

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
- 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, formerly 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.

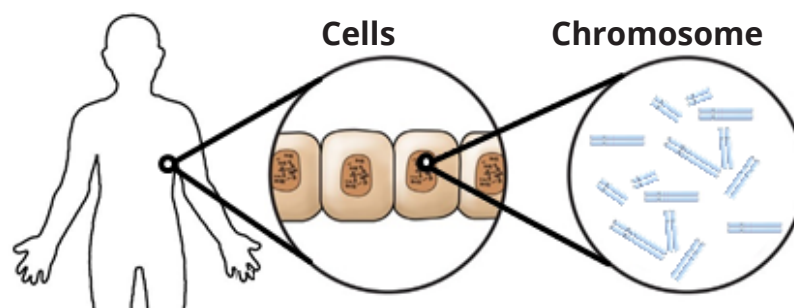
Our goal is to improve the quality of life for people with 22q and their families. Our world-leading research involves over 300 patients with 22q and their families.

What is 22q?

22q is a genetic condition that used to be known as velo-cardio-facial syndrome or DiGeorge syndrome. This condition can be associated with many health problems that may be present at birth or that appear later in life.

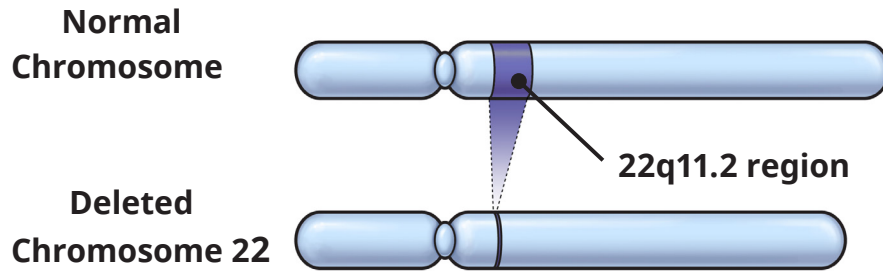
What causes 22q?

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 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 many people with 22q, their parents do not have the 22q deletion. But, anyone who does have 22q can pass it on to a child.

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:

- Birth defects of the heart
- Palate not working or not formed normally
- Trouble speaking or understanding language
- Trouble learning

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

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

People with 22q can have many health problems. This sometimes makes 22q hard to diagnose. It is important to have a health care team who understands and studies 22q. This specialized team can best care for patients who have the 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.

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 do cutting-edge research on 22q in our Clinic and through related programs.

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

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

Dr. Elemi J. Breetvelt, MD, PhD, Clinical Research Fellow

Lisa Palmer, BEd, MSW, RSW, Social Worker

Samantha D'Arcy, MHSc, RD, Registered Dietitian

Radhika Sivanandan, PhD, Patient Flow Coordinator

Erik Boot, MD, PhD, Specialist in Intellectual Disability Medicine (Utrecht)

Ania Fiksinski, MSc, Psychologist (Utrecht), PhD candidate

Joanne Loo, PhD, Patient and Family Educational Tool Developer | Website Manager

Tracy Heung, MClInPsych (Aus), Research Analyst

Administrative

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

Sandra Grgas, RRT, BA, M.HSM, Clinical Director

Mary Kay McCarthy, RN, M.HS, Senior Clinical Director

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

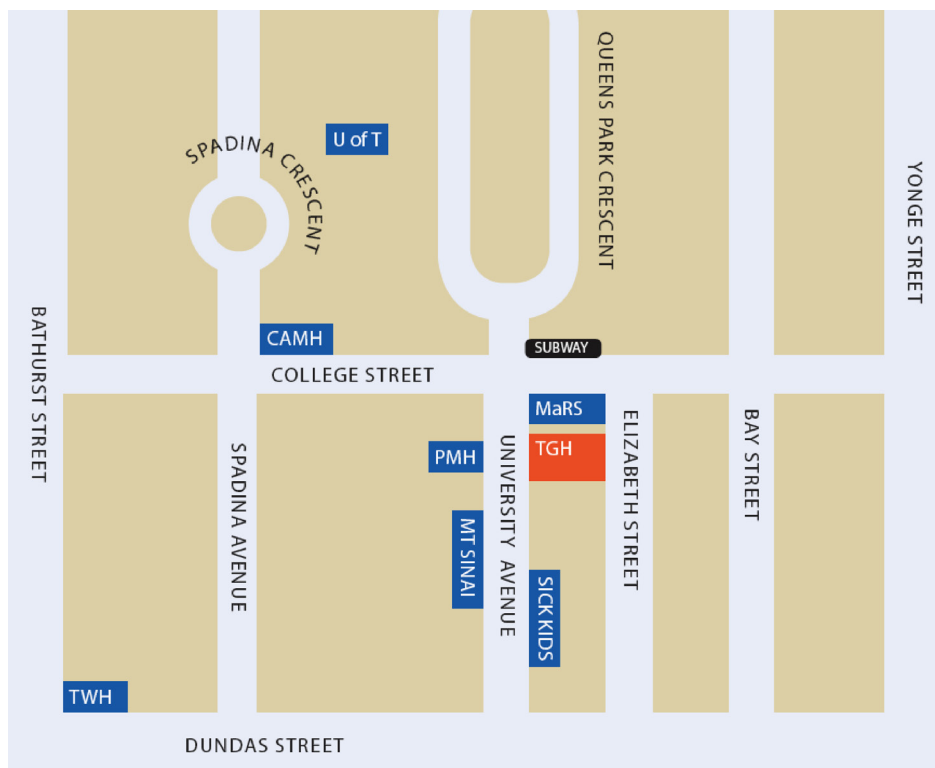
Consulting services

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 – 8NU (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 will take referrals from health care professionals from 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 Flow Coordinator will be happy to help you.

Visiting The Dalglish Family 22q Clinic

What to bring

- Ontario Health Card (OHIP)
- All medications you are currently taking, including herbal and over-the-counter remedies, puffers, lotions
- List of doctors, hospitals and past records
- Record of any changes to your condition
- Trusted friend or family member
- Questions for our team members

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 Flow 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

Toronto General Hospital
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8NU (Room 802)
200 Elizabeth Street
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Phone: 416 340 5145
Fax: 416 340 5004



Website: www.22q.ca

The Dalglish Family 22q Clinic

 Facebook:

www.facebook.com/DalglishFamily22qClinic

The Dalglish Family 22q Clinic was founded
by The W. Garfield Weston Foundation

Visit 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

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