

College of Business alumni couple begins publishing company to honor their son

by Dana Baumgart - Wednesday, June 22, 2011

<http://www.uwosh.edu/today/12971/college-of-business-alumni-couple-begins-publishing-company-to-honor-their-son/>

In November 2009, Darrin Anderson '10 (MBA) and his wife, Sarah Anderson '03 and '08 (MBA), suddenly lost their 3-year-old son, Henry Morgan Anderson, to an untreated and undiagnosed immune deficiency disorder.

The disorder, called Bruton's X-linked Agammaglobulinemia (XLA), affects the body's ability to fight infection. While those with XLA can fight off viral infections like the flu, they are not protected from bacteria. If left untreated, children who have XLA will succumb to bacteria infections, followed by septic shock and death. If born to parents who carry the disease in their DNA, children have a 50 percent chance of getting the disorder.

"At the time of his death, it was all a mystery of why he died," said Darrin Anderson, who was originally told his son died of septic shock. "Currently, no hospitals in America screen for this disease. A simple blood test could've saved Henry's life."

Without any answers about why their son died, and the worry their other son was also suffering from XLA, the Andersons began research of their own. They also began thinking of ways to honor their late son.

At night, Anderson said Henry told bedtime stories using his stuffed animals, inspired by the many days the family spent at the Menominee Park Zoo in Oshkosh. These imaginative tales would feature grand adventures with Henry as the hero, saving an animal in trouble.

"He would mix the animals with things he had done during the day or movies he had watched and come up with his own version of the story," said Anderson.

After his death, the Andersons used Henry's memorial fund to create The Adventures of Henry publishing company with a mission to design, produce and market stories created by children who face horrific, rare diseases or medical conditions. All profits are donated to causes such as medical research and care for rare diseases and life-threatening conditions faced by children.

The first book of the series, "Timmy the Goat – Spelunking Adventure," was self-published in March 2011 and sold 450 copies in just 90 days. The series will include seven stories, each about different animals. The Andersons hope to publish three more books this year and the remaining in 2012.

Each book features a teachable topic section to provide educational information about the characters, geography and history related to Henry's stories.

“We wanted to add more than just the story to make us different than other children’s books,” said Anderson. “Henry always asked a lot of questions so we put things like mnemonic devices, activities and character biographies to give children more information.”

Each story incorporates real-life children who are afflicted with a genetic diseases or medical circumstance. Through their attention to details and research, the Andersons have found many other children and causes to incorporate into the book series.

A boy named Timmy who lives on the East coast suffers from XLA and Crohn’s disease and was the inspiration for the first book. The Andersons worked with the Crohn’s and Colitis Foundation of America (CCFA), which has since been the recipient of direct donations. The goal, the Andersons said, “is to keep as much of the money going back to the cause.”

“When I was searching online to learn about what happened to Henry, Timmy’s story ultimately helped me discover the truth,” said Anderson. “One of the leading researchers of Crohn’s disease wrote an article that explains that children with immune deficiencies typically go on to develop Crohn’s. The article is featured at the back of the first book.”

Meanwhile, the Anderson’s surviving son, Jack, does have XLA and is currently being treated through an intravenous immunoglobulin (IVIG) infusion, which contains a pool of extracted plasma from more than 1,000 blood donors. He receives treatment every three to four weeks at Children’s Hospital in Milwaukee. Jack’s life-saving plasma is donated at plasma banks across the country such as the BioLife Plasma Services in Oshkosh.

“The plasma is filled with thousands of other people’s antibodies that give Jack resistance and help him fight bacterial infections,” said Anderson. “Without this treatment, Jack would meet the same fate as Henry.”

While the Andersons do the research and story generating, editing and project management for their self-started publishing company, they went back to their UW Oshkosh roots to find an art student who could illustrate the books.

Oshkosh native and current art major Sonja Funnell was a great fit, Anderson said. She illustrated “Timmy the Goat” and is currently working on the next two books in the series.

Additional books include stories about a camel, frog, wolf, snake and turtle. A book scheduled to be released later this year will honor Charlie Knuth, a 4-year-old boy from Darboy, Wis. who suffers from a genetic disorder called Epidermolysis Bullosa, which causes painful open sores on soft tissues inside and outside the body.

Future plans include partnering with larger retailer programs to sell the books throughout the country.

Beyond getting their children’s books out there, the Andersons have made it their mission to use the death of their son to educate others about the XLA disorder and the importance of blood screening.

“Since losing Henry, I have learned to take it one day at a time,” said Anderson. “I miss Henry an awful

lot and am sad that he could've been saved with a screening test.”

Darrin Anderson received a master's degree in business administration from UW Oshkosh and currently works in IT consulting and project management. Sarah Anderson stays home with 3-year-old Jack and was previously employed at the Office of Graduate Studies on the UW Oshkosh campus.

For more information or to support The Adventures of Henry series, please visit www.facebook.com/pages/Adventures-of-Henry/176270505740177. Books from The Adventures of Henry series can be purchased online by visiting www.adventuresofhenry.com. Local organizations and bookstores also carry the series.

Read more:

- [Sports talk: UWO alumnus anchors Sports Central](#)
- [Batter up! UWO alumna diversifies MLB](#)