

aHUS

atypical hemolytic
uremic syndrome

Symptom Tracker



ALEXION[®]
AstraZeneca Rare Disease

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Keeping track of your health

Record your signs and symptoms of aHUS, and your lab results, for your next doctor's visit.

As you know, atypical Hemolytic Uremic Syndrome (aHUS) is a serious, genetic, lifelong disease. Regularly tracking your overall health, as well as the results from your doctors' visits, can help you and your healthcare team get a better sense of how well your aHUS is being managed.

This diary will help you track how you're feeling, monitor any signs and symptoms of aHUS, and house some of your lab results.

Let's begin here.

Work with your doctor to complete the following important background information. This information will help provide valuable insight into your health history so your healthcare team can provide the best care possible.

Date of birth:

Age at diagnosis:

Date of confirmed aHUS diagnosis:

Atypical HUS History:

History of TMAs? Yes No

If yes: How many TMAs did you experience prior to your diagnosis?

When did these occur?

At what age?

Additional Notes (ie. What triggered your aHUS: infection, surgery, pregnancy, etc. ?)

Family history of TMAs or aHUS? Yes No

Which relative(s)?

Additional Notes:

Keeping track of your health

Identified genetic mutation? Yes No

Family member(s) with a genetic mutation? Yes No

Which relative has a genetic mutation?

Additional Notes:

Renal insufficiency? Yes No

On Dialysis? Yes No

Kidney transplant? Yes No Date of transplant:

Additional Notes:

How is your aHUS currently being managed/treated?

Quality of life: Has your health affected any daily activities like:

Sleep? Please Explain

Yes No

Concentration? Please Explain

Yes No

Work or school? Please Explain

Yes No

Being active
(e.g., playing sports)? Please Explain

Yes No

Other:

Using your symptom tracker to discuss your health with your healthcare team

How to use this tool:

Record all the signs and symptoms you may be experiencing between each doctor's appointments by using the symptom monitoring form.

Bring your Symptom Tracker to your next doctor's appointment.

Review signs and symptoms with your healthcare team.

Track the lab results you receive at your doctor's appointments.

Topics you may want to discuss with your healthcare team.

To help you start a discussion with your healthcare team, here are a few suggested topics:

- How treatment can help manage aHUS
- Frequency and importance of regular doctor's visits
- Signs and symptoms of aHUS that should be brought to your healthcare team's attention

Important facts about aHUS

- aHUS is a serious, genetic disease that requires lifelong care
- The risk of aHUS may include complications related to the brain, heart, kidneys, lungs, blood, and digestive system

Speak with your healthcare team about important lab test results.

Monitoring your signs and symptoms

Record your signs and symptoms of aHUS and discuss them with your healthcare team

Signs and Symptoms	Today's Date:				Today's Date:				Today's Date:			
	Daily	Weekly	Once / Month	Never N/A	Daily	Weekly	Once / Month	Never N/A	Daily	Weekly	Once / Month	Never N/A
Confusion												
Seizure												
Headache												
Inability to concentrate												
Chest pain												
Difficulty breathing												
Shortness of breath												
Swelling												
Facial "puffiness"												
Abdominal/Stomach pain												
Diarrhea												
Nausea/Vomiting												
Fatigue												
Weakness												
Abnormal bleeding												
Easy bruising												
Irritability/Anxiety												
Yellow discoloration of eyes and/or skin												
Lack of appetite												
Overall impact on quality of life (e.g., sleep, work/school, social interactions)												
Eye pain												
Blurred vision												
Other (new trigger or symptom)												

Recording your signs and symptoms, questions for your healthcare team, and tracking your lab test results

Record your signs and symptoms, and questions for your healthcare team

Track your lab results (if known)

	Date of Test		Date of Test		Date of Test	
Hematology						
Platelets						
Lactate dehydrogenase (LDH)						
Hemoglobin						
Haptoglobin						
Hemoglobinuria						
Schistocytes	Yes	No	Yes	No	Yes	No
Renal						
Serum creatinine						
eGFR						
Urinalysis						
Protein in urine	Yes	No	Yes	No	Yes	No
Urine volume/Output						
Other tests						
Blood pressure		/		/		/
Weight						

Speak with your healthcare team about other important lab test results.