

# Welcome to the UHN Adult Tuberous Sclerosis Complex Clinic

## For people who want to learn more about Tuberous Sclerosis Complex (TSC)

Read this brochure to learn more about:

- How the UHN Adult Tuberous Sclerosis Complex Clinic can help you
- How you can get a referral
- What to expect at your appointment



## **What is Tuberous Sclerosis Complex?**

Tuberous Sclerosis Complex (TSC) is a rare genetic disease. It is caused by harmful changes (mutations) in the TSC1 and TSC2 genes. People with TSC have a higher chance of developing benign (non-cancerous) tumours.

These tumours can be in different parts of the body such as:

- brain
- kidneys
- heart
- eyes
- lungs
- skin

These benign tumours can cause different symptoms. Each person with TSC can have different health needs.

Find out more about TSC online at <https://www.tscanada.ca>.

## **Who can visit the UHN Adult TSC Clinic?**

- People diagnosed with TSC
- People with signs of TSC who need to have more tests
- People with a family member known to have TSC

## **How can the UHN Adult TSC Clinic help me?**

Our team can examine you to see if you have TSC.

Once you are a patient of the UHN TSC Clinic, you can expect:

- ✓ regular check-ups by our team of specialists including a family doctor, medical geneticist and genetic counsellor
- ✓ help managing the disease
- ✓ help scheduling tests and screenings, when needed
- ✓ referrals to other specialists you may need such as nephrology, neurology, respirology, dermatology and ophthalmology

The number of times you visit the clinic will depend on your health needs.

## **How can I be referred to the UHN Adult TSC Clinic?**

Ask your family doctor or specialist to make a referral to the UHN Adult TSC Clinic:

60 Murray Street, Box 34

3rd floor, Room 400

Toronto, ON M5T 3L9

Phone: 416 586 4800 ext. 4220

Fax: 416 619 5523

## What do I need to know about my first appointment?

- Bring your OHIP card and any medical records (including imaging such as MRI or ultrasound reports/discs)
- Bring any medications you take
- If you can, bring medical history information about your family members
- Appointments take about 1 to 2 hours. You may meet with a genetic counsellor and a doctor.
- Even if you attend the TSC Clinic you still need your family doctor. Your family doctor will help you with health concerns not related to TSC. Other doctors who are specialists may also be part of your health care team.

Visit [www.uhnpatienteducation.ca](http://www.uhnpatienteducation.ca) for more health information.

Contact us to provide feedback or request this brochure in a different format, such as large print or electronic formats: [pfep@uhn.ca](mailto:pfep@uhn.ca)

---

© 2019 University Health Network. All rights reserved.

Use this material for your information only. It does not replace advice from your doctor or other health care professional. Do not use this information for diagnosis or treatment. Ask your health care provider for advice about a specific medical condition. You may print 1 copy of this brochure for non-commercial and personal use only.

Form: D-8795 | Author: Nicole Forster and Monika Madan | Created: 04/2019