



Coping Strategies for Managing the Stress of Caring for Children with Complex Medical Needs

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International CHI-meeting Athens,
2018

Stella Promussas

- Born in 1999
- Diagnosis Congenital Hyperinsulinism, diffuse
- Genetics confirmed
- Nearly one year in hospital



Stella's Therapy at AKH Vienna

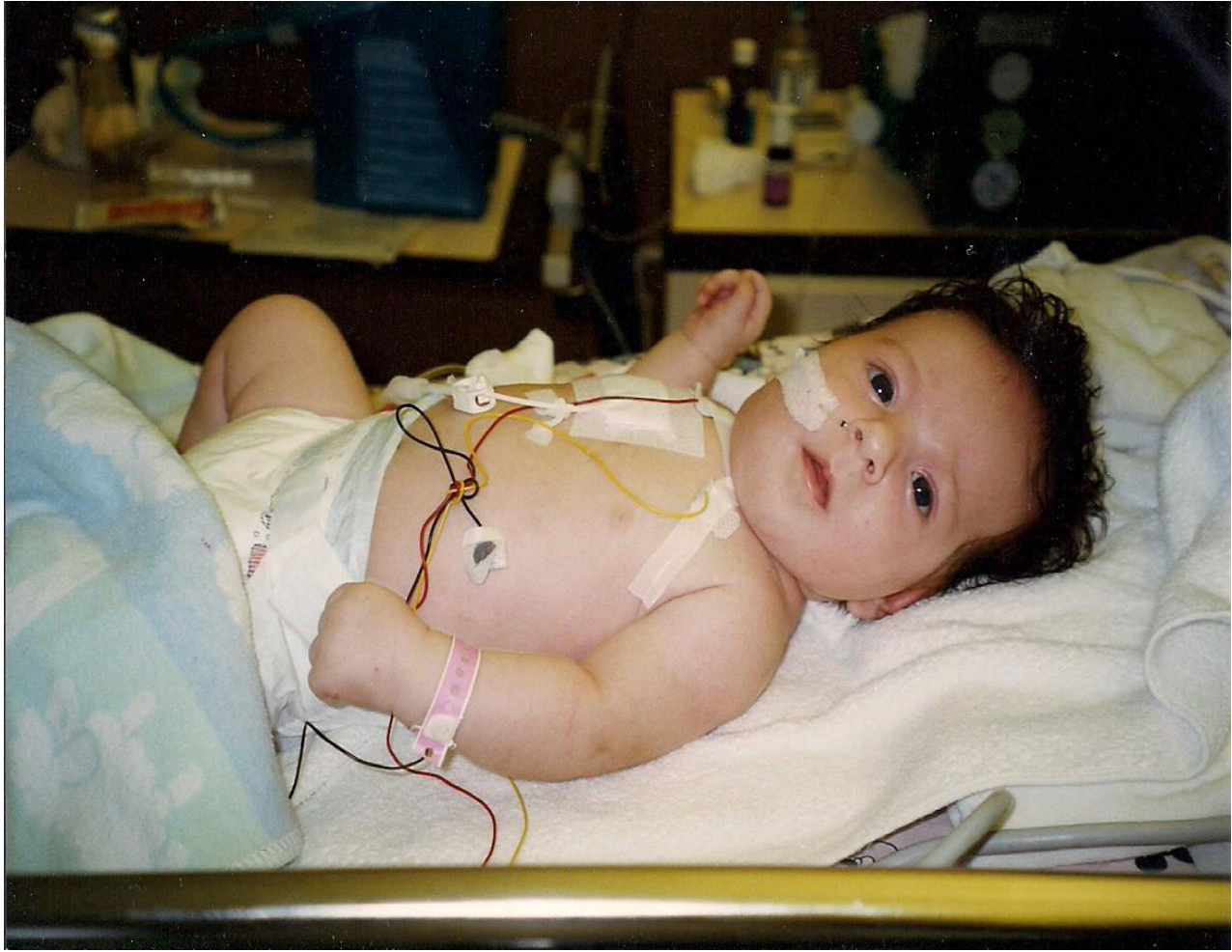
- Octreotide per pump, PEG-tube
- Blood sugar level measuring every 3 hours
- 7 bottles a 140 ml with cornstarch and meds totally fed by tube until age 3, bad eater until 10
- Nutricion pump during the night
- No pancreatectomy

Giving birth to a CHI-baby means..

- To be confronted with a rare disease
- Fear of brain damage from low blood sugars
- Isolation from friends and family because of caring for the sick child around the clock
- Stress over child not wanting to eat and seizures
- Missing time from work, giving up work
- Post traumatic symptom?
- Decision about having another child?
- And many other sorrows...

What made life really difficult for me?

- To fear for the child's life
- To be a single mom
- Not having a family around
- When doctors and parents do not know really much about a rare disease (1999)
- Not having any break
- Functioning all day like a robot
- Not having enough sleep



What helped?

- Friends
- **The international CHI group!!!!**
- Looking for small normal things of everyday's life
- Talking to other concerned families

But...

- Mainly, it was not the disease itself, but difficulties with public authorities, kindergarten, school, employment centers which complicated our lives. That's why it came to...

Forming the association in 2005



Neutral society of
concerned families,
organisations, self
help groups and
doctors

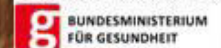
Lobby4kids Database



KI(N)D SEIN
DABEI SEIN!



Dieses Projekt wird vom BM
für Gesundheit gefördert.



Conclusion: Strategies

- Accept offers of help by friends and family
- Be super organized but don't try and be superwoman
- Take care of yourself: Example: Yoga or a sport, eat well, figure out a way to get enough sleep.
- If possible, go to work!!!





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Further..

- Don't compare your life to others
- Take each day one day at a time
- Breathing and relaxation techniques
- **Be part of an HI support group!!!!**

<http://www.congenitalhi.org/>

- **Home**
- Congenital Hyperinsulinism International (CHI) is a charitable organization dedicated to improving the lives of children, adults, and families living with congenital hyperinsulinism.
- **What We Do:**
- Advocate on behalf of children and adults with congenital hyperinsulinism.
- Create and provide educational resources about congenital hyperinsulinism to patient's, families, medical professionals, school personnel, and any other interested parties.
- Support research and development of medical knowledge and medical devices to better understand and treat congenital hyperinsulinism.
- Support children, adults, and their families living with congenital hyperinsulinism.
- Increase awareness of congenital hyperinsulinism, especially among medical personnel, in order to improve timely diagnosis.



Kongenitaler Hyperinsulinismus e.V.

- The Group
- Aims
- Every year's conference
- Contemporary issues



The German CHI Group

- Founded in 28.02.2011
- Members : 167, most concerned families from Germany, Austria, Switzerland, Sweden 😊
- Many interested people and partners



Aims

- Networking between doctors and concerned families, partnerships
- Help and information
- Introduction and notification of HI
- Organisation of HI-meetings



Vienna CHI meeting 2018





What helps most:

Get positive energy out of being an HI advocate. Help others!!

Internet

- www.lobby4kids.at
- www.hyperinsulinismus.de
- www.congenitalhi.org

Thank you!

