

3rd CNE International Cystinosis Conference



Innovative tools for patients

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My Cystinosis Story

Presentation toolkit for children with cystinosis

A collaboration between:

- **UZ Leuven, UZ Gent, UCL, CHU Liege, UZA Antwerpen**

Prof. Raes, Prof. Ranguelov, Ari Van Hulle, Lore Willem,
Dr. Collard, Dr. Veys, Prof. Levtchenko, Prof. Trouet

- **Patients and patient association**

Visiting patients and their parents, Marjolein Bos, Fons Sondag

- **Service design agency**

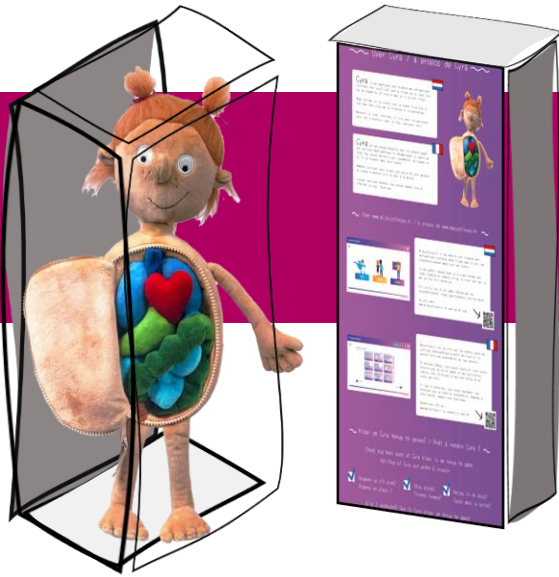
Ideate



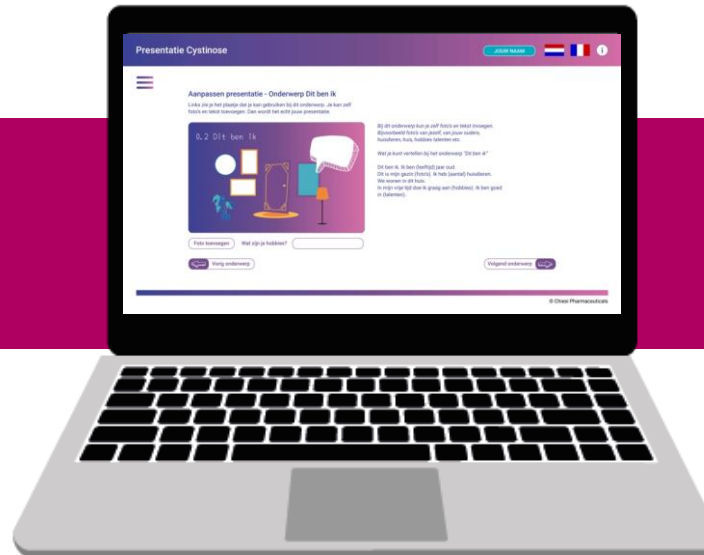
My Cystinosis Story

Presentation toolkit for children with cystinosis

My cystinosis story contains:



Doll for demonstration of the organs



Website with slide builder containing images and text to create your personal story about the disease



Sessions with presentation coach Veronique Hoex for confidence and practice

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Presentation toolkit for children with cystinosis

How it works:



At the hospital a nurse hands you a doll



At home you read the information on the back of the doll's container



You visit the website and build your own story



You practice your story with a coach and become a star at presenting!



Now you are able to share with anyone who you are, what you are going through and how others can help!

My Cystinosis Story

Presentation support for children with cystinosis

