Atypical Hemolytic Uremic Syndrome (aHUS)

Patient Journey

1. First Symptom
   Severe high blood pressure
   Moisture retention
   End stage renal failure

2. Diagnosis
   TMA: hematuria, proteinuria
   aHus: kidney biopsy
   Gen Mutation: genetic testing

3. Treatment ...
   Hemodialysis
   Blood pressure reduction
   Low-salt, low-potassium & high-protein diet
   Moisture limitation
   Treatment with eculizumab every 4 weeks

4. Surgery
   Shunt, to be able to start hemodialysis
   Kidney transplant

4. Follow Up
   Treatment with eculizumab
   Blood pressure treatment

Needs:
- Information about treatment options. Liaison to patient organization/ other patients.
- Information about the rare disease and genetic counseling.

Ideally:
- Well informed patient
- Complete understanding of disease and consequences for life

Needs: Information about alternative treatment options (transplantation in combination with your rare disease)
- Discuss dialysis options
- Information about chance of success and start treatment eculizumab (if available, due to extreme high costs)

Ideally:
- Guidance by a dietician, on a regular basis
- Good working shunt

Needs: Start and stop criteria.
- Information on the forehand that blood pressure treatment remains necessary, even after transplant

Ideally:
- Individualized treatment with eculizumab, with approval of Health Minister and funded by health insurance
- Alternative in food instead of drugs