

My personal experience

Ellen Vrieze-Hermans

Who I am...

- My name is Ellen Vrieze
- Diagnosed with ADTKD-HNF1B (Autosomal Dominant Tubulo-interstitial Kidney Disease – Hepatocyte Nuclear factor 1 beta)
- Dutch Kidney Patient Federation
→ Patient Representative
- Reviewing texts Nieren.nl
- Parent



What is conect4children (c4c)?



- c4c is a collaborative network that aims to establish a coordinated approach to facilitate the delivery clinical trials in sites across Europe **for all paediatric age groups and diseases.**
- c4c is piloting its network with a small selection of studies but will scale up when the successor organization is established.
- One of the services that c4c offers to its partners in its network is the expert advice input on study or protocol design and/or paediatric development programmes → **Patients, parents and carers are considered experts** and they are involved in advisory activities.

How I have been involved in c4c?

- I have participated as a *patient expert* to provide my feedback to include the patients perspective in a future paediatric clinical trial.
- Topics in which other parents and I have given input:
 - I. The acceptability of a potential study design.
 - II. The patient journey through a clinical trial protocol: opinion & insights on an hypothetical study:
 - Schedule of visits
 - Treatment plan as well as on the device being used in an study
 - Others.
- To do so, I have participated in different activities like:
 - I. Individual interview
 - II. Focus group meeting with other parents like me

Why I decided to collaborate with c4c?

- Important to contribute in the development of clinical trials for the future
- Input & insights of the today's medical treatments as well communication
- Involvement in the development of processes and protocols
- Learning about the set up of processes and protocols
- In order to be able to compare different protocols & processes, it is necessary to collect data from sufficiently large patient groups.

Challenges of joining c4c

- Expressing your feelings in general and another language
- Explain the processes and procedures normal / extraordinary
- Sharing the important medical terms
- Challenge with a rare disease and the complicated casus

How I think my contribution will help

- Sharing expertise as a patient / parent
- By participating, you are helping to advance protocols, processes or medicine, which is in the public interest of society
- The results of the study may help patients with a similar condition in the future
- As a patient, you can sometimes benefit from a new protocol or treatment yourself, but that is not always the case

How can people collaborate with c4c?

- The c4c has setup a **database** of young patients and families, patient's organisation that want to collaborate in these activities.
- Interested people can submit their contact details and their expression of interest to join the c4c pool of *patient experts*.
- If their help is needed, c4c will provide the information about the activity (goal, time to commit, etc.) to the selected candidates and will facilitate their participation in the c4c patients' involvement activities.

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Heel erg bedankt!

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