



Understanding Tuberous Sclerosis Complex, A Challenging Lifelong Condition

(NAPSA)—Tuberous Sclerosis Complex Awareness Month is a time to educate those unfamiliar with the rare genetic disorder, tuberous sclerosis complex. To promote understanding, Dr. Steven Roberds, the Chief Scientific Officer at the Tuberous Sclerosis (TS) Alliance, a patient advocacy group, provides answers to some common questions about this lifelong condition.

Q: What is Tuberous Sclerosis Complex?

A: Tuberous sclerosis complex—or TSC—is a multisystem disorder that causes tumors to form in vital organs, including the kidney, brain, lungs, heart, eyes and skin. Although non-cancerous, these tumors may lead to severe complications and even death.

TSC is a genetic disease affecting approximately 25,000 to 40,000 people in the U.S., and many individuals with TSC show evidence in the first year of life. However, since the severity of the manifestations, such as seizures, skin lesions, brain tumors and kidney tumors, can vary from person to person, and may take years to develop, some individuals are not diagnosed until later in life. Due to the multiple and sometimes unpredictable challenges that living with TSC can present for the people with this

condition and their family, it can significantly impact the quality of life for all those touched by the disease.

Q: Does everyone with TSC experience the same symptoms? When do the symptoms typically occur?

A: Individuals with TSC usually develop different manifestations at certain ages, and not everyone with TSC experiences the same set of symptoms. For example, skin lesions, which affect more than 90 percent of individuals with TSC, may develop during infancy and become more prevalent with age. Children may also develop non-cancerous brain tumors called subependymal giant cell astrocytomas, or SEGAs, which occur in up to 20 percent of people with TSC. Often times, children with TSC may experience seizures, and some are diagnosed with neurological disorders such as autism. Non-cancerous kidney tumors, also known as renal angiomyolipomas, occur in up to 80 percent of individuals with TSC, and are typically first identified in teenagers or during adulthood.

Q: How can people with TSC manage their condition?

A: Due to advances in research, doctors now have a deeper understanding of TSC and more resources are available to help people with TSC better manage the disease. Individuals with TSC

need to be regularly monitored by a physician, preferably one who is experienced with the disorder and who can coordinate comprehensive care with other specialists, to receive proper treatment. As TSC can affect many different parts of the body, several doctors with different medical specialties may take part in caring for someone with TSC over the course of their life. Long-term follow-up care, including the monitoring of tumor growth, is important.

Q: Are there resources available for people living with TSC? How can I provide support to the TSC community?

A: Having access to support services is vital to families affected by TSC, as living with TSC can take an emotional toll on both individuals with TSC and their caregivers. For some, the disease may even lead to depression and anxiety. The TS Alliance provides a full-time advocate available by telephone and e-mail and a comprehensive website with free publications, videos and recordings designed to educate and offer support. The TS Alliance also supports 32 volunteer-run branches across the country called Community Alliances to help those who are faced with the challenges of TSC by offering experience, knowledge and support. Online social networks dedicated to TSC are sponsored by the TS Alliance to connect those affected by TSC regardless of where they live.



Dr. Roberds

Like the TS Alliance, Novartis is dedicated to raising awareness of TSC. Novartis is committed to understanding and improving the lives of people with tuberous sclerosis complex through clinical research, education and collaboration with the TSC community. In 2011, Novartis Pharmaceuticals Corporation was first recognized by the National Organization for Rare Disorders for the company's research in the area of tuberous sclerosis. Learn more about tuberous sclerosis from the TS Alliance at www.tsalliance.org and from Novartis at www.FacingTSC.com. The TS Alliance and its website are independently operated and not managed by Novartis Pharmaceuticals Corporation, which assumes no responsibility for any information they may provide.