



**williams**syndrome  
ASSOCIATION

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**Nationwide Clinical Consortium and Comprehensive Research Network  
for Williams Syndrome Established**

*Establishment of Consortium Expected to Accelerate Research  
and Quality of Life for individuals with Williams syndrome*

**Troy, MI** - The Williams Syndrome Association, Inc. (WSA) today announced the creation of a nationwide consortium and comprehensive research network to support individuals with Williams syndrome, a rare genetic condition affecting nearly 30,000 people in the U.S. which occurs spontaneously when approximately 26 genes are deleted from chromosome 7. Private donors Judy and Mike Van Handel of Mequon, WI and Indian Wells, CA presented the WSA with a \$450,000 gift to establish the consortium.

The Williams Syndrome Association, a national non-profit based in Troy, MI, is the leading source for educational and medical expertise for families and medical professionals. The newly established consortium will describe best practices to standardize and improve clinical care worldwide and create a collaborative natural history database and virtual biobank. The database will provide a foundation for clinical trials, along with the research network, the consortium plans to incentivize new researchers to join the field, with the goal of identifying novel treatments for key issues including cardiovascular disease and anxiety - some of the top medical issues of the individuals.

“We are excited to contribute to this especially important project. Our WSA community is at a key point to bring the current researchers together and develop excitement for studying Williams syndrome among new investigators,” noted Judy Van Handel. “We hope our gift will inspire others to make gifts to build on research opportunities.”

The initial phase is to create a medical survey fielded to all new patients seen at the nine Williams syndrome clinics across the country, focusing on collecting data on cardiovascular, gastrointestinal and neurodevelopment topics. That data will later be used to assist medical providers around the country with best practices, helping children who may have limited access to specialty healthcare due to geographic or economic constraints.

“The WSA is thrilled to initiate this major clinical and research initiative for Williams syndrome. It is estimated that nearly one-third of all individuals are undiagnosed, misdiagnosed or diagnosed later in life,” said WSA Executive Director Terry Monkaba. “The support of the Van Handel family to create this initiative will brighten the future for people with Williams syndrome.”

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**About:** The Williams Syndrome Association (WSA) is the most comprehensive resource organization for Williams syndrome in the United States. The WSA advances the interests of all individuals with Williams syndrome throughout their lifespan with a vision to ensure they have the support needed to live a healthy, self-directed, productive and meaningful life. For more information, visit: [www.williams-syndrome.org](http://www.williams-syndrome.org)