

The Dalglish Family 22q Clinic

Information for patients and their families

This brochure will help you learn more about:

- What 22q (22q11.2 deletion syndrome) is
- Signs and symptoms of 22q
- How the Dalglish Family 22q Clinic can help
- Who to contact for more information



Welcome to the Dalglish Family 22q Clinic

The Dalglish Family 22q Clinic, originally known as the Dalglish Family Hearts and Minds Clinic, provides specialized care for adults with 22q11.2 deletion syndrome (“22q11.2DS” or “22q”).

Our staff includes health care experts from many specialties. Our Clinic at the Toronto General Hospital is the first adult 22q clinic of its kind in the world.

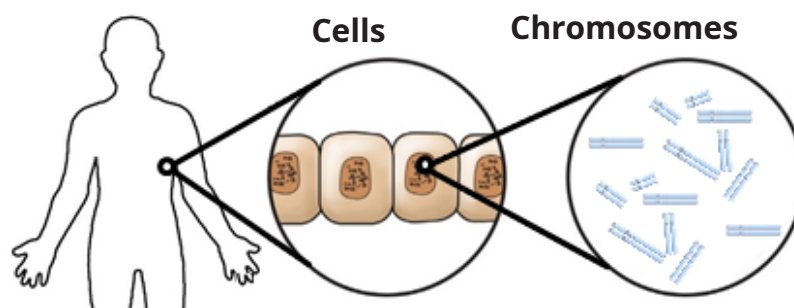
Our goal is to improve the quality of life for people with 22q and their families. Our world-leading research involves over 400 patients with 22q and their families.

What is 22q?

22q is a genetic condition that used to be known as DiGeorge syndrome or velo-cardio-facial syndrome. 22q affects 1 in 2148 newborn babies—more than cystic fibrosis. 22q can be associated with many health problems, some that may be present at birth and many that can appear later in life.

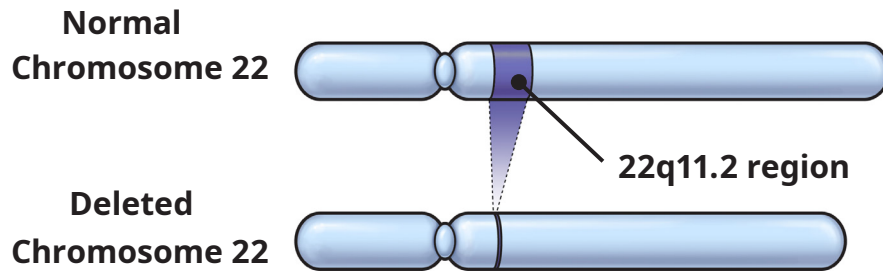
What causes 22q?

22q is caused by a missing piece (deletion) of genetic material (DNA).



DNA is found in all the cells inside a human body. Chromosomes are made up of DNA. Humans have 23 pairs of chromosomes in each cell. They are numbered from 1 to 22, plus 1 pair that determines whether we are male or female.

People with 22q are missing DNA from part of one chromosome 22 (the deletion chromosome). The other chromosome 22 does not have a piece missing.



Most often, the deletion that causes 22q is a **new** genetic change in the family. This means that for most people with 22q, their parents do not have the 22q deletion. But, anyone who does have 22q has a 50/50 chance of passing on the deletion at each pregnancy.

What are the signs and symptoms?

People with 22q may have many signs and symptoms. Some are mild while some can be more serious.

Sometimes, the symptoms can be noticed at birth or in young children. For example:

- Heart defects
- Palate not working or not formed normally
- Delayed speech
- Learning difficulties

As someone with 22q gets older, other health issues can become noticeable:

- Not enough calcium (can cause seizures if severe)
- Not enough, or too much, thyroid hormone
- Nervous system problems like seizures, epilepsy, or movement disorders
- Mental health problems like anxiety disorders or schizophrenia

People with 22q can have many health problems in different parts of the body. This sometimes makes 22q hard to diagnose. It is important to have a health care team who understands 22q. This specialized team can best care for patients who have the health problems caused by 22q.

What to expect at the Clinic

1. Excellent care

Our team of experts represent many health care professions. They work together to provide the best possible care. Our treatment plans are based on the most up-to-date research available. We focus on preventing illness and improving your well-being and quality of life.

2. Education

We teach health care providers, students at all levels, the public, patients and their loved ones about 22q and about how to provide or get the best care possible.

3. New treatments

We bring the newest treatments and most up-to-date research to our patients and their families.

4. New research

We are world leaders in research on 22q at our Clinic and in partnership with our patients and their families.

Our vision

Our goal is to be:

- Specialists in patient-centred care for adults with 22q and their families
- Leaders in education for patients, families, trainees and health care providers
- World-class researchers in 22q so we can improve care and patient outcomes

Who we are

We are world leaders in clinical care and research.
Our professional team provides many services for 22q.

In-house clinical and research staff

Dr. Anne Bassett, MD, FRCPC, Director
Dr. Maria R. Corral, MD, FRCPC, Consultant Psychiatrist
Lisa Palmer, BEd, MSW, RSW, Social Worker
Samantha D'Arcy, MHSc, RD, Registered Dietitian
Radhika Sivanandan, PhD, Patient Care Coordinator
Erik Boot, MD, PhD, Specialist in Intellectual Disability Medicine (Utrecht)
Joanne Loo, PhD, Education and Communication Officer
Tracy Heung, MClInPsych (Aus), Research Analyst
Joanne Ha, Research Assistant

Administrative

Dr. Susan Abbey, MD, FRCPC, Psychiatrist-in-Chief

We also provide training to students in medicine and allied health areas.

Consulting services

Our Clinic works closely with other specialties who are also involved in the care of our patients.

