

FOR IMMEDIATE RELEASE,

A Twist of Fate-ATS appoints April 7th as International ATS Awareness Day

Richfield, Wisconsin—April 7, 2018—Join patients, families, researchers, physicians and other stakeholders around the world looking to make a difference for those with a rare disease, arterial tortuosity syndrome (ATS) on April 7th.

There are estimated over 100 people around the globe who have arterial tortuosity syndrome, which is known for causing the mid to large sized blood vessels throughout the body to kink and twist. However, we know there are many more patients and carriers of the SLC2A10 gene mutation, but because of lack of education and awareness we have not found them yet. ATS effects the entire body. Some patients may have severe hypermobility (loose joints), hernias, vision impairment, aneurysms, heart attacks and strokes. This syndrome effects mostly children and young adults with the median age only 9 years old and is often misdiagnosed with ehlers danlos syndrome, marfans syndrome, loeys-dietz syndrome and other connective tissue disorders that can cause mild tortuosity.

My daughter Maggie is 7 years old. She has arterial tortuosity syndrome (ATS). Maggie is the sweetest, bravest child. Maggie has to have frequent doctor appointments because ATS affects almost every system in her body. We have many specialists at Children's Hospital of Wisconsin. There is so much we need to learn about ATS. It is a very complex disease.

To spread awareness regarding ATS, Governor Scott Walker made a proclamation to make April 7th Arterial Tortuosity Awareness Day.

Let's wear purple or an A Twist of Fate t-shirt on April 7th to recognize Arterial Tortuosity Awareness Day.

The worldwide event is organized by patients and families with ATS, along with Andrea Taylor, President/Founder of A Twist of Fate-ATS, the only nonprofit/patient group in the world for arterial tortuosity syndrome. Our goal is to bring awareness and education to the community about this rare disorder and to aid in better diagnosis, treatment plans, and to help those with ATS to more hope for a brighter future. ATS is one of over 7,000 different rare diseases and part of the 95 percent that does not have a cure.

Please visit our website to learn more about arterial tortuosity syndrome and the patients it effects

At: www.atwistoffate-ats.com

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where Relation to the connective-tissue disorder that is known for causing the arteries throughout the body to grow too long, causing abnormal kinking and twisting of the mid- and large-sized vessels; and

whtereas ATS causes an increased risk for heart attacks, strokes, aneurisms, and affects daily life; and

 $\psi \nu f E \chi E \chi S$; ATS is a life-threatening disorder that affects mostly children and young adults, and there is no known cure; and

worldwide observance of ATS day on Saturday, April 7, 2018; and worldwide observance of ATS day on Saturday, April 7, 2018; and white REAS, promoting awareness of the disease helps in funding research, improving

diagnosis, finding a cure, but, most importantly, giving hope;

NOW, THEREFORE, I, Scott Walker, Governor of the State of Wisconsin,
do hereby proclaim Saturday, April 7, 2018 as

ARTERIAL TORTUOSITY SYNDROME AWARENESS DAY

throughout the State of Wisconsin and I commend this observance to all of our citizens.



IN TESTIMONY WHEREOF, I have bereunto set my hand and caused the Great Seal of the State of Wisconsin to be affixed. Done at the Capitol in the City of Madison this 8th day of March 2018.

SCOTT WALKER GOVERNOR