

How my ERN improves my healthcare

Author: Susana Carvajal Arjona by HIPOFAM/FEDERG

The patient as the central axis of health care in a European reference/expertise hospital

Care

The human face of a day in the hospital

Multidisciplinary care specialized in chronic renal patients with rare diseases.

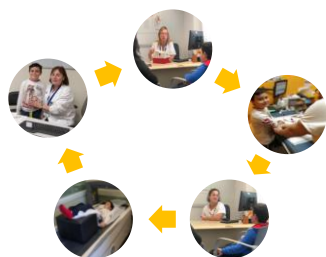
Professional medical monitoring:

✓ **Psychology**: monitoring the evolution of the patient in his family and school life.

✓ **Nutrition and pharmacy**: monitoring and control of the patient's diet, special medication corresponding to the evolution of his rare chronic kidney disease.

✓ **Nursing**: monitoring and accompaniment of the patient in their different stages of their disease.

Coordination of the appointment agenda with the different specialists in the same hospital center in the least number of trips to hospital.



Share

Long way, easy travel

European rare networks ERNs. ERKnet, an open door with easy access

✓ **Contact** doctors, researchers and patients,

✓ **Exchange** opinions regarding treatments, diagnoses and health care,



✓ **Promote** research,
✓ **Create** European Reference/expertise hospitals.



Cure

Our strength is our group collaboration and our hope is to promote research.

Involvement of patients associations with their researchers in their reference/expertise hospitals.

✓ **Learning and exchanging** information about our disease

✓ **Facilitating** sampling through patient associations

✓ **Financing** projects



The human face of research



Involvement of active patient (e-pag) with their researchers in European networks:

✓ **To give voice** to the specific and common needs of patients with rare diseases,

✓ **To learn and share** the specification of our diseases to other patients,

✓ **To get together** and show that we are **not alone**.

