The Patient’s Voice: Children’s empowerment

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Stella Promussas

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

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» Czernin Verlag
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 or children with chronic diseases
- Deficiencies in health systems appear in a special way in these children
- Parents are overburdened with management and caring
Forming the association in 2005

Neutral society of concerned families, organisations, self help groups and doctors
Aims of Lobby4kids

**Medicine:**

- National healthplan
- Improvement of medical care of children with chronic diseases or disabilities
- Teams of emergency pediatricians all over Austria
- Nationwide mobile home nursing for free
- Establishment of departments for rare diseases
Aims of Lobby4kids

Social area:

• No patient´s contribution for receipts or hospital stayings for children
• Expertise for aliments via pediatricians or nurses
• Financial securing of needed resources for children´s hospitals or medical centers
• Plans for improvement of socially disadvantaged families
Aims of Lobby4kids

Social policy and law:

- sensibilising the public for a children´s lobby
- Implementing patient´s rights especially for children and adolescents
- Establishment of a patient´s lawyer for children in every province
- Crosslinking and integration of all initiatives advancing children´s health
Some members of Lobby4kids
Lobby4kids and Kongenitaler Hyperinsulinismus.e.V are partners!!
Aims of Lobby4kids

Ethics:

• Public acceptance of the EACH – Charta (European Association for Children in Hospital) and its realisation in hospitals
EACH Charta

• Children shall be admitted to hospital only if the care they acquire cannot be equally well provided at home or on a day base.

• Children in hospital shall have the right to have their parents or parent substitute with them at all times.
Activities of Lobby4kids

- Internet quick support:
  - Problem of concerned family
  - E-Mail to Lobby´s network
  - Solution within 48 hours

- Individual case support

- Public relations
Lobby4kids Database

KI(N)D SEIN DABEI SEIN!
Problem „Inclusive Education“

- Children with chronical diseases and disabilities are entitled to be integrated and to get „inclusive education“ – this starts at the kindergarten
- Problem: in Austria no legal claim to kindergarten or after school care club
- Principle of voluntariness, Paragraph 50 medical law
Problems in practical experiences

- Children with PEG - tubes don´t get anything to drink because nobody wants to touch the tube
- Single parents get into poverty trap
- Children don´t get real integration
- Far too little places for disabled children at the kindergarten
Some achievements of last years

- Forming public consciousness for disabled children
- Negotiations with urban administrations resulted in additional budget for hours of support and caring
- Topics of children with chronical diseases are more present in media
Next „TO DO´S“ Lobby4kids

• Support and caring for disabled children at schools, kindergarten and after school clubs have to be improved – we keep on fighting

• „Inclusive Education“ has to be attended by concerned families

• Gaps within the supplementary network of supplies (e.g. places on a treatment programme) have to be closed
Visit our Homepages!!

[Image: Lobby 4 Kids]

www.lobby4kids.at
www.hyperinsulinismus.de
Thank you for your attention!