- ✓ Cardiology (heart medicine)
- ✓ Endocrinology (hormone medicine)
- ✓ Neurology (medicine specializing in the nervous system)
- ✓ Genetics and genetic counselling
- ✓ Neuropsychology (brain functions such as memory and attention)

Where are we located?

Toronto General Hospital

Norman Urquhart Building (NU) – 8th Floor, Room 802

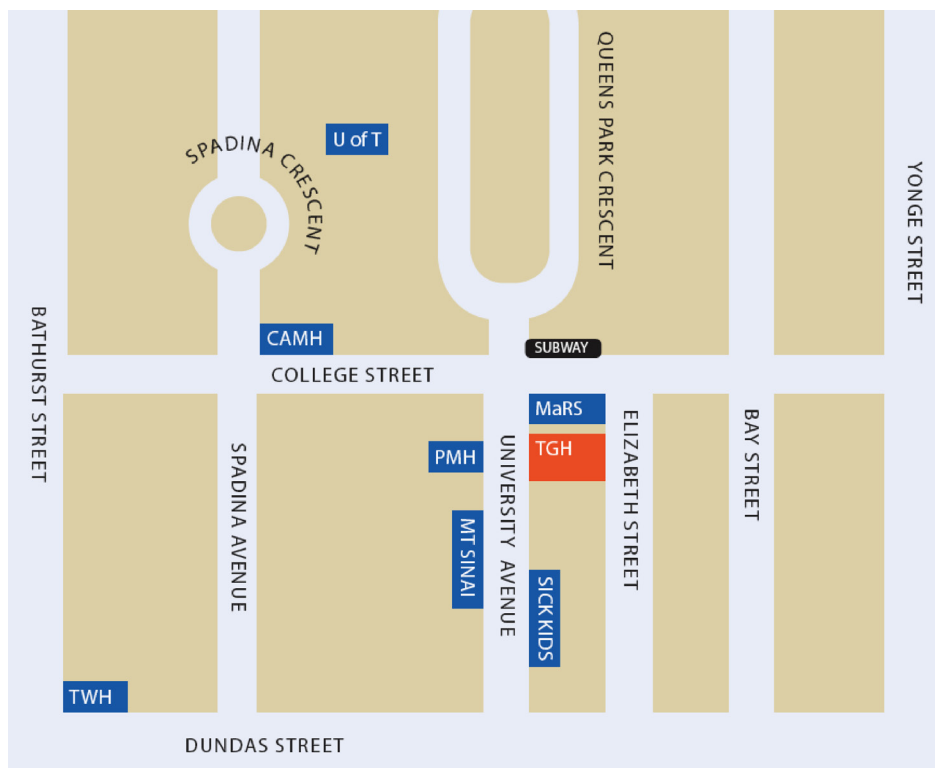
200 Elizabeth Street

Toronto, Ontario M5G 2C4

Phone: 416 340 5145

Fax: 416 340 5004

Website: www.22q.ca



How to find us

Parking near the Clinic is limited and can be expensive. If possible, use public transportation.

Public Transit (TTC)

Subway

- The closest subway station is Queen's Park, on the Yonge-University Line (Line 1). Enter the Toronto General Hospital at the University Avenue entrance.
- You can also take the Yonge-University Line to the College Subway Station. Walk west towards Elizabeth Street and south to the Elizabeth Street entrance of Toronto General Hospital.

Streetcar

- For the Elizabeth Street entrance of Toronto General Hospital, exit the College Streetcar at Elizabeth Street.
- For the University Avenue entrance of Toronto General Hospital, exit the College Streetcar at University Avenue.

Wheel-Trans

TTC provides door-to-door accessible transit service for people with physical disabilities.

Driving

Directions

- From the 401: Drive south on Avenue Road. Avenue Road becomes Queens Park Crescent West and then University Avenue south of the Legislative Assembly of Ontario (which is south of Bloor Street).
- From the Gardiner Expressway: Exit on York Street and travel northbound. York Street turns into University Avenue, if you stay in the left hand lane.

Please call if you need further assistance with directions (but not while driving).

Making appointments or referrals

We welcome referrals from health care professionals from across Ontario and elsewhere in Canada.

If you have any questions about your appointment, or if you need to cancel or change the date or time, please call the Clinic at 416 340 5145 and our Patient Care Coordinator will be happy to help you.

Visiting The Dalglish Family 22q Clinic

What to bring

- Ontario Health Card (OHIP card)
- All medications (including herbal, natural, supplements, over-the-counter) in their original bottles, packages, or blister packs
- List of doctors
- Forms or documents you need reviewed
- Report cards, IEPs
- Psychoeducational assessment

What to expect for your first visit

Your first appointment will take about 4 to 6 hours. You will have the chance to meet with our social worker, dietitian and doctor, who all specialize in 22q11.2DS. Our Patient Care Coordinator will call you ahead of time to explain this process. We try and make the visit as simple and convenient for you and your family as possible.

What to expect for your follow-up visit

Your follow-up visit will be shorter than your first visit, but this will depend on the type of appointment you have and which specialist(s) you are seeing. Plan for this visit to take about 1 to 2 hours.

Our team is dedicated to providing the most comprehensive and seamless care to patients, families and caregivers. We will do our best to plan your care with different specialties all in one visit (for example: psychiatry, cardiology, and endocrinology).

Contact us for more information

The Dalglish Family 22q Clinic

(Dalglish Family Hearts and Minds Clinic)

Toronto General Hospital
Norman Urquhart Building,
8NU (Room 802)
200 Elizabeth Street
Toronto, Ontario M5G 2C4
Phone: 416 340 5145
Fax: 416 340 5004



Website: www.22q.ca

Email: 22q@uhn.ca

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