A Collaborative Network of Patients, Families, and Researchers

The Foundation for Children with Atypical HUS

For Immediate Release

Foundation for Children with Atypical HUS recognizes first treatment approved for extremely rare disease

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St. Louis, MO – September 23, 2011 – Having a child or loved one diagnosed with a rare and deadly disease is one of the most devastating experiences a family can face. Now, imagine discovering that there is very little information available, no cure, and most physicians and nurses have never had first-hand experience with this particular ultra-rare disease.

In the past, this is what the diagnosis of Atypical Hemolytic Uremic Syndrome (Atypical HUS or aHUS) has meant for families in the United States and around the world. Atypical HUS is a devastating and extremely rare disease that leads to serious medical consequences, including kidney failure, heart attack and stroke. Atypical HUS and its complications are dangerous and can be deadly.

Today, Atypical HUS patients have an effective new treatment. The U.S. Food and Drug Administration (FDA) has approved Soliris, also known as eculizumab, to treat children and adults with Atypical HUS. This is the first treatment specifically approved for Atypical HUS and the only one that targets the cause of the disease: over-activation of complement proteins that the body uses to fight infection.

In clinical trials, Soliris inhibited complement and reduced the blood clots that damage blood vessels, kidneys and other organs in patients with Atypical HUS. Soliris also maintained or restored kidney function and improved quality of life in patients in the studies. Based on these results, Soliris is a tremendous step forward in caring for patients with Atypical HUS.

“With FDA approval of Soliris, patients with Atypical HUS and their families now have the effective treatment they’ve been seeking for decades,” said Bill Biermann, Founder and Director of the Foundation for Children with Atypical HUS. “Through clinical trials and compassionate use, we’ve seen how Soliris can dramatically benefit the lives of patients with Atypical HUS who have endured frequent hospitalizations and the constant threat of complications. Our goal now is to increase awareness of Atypical HUS, so patients receive an accurate and timely diagnosis and early treatment with an effective therapy.”

Bill Biermann, Director · One Campbell Plaza, Suite 2B, St. Louis, MO 63139

The Foundation for Children with Atypical HUS is a 501c3 nonprofit organization.

About Atypical HUS

Atypical HUS is an extremely rare, serious disease in which blood clots form in small blood vessels throughout the body. Patients with Atypical HUS often experience severe anemia and acute kidney failure, potentially requiring dialysis and lengthy hospitalization. Patients may eventually develop chronic kidney disease and end stage renal failure. Cardiac issues are an added risk for patients, including chronic high blood pressure. Neurological problems such as seizures, blindness and coma can also develop in some cases. Atypical HUS can affect adults and children and often presents at a very young age.

For more than 40 years, physicians have cared for patients with Atypical HUS by using plasma exchange, plasma infusion and kidney dialysis. However, these strategies are often ineffective, cumbersome, and do not stop the progression of the disease. Some patients with Atypical HUS have opted for transplant procedures with a very high risk of failure because the disease often reoccurs in the new kidney.

Related links

To learn more about Atypical HUS, to read patient stories and more information about the Foundation please visit www.atypicalhus.org.

About The Foundation for Children with Atypical HUS

The Foundation for Children with Atypical HUS is a 501c3 nonprofit organization dedicated to helping patients and families affected by this rare disease. The goal of the foundation is to provide information and data to patients and families about this ultra-rare disease, to provide support by establishing a global network so interested individuals can communicate with one another to exchange opinions and experiences, and to provide funds for medical research to offer improved prognosis for aHUS patients. The Foundation for Children with Atypical HUS encourages patients and investigators to share information and explore options as we work together to gain insight into this rare and complex disease.

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Contact

Bill Biermann
Founder and Director
Foundation for Children with Atypical HUS
bbiermann@premier-ks.com
314-596-6738

Phyllis Talbot
Board Member
Foundation for Children with Atypical HUS
pabilltalbot@comcast.net
404-441-5537

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