

Williams Syndrome Association
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MEDIA ADVISORY

#Walk4Williams: Residents Help Raise Awareness of Williams Syndrome!

Individuals with Williams syndrome (WS) have extraordinary gifts and unique challenges. But not enough people know that. During a full month of activities in May, volunteers for the Williams Syndrome Association are working to inform our community and others across the country about Williams syndrome.

As part of the WS Awareness Month, *Walks for Williams* and other special events will take place in locations throughout the country. More than 10,000 people are expected to participate nationwide. Locally, a walk will be held at Walden Grove High School in Sahuarita on May 21 at 9:00am. Brandon and Carley Neilson are organizing the local walk. They will be joined by local volunteers from across the Tucson area to help "spread the word" about Williams syndrome and raise critical funding for research and scholarship programs. In addition to the Walk, activities at the event will include a silent auction, carnival games, music, and a picnic on the Walden Grove Football field.

Featured on 20/20, MSNBC, and an episode of the television show *Chicago Med*, Williams syndrome is a genetic condition that is present at birth and can affect anyone. It is characterized by medical problems, including cardiovascular disease, developmental delays, and learning disabilities. These occur side by side with striking verbal abilities, highly social personalities and an affinity for music. Williams syndrome affects 1 in 10,000 people worldwide – an estimated 20,000 to 30,000 people in the United States. Unfortunately, many of these individuals are undiagnosed or misdiagnosed. Proper diagnosis is critical to acquiring the medical, therapeutic and educational treatments and strategies that dramatically improve the life of an individual with Williams syndrome.

Children with Williams need costly and ongoing medical care, and early interventions from speech, occupational and physical therapists that may not be covered by insurance or state funding. As they grow, children struggle with things like spatial relations, numbers and abstract reasoning, which can make daily tasks a challenge.

The Williams Syndrome Association is the most comprehensive resource for people and families living with Williams syndrome as well as doctors, researchers and educators. The WSA provides resources, support and the latest medical information to help children with WS today and throughout their lives. Awareness month activities will help fund the Williams Syndrome Association's research, medical emergency and scholarship funds. The medical fund provides financial support directly to families for expenses associated with costly medical procedures for their children. Scholarships are provided for summer enrichment, post-secondary and transition programs as well as grants to educational conferences and conventions.

Local residents are encouraged to come out and support families affected by Williams syndrome and the WSA. If you would like more information about this event, please contact: Brandon Neilson at 520-262-9486. For more information about Williams syndrome, visit Williams-syndrome.org.

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