Project PEAK
Participation and Empowerment of Kids with Congenital Hyperinsulinism

Congenital Hyperinsulinism Family Conference

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overview

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

- 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

• 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

• 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“

PEAK

Participation and Empowerment of Affected Kids with congenital hyperinsulinism
Other cases in the family

- Yes: 5
- No: 13

HI-Phenotype

- Atypical: 2
- Diffuse: 11
- Focal: 5
Eating disorder at birth & today

- At birth: 5 normal nutrition, 13 eating disorder
- Today: 11 normal nutrition, 7 eating disorder

Initial eating disorder (n=13)

- No peg tube: 6
- Peg tube: 7

(normal nutrition)
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

• Partnership: systematic consulting and mediation between families
• Project PEAK to expand → registry
• Join global registry
• Networking
  – www.portal-se.de
  – www.se-atlas.de
  – http://betacure.eu/
Thank you for your attention!
Outlook

• Networking
  – www.portal-se.de
  – www.se-atlas.de

• Join global registry

• Support research projects

• Transition as topic for teenage members