Coping Strategies for managing a child with complex medical needs

Irene Promussas, PhD
International CHI Conference,
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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!
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!!!
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!!!!!!
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
www.lobby4kids.at