



Amy Robasse & Savannah Fleeman
Arthritis Walk Honorees
Cedar Rapids, IA

Dual honorees, mother and daughter Amy and Savannah both have been diagnosed with Ehlers-Danlos Syndrome (EDS). Amy was diagnosed in 2010 just five years after her daughter's diagnosis. EDS is a genetic condition that affects the connective tissue in the body. Common symptoms include joint hypermobility, loose/unstable joints that are prone to frequent dislocations, joint pain, hyper-extensible joints (joints move beyond their normal range), early onset of osteoarthritis, soft velvety like skin, fragile skin that tears or bruises easily (bruising can be severe), severe scarring, slow/poor wound healing, and the development of molluscoid pseudotumors (fleshy lesions associated with scars over pressure areas).

Amy had been forewarned that she almost certainly had EDS. Concerned that an official diagnosis could cause havoc with her healthcare coverage, she put off visiting a geneticist until her knee pain became severe. Amy knew that being labeled with a pre-existing condition would be disastrous if she ever lost her healthcare insurance.

One of the first things Amy did after getting her EDS diagnosis was pay a visit to the occupational therapy department for ring splints. The rings were made by the Silver Ring Splint Company <http://www.silverringsplint.com>. The ring splints help provide stability to the fingers, akin to what a brace does for a weak wrist. The splints have reduced the pain in Amy's hands and prevent her fingers from fatiguing so quickly.

Amy knew her diagnosis of EDS would mean a career change. At the time of her diagnosis Amy was a para-educator with special needs children. After consulting with her doctors, and doing some research she decided to go back to college and get a degree in something that would allow her to move on in her career, despite having EDS. With the help of Iowa Vocational Rehabilitation, she is halfway towards meeting that goal.

Amy's daughter, Savannah seemed to be a typical baby and toddler. She loved to play with her friends and attend preschool. She was always happy, always smiling. She fell down often, and seemed really clumsy, but it didn't alarm her family. She was also plagued with bruising and slow wound healing, but her family still had no major worries. It wasn't until her kindergarten teacher called with concerns about

Savannah's fine motor skills that the family realized there was more wrong than they initially thought. For the first time her mom was really scared.

Savannah was referred to the Pediatric Genetics Clinic at the University of Iowa Hospital. It was here that she received her diagnosis of EDS. There are six different types of EDS and Savannah suffers from the Hypermobility type.

Because Savannah was diagnosed at the tender age of just five years old, necessary precautions were taken to avoid activities like gymnastics and contact sports which are too dangerous for someone with EDS. Instead, Savannah has developed a love of reading, writing, singing and drama. She credits her close spiritual relationship with God as her reason for being able to cope with the challenges of EDS. Savannah feels blessed to have a wonderful team of doctors at the University of Iowa, including her geneticist, Dr. Pamela Trapane, and her pediatrician/sports medicine doctor, Dr. George Phillips. They have played an integral role in keeping Savannah healthy; and teaching her what to do to prevent joint damage that could plague her later in life. An energetic pre-teen, Savannah has become a passionate advocate who continues to educate others about Ehlers-Danlos Syndrome. This year's Arthritis Walk will be the fifth for Savannah, and her mom!

The strength, bravery and determination displayed by Amy and her daughter Savannah makes the Arthritis Foundation proud to honor them both as the Cedar Rapids, Iowa 2013 Arthritis Walk Honorees.

About the Arthritis Foundation

The Arthritis Foundation (www.arthritis.org) is committed to raising awareness and reducing the unacceptable impact of arthritis, which strikes one in every five adults and 300,000 children, and is the nation's leading cause of disability. To conquer this painful, debilitating disease, we support education, research, advocacy and other vital programs and services.