Understanding And Overcoming An Ultra-Rare Bleeding Disorder

(NAPSA)—Imagine a mother holding her newborn baby in her arms when, suddenly, she notices considerable bleeding from the site of the baby's umbilical cord. And it simply won't stop. In moments, her joy and happiness turn into an unimaginable sense of fear and a frantic search for a solution.

For people born with one of the rarest bleeding disorders in the world, such bleeding is often one of life's first challenges.

Congenital fibrinogen deficiency, or Type 1 CFD, is a rare, potentially life threatening, hereditary bleeding disorder that can result in spontaneous, unexplained, ongoing bleeding. The condition affects approximately one person per million, with an estimated prevalence of 300 patients in the United States. In people with Type 1 CFD, the body does not produce fibrinogen, a protein essential for the formation of blood clots. Or the body produces very low levels of fibrinogen.

Often diagnosed at birth through blood tests, early symptoms of Type 1 CFD may include excessive bleeding at the umbilical cord site or excessive bleeding following circumcision, heel stick or blood draw. Other symptoms, which vary based on the severity of the condition, include:

- easy bruising
- frequent or prolonged nosebleeds
- excessive bleeding from the gums or during dental procedures
- prolonged or excessive bleeding following injury or surgery
- heavy menstrual bleeding
- internal bleeding.

Recognizing the signs and symptoms of dangerous bleeding is important for people who suffer from CFD so they can receive treatment in a timely manner. Bleeding of the head, neck, chest or abdomen can be life threatening and may require immediate medical attention. This is especially important given that CFD-related bleeding can occur spontaneously.

There's hopeful news for those with a very rare bleeding disorder. Doctors have a new treatment option.

"While Type 1 CFD is a lifelong condition, effective management of fibrinogen levels can offer patients a normal lifestyle," said Dr. Jonathan Bernstein, Medical Director of the Children's Specialty Center of Nevada and the Hemophilia Treatment Center of Nevada. "It is crucial to avoid bleeding triggers, such as medications that may increase bleeding risk or contact sports, and to work closely with a hemophilia treatment center to maintain appropriate fibrinogen levels."

Treatments for acute bleeding episodes of Type 1 CFD include an FDA-approved fibrinogen concentrate that raises fibrinogen levels to an appropriate threshold in a person's body.

For more information on the signs and symptoms of congenital fibrinogen deficiency, visit www.allaboutbleeding.com.