



NephcEurope

CARE & CURE FOR NEPHROTIC SYNDROME

Strategical framework 2021-2025

Ongoing day-to-day activities

- Help patients with questions on their disease or treatment
- Coach patients and parents to represent themselves well in patient/doctor contact
- Create an international network of patient experts to inform each other and ask for input on questions of patients
- Create a multistakeholder network to the benefit of development new opportunities
- Identify international views of national patient groups for patient advocacy
- Involve international patients in policy development
- Lobby for policy development in areas of NS patient's interest
- Being a watch dog for patients rights within the GDPR and in other international settings

General aims, disseminate knowledge on and incorporate relevant patient stakeholders in

- 1) Collecting protocols of treatment in Europe (1st flare, 1st year, steroid dependency, steroid resistance, multidrug resistance, supportive cares)
- 2) Debate with other stakeholders on guidelines and create new ones from patient perspective (transition/psychological support)
- 3) Disseminate information on trials in progress
- 4) Request to relevant stakeholders to initiate new trials
- 5) Debate concepts of clinical trial set up
- 6) Suggest and promote basic science studies
- 7) Explore ways of homeopathic treatments

Further long term strategical activities

- 1) Identify hurdles for and opportunities to improve the research development for Nephrotic Syndrome;
- 2) Identify treatments
- 3) Promote organ donation and transplantation for patients that develop End stage renal disease
- 4) Identify the unmet needs of patients

- 5) Identify obstacles in HTA in case medications would come to the market
- 6) Identify if it would be possible to join efforts on a multi stakeholder way in order to provide perhaps a better financial fundament of all of our activities;
- 7) Stay involved and informed about the present research activities coming from the European reference network ERKNET and disseminate this European wide.
- 8) Promote ethical and sound medication development within a expertise network
- 9) Stimulate the development of Nephrotic Syndrome care in underdeveloped countries

ERKNET, the European reference network for rare Kidney diseases

NephcEurope has a prolonged commitment to ERKNET. NephcEurope considers the development of ERKNET crucial for the European Care for Nephrotic Syndrome. We hope that the reference network will facilitate:

- Development of a sustainable and long term financed International Registry for Nephrotic Syndrome, combining into one European Registry on Nephrotic Syndrome to show prevalence of both genetic and idiopathic nephrotic syndrome, drug use and statistics including patient datasets
- More research to find origin of NS and new treatments in a sound clinical setting where international cooperation is crucial to meet critical mass
- More international sharing of data and knowledge
- Development of guidelines for safe testing of new medication on children together with other ERN's
- Sustainable medication development and lobbying for HTA if medications have been found to be of effect
- Improved efficiency to speed up processes instead of all kind of local and national ethical boards an international ethical board for NS research
- International collaboration between researchers and logistical parties to facilitate research and succeed in including sufficient patients to be included and make a trial successful
- Development of a "biomaterial" bank, a so called biobank.