

FMI- FOR MORE INFORMATION AN AHUS RESOURCE LIST

PATIENT COMMUNITIES- LIVING WITH A DIAGNOSIS OF AHUS

- **Interactive website of The Foundation for Children with Atypical HUS.**
www.atypicalhus.org.
- **A NORD/Eurordis-** joint initiative: Rare Disease Communities helps patients to understand their condition, connect with other patients and provides tools for living with their diseases. [Go to website.](#)
- **aHUS Bootcamp:** aHUS basics, written by parents—for parents.
[Read more.](#)

Share information and insight
in a supportive network of
families, friends and researchers.

Join the community at:
www.atypicalhus.org

More info at:
www.atypicalhus50megs.com

MEDICAL INFORMATION - RESOURCES FOR AHUS INFO

- Atypical Hemolytic-Uremic Syndrome, GeneReviews, NCBI Bookshelf
[The "Book" —an aHUS Primer](#)
- aHUS Research article: **Drs. G. Remuzzi and M. Noris**, NEJM Oct 2009. [Download article.](#)
- MedlinePlus Medical Encyclopedia, a service of the [U.S. National Library of Medicine](#) and the NIH, [National Institutes of Health](#), offer detailed information on **lab test values** commonly used for monitoring the status of aHUS patients. [Read more.](#)
- **Complement Deficiency:** ARUP Consult, Your Online Lab Test Resource. [Go to website.](#)
- **Dr. Gary Pien - PowerPoint Presentation:** Atypical HUS and Complement Deficiencies.
[Download the presentation.](#)
- **Transplants and Patients with atypical HUS** (The Foundation for Children with Atypical HUS proudly partners with **University of Iowa**). [Read more.](#)
- **Dr. Carla Nester** et al: Article regarding use of eculizumab (Soliris) in renal transplant for aHUS patients. [Read article.](#)
- [Visit the Foundation's informational website](#) for detailed medical information specific to aHUS.

GENETIC TESTING - SCREENING FOR AHUS

- **The University of Iowa's MORL** (Molecular Otolaryngology and Renal Research Laboratory) genetic screening program is CLIA accredited and conducts much of the analysis for atypical HUS patients in the United States. **Dr. Richard JH Smith** is Director of MORL. [Visit their website](#) for specifics on aHUS genetic studies and screenings that are available.

Or contact them at: The University of Iowa 5270 CBRB Iowa City, IA 52242 phone: 319-335-6623 fax: 319-353-5869

- **Dr. Judith Goodship** - June 11, 2011 Presentation: Genetics and aHUS
The first UK aHUS patient family conference was organized by Dr. Tim Goodship in Newcastle upon Tyne, England on June 11th, 2011. A talk on "Genetics and aHUS" was presented by Judith Goodship, Professor of Medical Genetics at Newcastle University in England. [View her highly informative video presentation.](#)
- This document was developed by Linda Burke, founder of www.atypicalhus.org, the interactive website of the Foundation for Children with Atypical HUS. [Email Linda](#) with questions or comments.



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