


# CHI International

## Surgery/ medication



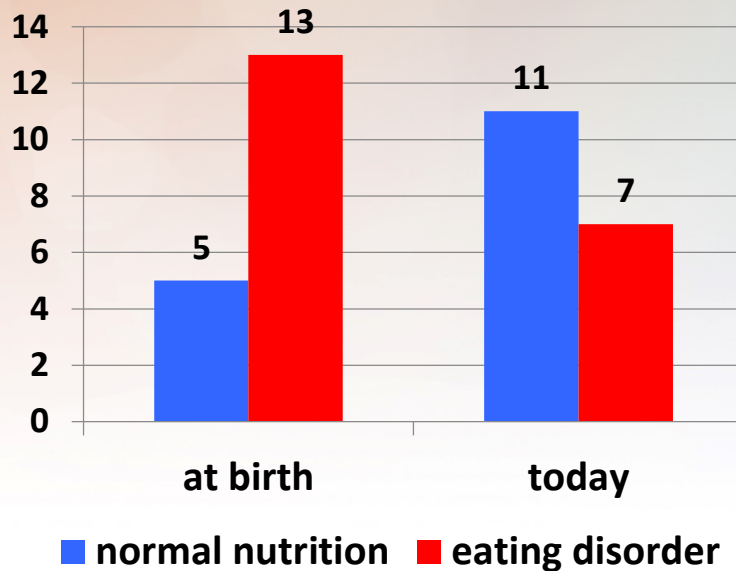
## Medication/ efficacy



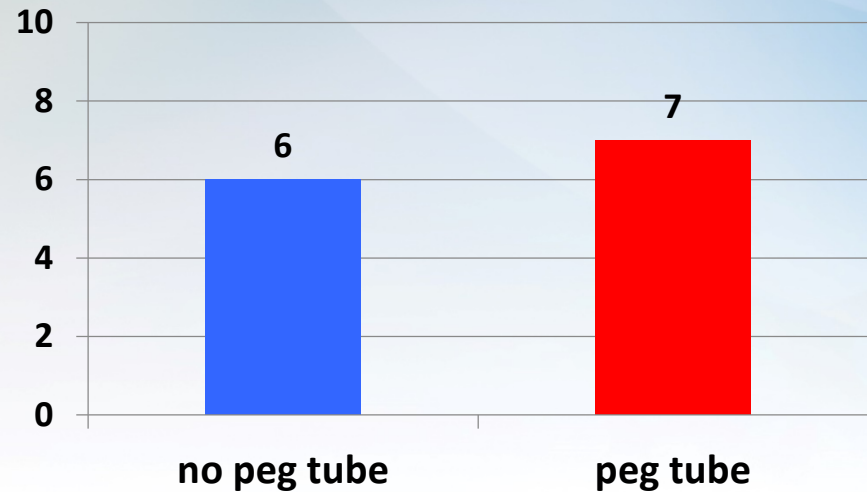


# CHI International

## Eating disorder at birth & today



## Initial eating disorder (n=13)





# data protection regulations

- Treating personal data strictly confidentially
- Password protected data base
- Access to data permitted exclusively for elected board
- Change and delete personal data at any time
- Participation should be voluntary



# Outlook

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- Partnership: systematic consulting and mediation between families
- Project PEAK to expand → registry
- Join global registry
- Networking
  - [www.portal-se.de](http://www.portal-se.de)
  - [www.se-atlas.de](http://www.se-atlas.de)
  - <http://betacure.eu/>



# Outlook

**Thank you for your attention!**





# Outlook

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- Networking
  - [www.portal-se.de](http://www.portal-se.de)
  - [www.se-atlas.de](http://www.se-atlas.de)
- Join global registry
- Support research projects
- Transition as topic for teenage members