1. First Symptom
Hematuria in urine, Proteinuria
Other affected organs (ear, eye)

2. Diagnosis
Hematuria, proteinuria
Kidney biopsy (20 years back)
Skin biopsy and genetic test

3. Treatment - No treatment except nutritional control
First medicine introduced in 2000 or renal protection with ACE inhibitor (Blood pressure reduction).

4. Transition & Adulthood
Depends on the stage of disease and care system.

5. Dialysis and transplant
Age of ESRD is depending on type of genetic disease, sex and type of gene default

**Diagnostic Needs:** Genetic counselling. Psychological support. Information and liaison with other patients.

**Ideally:** Perform genetic study include psychological support

**Treatment Needs:** Information about the medicine and possible secondary effect. Raise capacity in dealing with nutrition. Lighten medical load on patient and family by grouping the visits to medical doctors in hospital (Neprology, Hear, eye, nutrition, psychology...)

**Ideally:** Recognition of a chronic diseases requiring treatment for life

**Note:** Reduce anxiety for medical visit prior to a job. Decision about pregnancy

**Ideally:** Monitoring of the nephrology team
Subsidy of treatments by the public health system.
Support in school or work
Financial aid for assistive hearing devices.

**Note:** Identical to all others patients