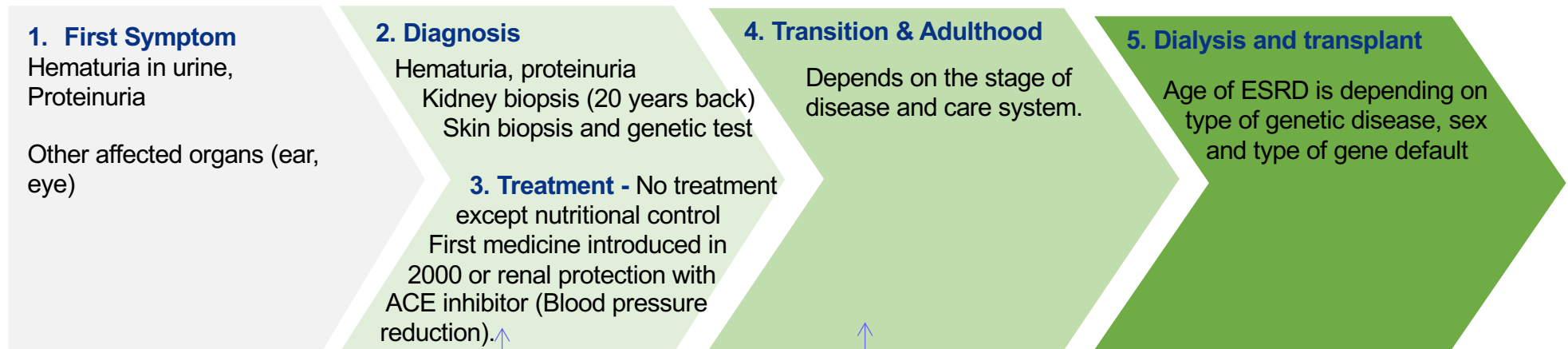


ALPORT Syndrome Patient Journey



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 (Nephrology, 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