

JOINT STATEMENT FOR RELEASE AT 10 AM EASTERN TIME, MAY 12, 2016

Tuberous Sclerosis Canada Sclérose Tubéreuse and Tuberous Sclerosis Alliance Announce Formal Partnership

In celebration of TSC Global Awareness Day, Tuberous Sclerosis Canada Sclérose Tubéreuse (TS Canada ST) and the Tuberous Sclerosis Alliance (TS Alliance) are proud to announce they have joined in a partnership that will enhance community support, clinical care and research efforts in North America.

TS Canada ST Co-Chairs Karen Shulist and Cathy Evanochko believe the partnership presents a wonderful opportunity for their organization. “We see the benefits of working with the TS Alliance on future projects and are thrilled to participate in its Global Alliance program,” Evanochko said. “Patients and families around the world are dealing with similar medical issues, so this affiliation allows the organizations to work in concert to improve outcomes for those living with TSC.”

TS Canada ST will become a Global Alliance Partner of the TS Alliance. Officially launched in 2014 with the TS Alliance of Israel, the Global Alliance program fosters stronger links between the TS Alliance, communities and individuals around the world. A Global Alliance is a structured group of empowered and caring volunteers who work closely with the TS Alliance to facilitate local connections for individuals and families affected by TSC, raise revenue and increase awareness while supporting the mission of their organization.

“Our partnership with the TS Alliance provided us with a much-needed jump start. Their support, through the Global Alliance program, has helped us to organize, increase awareness, and empower all of us coping with the impact of tuberous sclerosis complex,” said Dan Bloom, Chairman of the TS Alliance of Israel. “Now, with the addition of Canada as a partner, we can all work together, more efficiently and effectively, as members of a global community.”

The TS Alliance will provide a variety of services to TS Canada ST to build on their exceptional reputation of constituent support, ranging from educational conferences to global clinical trials education and recruitment to designation of TSC Clinics to helping identify and serve a wider constituency. TS Canada ST will also have one ex-officio position on the TS Alliance Board of Directors.

“We are absolutely thrilled to partner with TS Canada ST,” said TS Alliance President and CEO Kari Luther Rosbeck. “It’s a natural fit for us to help them with their advocacy and support services and to offer them our experience with special events and awareness-building activities.”

TS Canada ST is a voluntary, non-profit, charitable organization dedicated to the principles of raising public awareness of tuberous sclerosis complex, encouraging mutual support between individuals with TSC and their families, and promoting research and education. Established in 1990, TS Canada ST provides awareness and support for individuals with TSC and their families.

The TS Alliance is the only US-based national organization dedicated to finding a cure for tuberous sclerosis complex, while improving the lives of those affected. Founded in 1974, it works to improve quality of life for individuals and families affected by TSC by stimulating and sponsoring research; creating programs, support services and resource information; and developing and implementing public and professional education programs designed to heighten awareness of TSC.

On May 15, the two organizations kick off the partnership to mark TSC Global Awareness Day with fundraising walks – LIDS Step Forward to Cure TSC in the United States and Wild for a Cure in Canada.