



# Coping Strategies for managing a child with complex medical needs

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# Stella Promussas

- Born in 1999
- Congenital Hyperinsulinism, diffuse
- genet. determined
- First year of life spent in hospital, with a few breaks

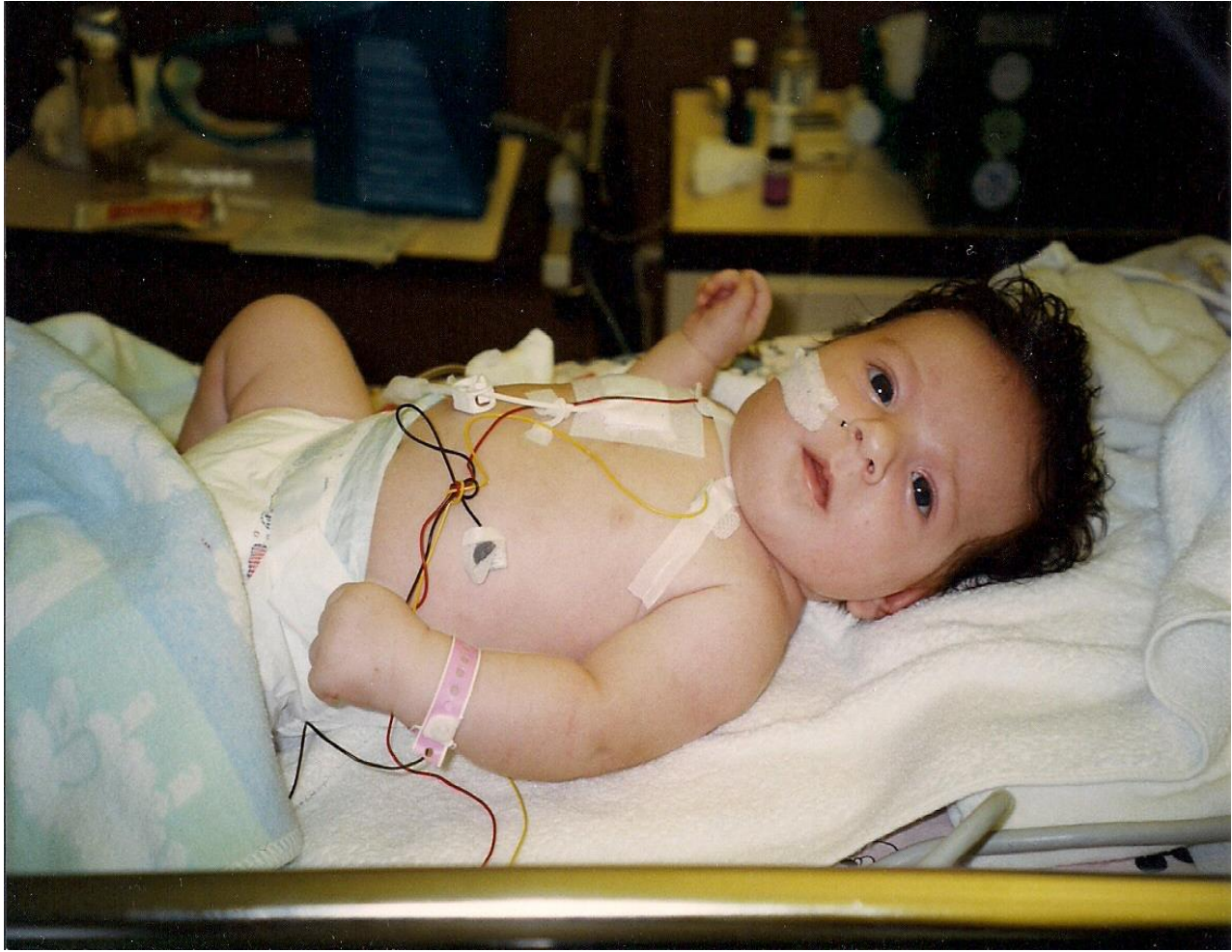


# Stella's therapy

- Octreotide per pump, PEG-tube
- Blood sugar level every 3 hours
- 7 bottles a' 140ml with cornstarch and meds
- Totally tube fed up to 3a, bad eater up to 10a
- Nutrition pump during the night
- No pancreatectomy

# What made life really difficult?

- 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 during the first time?

- 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



# Why do we need Lobby4kids?

- Children still don't get the importance they need
- They are not able to speak for themselves
- Life is still more difficult for disabled children and / or those with chronic diseases
- Deficiencies in health systems appear in a special way in these children
- Parents are overburdened with management and caring

# Activities of Lobby4kids

- „Internet quick support“:
  - Problem of concerned family
  - email to Lobby's network
  - solution within 48 hours
- Individual case support
- public relations

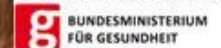
# Lobby4kids Database



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!!!!**



# Kongenitaler Hypeinsulinimus e.V.

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





# Our HI association

- Founded on 28.02.2011
- Members: 30 families and doctors from all of Europe
- About 30 persons who are interested and / or concerned



# Aims

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



# The meetings

- One big meeting in summer
  - meeting for the association
  - Exchange of experiences and scientific contents
- Regional meetings in Berlin, Düsseldorf and Stuttgart, Vienna planned 😊



# Contemporary issues

- Homepage
- Foto gallery
- More members wanted!!
- Future prospects



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



Thank you!!!

[www.hyperinsulinismus.de](http://www.hyperinsulinismus.de)

[www.lobby4kids.at](http://www.lobby4kids.at)