

About the Tuberous Sclerosis Clinic

What Makes Us Unique?

Expert Care for a Rare Disorder

The TS Clinic at Cincinnati Children's is one of the world's largest centers for treating this complex and misunderstood disorder. We care for nearly 820 children and adults, who come to us from across the nation and around the world.

Treating the Whole Person

Because TS affects so many of the body's systems, our program draws on the expertise of specialists, who see both kids and adults, from a variety of disciplines within our medical center. These specialists work together to provide a holistic approach to your or your child's care. And it makes care more convenient – you or your child can often be seen by multiple specialists on the same day.

Family-Centered Care

We realize that any disorder affects the entire family. Our family-centered care approach includes your family in our care plan. In addition to providing exceptional physical care for you or your child, we also tend to the emotional needs of our patients and their families.

Leading Research Means Advanced Treatments

As a major center for research into TS, we incorporate the latest scientific findings into our care. We were the first clinic in the nation to offer clinical trials of new treatments for TS, and we continue to offer highly promising and successful treatments to our patients.

We collaborate with other TS centers around the nation. This collaboration helps us rapidly adopt advances and evidence-based practices in the care of TS and enables us to better understand the broad range of issues that patients with TS face.

For appointments, referrals or general information about the Tuberous Sclerosis Clinic, contact:

Chris Backscheider
Tuberous Sclerosis Clinic Coordinator
Phone: 513-636-4222
Toll Free: 1-800-344-2462, ext. 4222
Email: tsclinic@cchmc.org

Tuberous Sclerosis Clinic at Cincinnati Children's



3333 Burnet Avenue, Cincinnati, Ohio 45229
www.cincinnatichildrens.org/tsc



Learning that you or your child has tuberous sclerosis (TS) can be overwhelming. But you've come to the right place. Regardless of the age of a patient, we can help. Our Tuberous Sclerosis Clinic is one of the nation's leading centers for identifying and treating this complex disorder.



What to Expect for Your Clinic Visit

Your first visit to the Tuberous Sclerosis (TS) Clinic will be more involved than a typical visit to your child's pediatrician or to your doctor. A visit here involves evaluation and treatment planning with the neurologist or neurology nurse practitioner, who see both children and adults with TS. You or your child may also see specialists from other areas, depending on your needs.

To ensure we can provide the best care, be sure your or your child's doctor sends us a medical history before the first visit.

Clinical Specialists

We take care of the families we see in clinic. All members of our multidisciplinary team are involved in each patient's care, no matter who you or your child sees at your appointment.

Your primary contact for information and appointments will be your TS Clinic coordinator but, because of our multidisciplinary approach, each appointment is tailored to the patient's needs. A patient may see a variety of specialists, including those in:

- Cardiology
- Dentistry
- Genetics
- Nephrology
- Neurology
- Neurosurgery
- Ophthalmology
- Psychiatry
- Pulmonology

Testing

Care team members may order tests or procedures during a visit to the TS Clinic, including:

- Blood tests
- Genetic tests
- Advanced neuroimaging
- Interventional radiology
- Embolization
- Renal ultrasound
- Pulmonary function tests
- Electroencephalogram (EEG)
- Electrocardiogram (EKG)
- Magnetic resonance imaging (MRI)
- Chest computed tomography (CT) scan

If you or your child has had testing, it is important to send those results to us ahead of your appointment so that we may avoid duplication of tests. Other testing may be recommended to help care team members better understand your specific needs. These tests may be scheduled to happen after a clinic visit.

Follow-Up Visits

After the initial appointment, TS Clinic specialists will request follow-up visits to address specific medical issues, such as seizures and behavioral problems. Follow-up visits provide ongoing management of medical, neurological and psychological problems for children and adults.

Resources for Families

The TS Clinic has a social worker on staff who will assist patients and families with supportive counseling, advocacy for resources and problem solving. For more information, contact:

Linda Wallace, MSW, LISW-S
513-636-9096
linda.wallace@cchmc.org

Cincinnati Children's has other resources to help you or your family:

- The [Family Resource Center](#) offers families more information and provides laptops and reading materials.
- [Guest Services](#) provides out-of-town families with travel and lodging assistance.
- [TS Summer Camp](#) gives children with TS the opportunity to form friendships and gain confidence.

Help Us with Tuberous Sclerosis Research

The Tuberous Sclerosis Clinic at Cincinnati Children's is active in many research studies aimed at improving care for children and adults with tuberous sclerosis, including those to:

- Treat tumors in the brain, kidneys and lungs
- Investigate the use of medications to treat seizures, behavioral problems and cognitive impairments associated with TS
- Better understand how TS develops in individuals with genetic mutations
- Provide improved diagnostic tools and treatment approaches for TS

But, we cannot conduct research on our own. We need your help to continue our research and change the outcome for those with TS, both now and in the future.

What You Should Know About Participating in Research

What is Research?

Research (sometimes referred to as a "research study", "medical research", "clinical research study" or "clinical trial") is a carefully planned test to learn more about health, diseases, medicines and new treatments.

Why Does Cincinnati Children's Conduct Research?

Cincinnati Children's is involved in research because it is very important to understanding conditions and diseases, like TS, and developing new ways to prevent and treat health problems in children and adults.

Why Participate in Research?

Participation in research may lead to knowledge that could benefit you, your child and others. Depending upon the research, participants may learn new information about their condition(s).

Research may also help determine things like correct dosage, medication safety, how well medicine works and side effects.

What Should I Know about Research Participation?

Deciding whether or not to participate in research, or to let your child participate in research, is an important decision. We appreciate your interest and encourage you to ask questions about participation or current research studies being conducted at Cincinnati Children's.

Who Conducts TS Research?

Clinical research for the TS Clinic is led by David Franz, MD; Darcy Krueger, MD, PhD; and Francis X. McCormack, MD, in close collaboration with researchers in many departments at Cincinnati Children's, the University of Cincinnati College of Medicine, and around the world.

Who Do I Contact for More Information about TS Research Studies?

For information about TS specific research studies, please contact:
TSC Research Coordinators
513-636-9669
TSCResearch@cchmc.org

To see a current list of all research studies being conducted at Cincinnati Children's, please visit our web site at www.cincinnatichildrens.org/clinical-studies.