



Sixteen years ago, Kelleigh Gustafson was diagnosed with massive arteriovenous malformations (AVM), a rare inoperable and life threatening defect with no known cure.

What is an AVM? Normally, arteries carry blood with oxygen under high pressure from the brain and the body. When an AVM occurs, the capillaries are missing and the arteries connect directly to the veins causing the blood to flow very fast through these large vessels and raising the blood pressure in the vein. AVMs patients endure swelling and pain, hemorrhaging, headaches and other neurological symptoms, and potential heart failure.

Kelleigh's AVMs affect the major blood vessels on the right side of her head, neck, and airway. She's undergone over 70 operations and suffered innumerable complications from the defect. However, rather than being discouraged, Kelleigh decided to use her condition as an opportunity to educate the public about AVMs and raise money to advance AVM research through her charity Kelleigh's Cause.

To date, Kelleigh's Cause has raised over \$150,000 and 100 percent of it has put toward research at the Children's Hospital of Wisconsin, including recently hiring the inaugural Kelleigh Gustafson Research Fellow. This fellow works under the direction of Ramani Ramchandran, PhD, Professor of Pediatrics and the Patrick J. and Margaret G. McMahon Professor of Obstetrics and Gynecology, and Patricia E. Burrows, MD, Professor of Radiology at MCW and Interventional Radiologist at Children's Hospital of Wisconsin.

Dr. Ramchandran and his team, in collaboration with Dr. Burrows, are conducting AVM research using zebrafish. Zebrafish share the same genes that humans have, and their blood vessels are easier to access thereby making them a suitable model for AVM studies. The ultimate goal of the research is to find a treatment for people with AVMs. They are currently identifying biomarkers for AVMs that will hopefully correlate genetic defects with types of AVM – a task that will help physicians more easily determine what type of AVM a patient has.

In addition, Kelleigh's Cause has worked with state government representatives to declare AVM Awareness Weeks each July in New York, Michigan, Wisconsin and Colorado, and is currently working with other AVM advocacy groups. Kelleigh's Cause raises money through fundraising events such as run/walks, including The Color Run, and school dress-down days, sales of bracelets and tee-shirts as well as individual donors. Donate to Kelleigh's Cause here: www.kelleigh.org.