



We Need You!

for an atypical HUS longitudinal study

- **What is a longitudinal study?**

It is a study that takes several years to complete. People participating in the study provide samples many times – when they are healthy, and when they are sick. And they provide medical reports. They are followed ‘longitudinally’ over time.

- **Why do we need an aHUS longitudinal study?**

Good question. It is because there are many questions about aHUS that remain unanswered. We cannot address these questions unless the aHUS community helps us.

- **But I feel fine. Why should I participate now?**

Because we would like to study the aHUS community at all phases of disease....when aHUS first shows up (called the acute phase) and when the disease is brought under control (called the chronic phase). This will help us understand what is happening over time. We now know a lot about the acute phase of aHUS because everyone is eager to participate at that time. We know far less about the chronic phase.

- **But I’m on eculizumab so I’m cured.**

Eculizumab stops the last part of the complement system from working and that is how it is helping you. But the complement system and aHUS are both very complicated. We want to see whether any abnormalities in complement protein levels persist over time even with treatment. We are



also interested in following the aHUS symptoms not related to the kidney (“extra-renal consequences”) and those symptoms that come long after the disease has started.

- **If I still have some abnormal complement protein levels, is that bad?**

We don’t know whether we will find anything abnormal, which is one of the reasons for this study. But if we do find an abnormality, figuring out what it means is one of the goals of the study.

- **And ‘...following the extra-renal consequences of aHUS...’, what is that all about?**

Well, as you know, aHUS affects the kidneys. But in some people it can also affect other parts of the body, for example the heart, lungs and brain. That means it can cause cardiac, pulmonary and neurologic problems as well. We really don’t know what is occurring long-term and we would like to begin to figure that out.

- **So if I participate will you tell me what you find?**

Yes, but we may not be able to tell you what the findings mean until we do more studies.

- **Okay. I’d like to help. What do I have to do next?**

Please email us at AHUS-STUDY@uiowa.edu and we will provide information on the next steps.