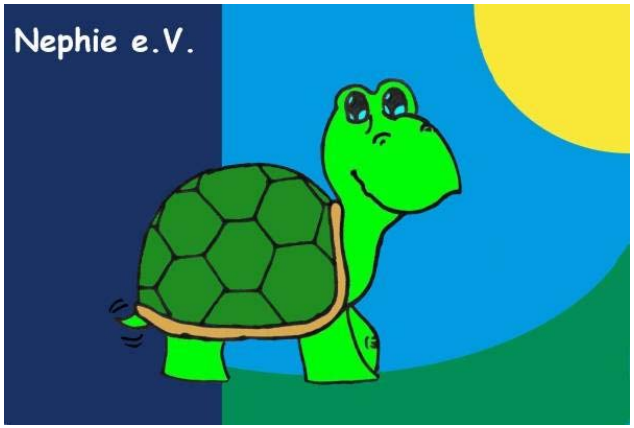
Information for Patients and Interested People



Empowerment organization
for idiopathic nephrotic syndrome

Nephie e.V.
Neu St. Juergener Straße 1
D-27726 Worpswede
Tel: +49.4792.7490
E-Mail: nephieev@googlemail.com
Contact:
Johanna Kiltz, Stefan Barthels
www.nephie.de

Priority Objectives:

We want to contribute to prevention and healing of the very rare, presumably immunological idiopathic nephrotic syndrome. Evaluation of observational research in order to find more considerate therapies giving a chance to children's self-healing competence.

Goals of Empowerment:

- Information and education
- exchange of expert knowledge, patients' meetings, organization of scientific symposia for interested families
- communication and public work, information of doctors, hospitals and insurers
- assistance and advice of concerned families in respect to their illness
- encouragement of interdisciplinary collaboration of renal centers
- internet: general information, forum and chat

About us

Nephie e.V. was founded on 4 July 2009 encouraged by a European parents initiative. Our members live all over Germany (Leipzig, Berlin, München, Lüneburg, Hamburg, Moormerland, Hohenlockstedt, Worpswede, Rostock, Stuttgart i.a.) as well as in Austria and Luxembourg.

Via European parents and thus via the Society for Paediatric Nephrologists (ESPN) we have direct contacts to pediatric nephrologists in the Netherlands, France, Belgium, Austria, Switzerland and England..

We attend conferences and congresses and thus stay informed about relevant and newly published developments in the treatment of the nephrotic syndrome. We want to support specific research for a treatment of the nephrotic syndrome with less side effects.

Via a public internet forum we are in indirect contact with about 300 concerned families and have 40 member families.

On 16 April 2010 we have been accepted as member of ACHSE – Alliance of chronic rare diseases www.achse-online.de.

We want to support families, encourage them and be their „voice". We want to inform about this small sub-group of kidney diseases, for which transplants are no solution.

Member of „Allianz Chronischer Seltener Erkrankungen (ACHSE)"
www.achse-online.de

achse

Situation

2 – 5 of 100,000 children develop an idiopathic nephrotic syndrome, this means about 250 new cases every year in Germany, tendency to rise.

The idiopathic nephrotic syndrome has a good chance for full recovery. Still, with some patients the disease persists to adulthood.

Individual therapy, close to trigger events as well as complementary medical treatment may help to avoid problems like

- steroid dependence,
- continued immunosuppression and chemotherapy

In today's hospital situation with its enormous cost pressure and lack of personnel often little room is left for basic research concerning idiopathic diseases.

Nephrotic Syndrome:

The nephrotic syndrom is characterized by a high loss of protein via urine. Urine purifies the body from many organic waste products but contains normally only a smallest trace of protein. By massive proteinuria in connection with nephrotic syndrome albumin level in the blood decreases and oedema develop all over the body of the patients.

By massive proteinuria and hereby developing oedema the nephrotic syndrome is typically characterized by a quick increase in weight, sometimes several kilograms within a very short time period.

There are several diagnoses to mention: Steroid Sensible Minimal Change Nephrotic Syndrome, the Steroid Resistant Nephrotic Syndrome up to Focal Segmental Glomerulosclerosis (FSGS).

Treatment and Risks:

Some children relapse only once or twice a year. These children can be stabilized quickly by prednisone. Other little patients have three or more relapses a year and develop severe prednisone dependence. This frequent relapsing may lead to kidney failure. These are the difficult cases of the Minimal Change Nephrotic Syndrome, which are treated currently with long term immunosupression and chemotherapy.

Children not responding to steroids (less than 5 % of the cases) develop scaring of the kidneys and thus suffer from limited kidney function or even kidney failure. These children need to be transplanted very quickly; but it is very often the case that the proteinuria persists in the new kidney.

Also the Focal Segmental Glomerulosclerosis may destroy kidney function and leads to dialysis and transplants.