



TORONTO GENERAL HOSPITAL  
Peter and Melanie Munk  
Patient & Family Learning  
Centre and Library Newsletter

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## An Inside Look at the Dalglish Family 22q Clinic



The Dalglish Family 22q Clinic, formerly known as the Dalglish Family Hearts and Minds Clinic, is the world's first multidisciplinary clinic providing specialized care to adults with 22q11.2 Deletion Syndrome ("22q") and their families. Located at the Toronto General Hospital, the team includes health care experts from many specialties, including psychiatry, cardiology, nutrition and social work.

### What is 22q?

22q is a genetic condition that has many features. It is a multisystem condition, which means it can affect every part of the body. People with 22q can have only a few or many features of the condition, with different degrees of severity.



### Quick Facts about 22q

- 22q is caused by a missing piece of genetic material on chromosome 22
- 22q affects multiple systems of the body; some features are present at birth and others develop later in life
- Adults with 22q have an average of 9 major health conditions

- Previous names for 22q include velocardiofacial syndrome or DiGeorge syndrome
- 22q is the most common microdeletion syndrome in humans
- There is a blood test to diagnose 22q

## How Common is 22q?

- Estimated to affect about one in every 3000 live births; 2,900-5,800 Ontarians
- More common than cystic fibrosis or Huntington's disease
- The second most common genetic cause of intellectual disabilities after Down syndrome
- About 1 in every 8 people with tetralogy of Fallot ("blue babies") have 22q
- About 1 in every 100 people with schizophrenia have 22q

## Some Common Features of 22q

- Birth defects such as congenital heart disease, palate abnormalities or scoliosis
- Psychiatric illnesses such as anxiety disorders (most common) or schizophrenia
- Learning difficulties (most common) or intellectual disabilities
- Endocrine conditions such as low calcium levels or thyroid disorders
- Neurological issues such as seizures, epilepsy or movement disorders

Many patients with 22q face years with multiple health problems without knowing the underlying genetic diagnosis. Their "diagnostic odyssey" is due to a lack of awareness about 22q in the healthcare community and in the general public.

Families often report a sense of relief once they have a diagnosis of 22q after years of wondering "**How can one person have so many things wrong with them?**" Once diagnosed, they have access to knowledge about 22q and its lifelong management, and to support systems.

## We Are World Leaders

- Our **multidisciplinary team** of experts in 22q uses a holistic approach to assessments and ongoing anticipatory care to assist patients, their families, and primary care and other clinicians. We also facilitate access to peer-support networks
- Ongoing **research** into 22q allows for evidence-based practice and is an integral part of care. Our team is the world leader in studies of adults with 22q.
- Our **Transition Clinic** for youths with 22q, maintains a close liaison with the 22q Clinic at SickKids, ensures continuity of care, and aims to prevent hospitalizations including those for severe psychiatric illness

On Nov 12<sup>th</sup> -13<sup>th</sup>, 2016 the 3<sup>rd</sup> Annual 22q11.2 Deletion Syndrome Family Conference will be held at SickKids Hospital. The Dalglish

Family 22q Clinic will be participating by presenting on various topics and facilitating workshops for parents, teens and adult population.

One patient reports...  
**“It’s almost lucky that I have (been diagnosed with) the syndrome, because I have so much support”.**

## Genetic Testing and Counselling

If you or someone you know has features of 22q, genetic testing with a simple blood test may be recommended. Talk to your doctor or a member of our Clinic staff.

## Learn More

Your support is greatly appreciated and can improve patient care, education and world class research.



For more information about the 22q Clinic, please visit our website at [www.22q.ca](http://www.22q.ca) or visit our Facebook page.



Connect with us on Facebook:  
[www.facebook.com/  
DalglishFamily22qClinic](http://www.facebook.com/DalglishFamily22qClinic)

## Food Drive for the Fort York Food Bank (FYFB)

UHN Patient and Family Libraries will be accepting donations of non-perishable food items for the Fort York Food Bank (FYFB) for the holiday season starting in November. Please drop off your items to the Patient & Family Learning Centre and Library by 4:00 pm on Wednesday, December 21<sup>st</sup>.



For more information about the FYFB, including what items they are most in need of at this time, visit: [www.fyfb.com](http://www.fyfb.com).

*We thank you for your support in advance!*

## Holiday Library Book Drive

Do you know of a book, video or CD that helped you learn more about your health condition, healthy living, or helped you to cope during a difficult time? Would you like to “give back” to our Library?

We will be putting together a Wish List of items that we think may be helpful for our patients, caregivers and UHN staff for those who would like to donate.

If you have recommendations for our Wish List, or want to purchase an item to donate to our Library, contact us to let us know!

# Peter and Melanie Munk Patient & Family Learning Centre and Library

at the Toronto General Hospital

## Contact us

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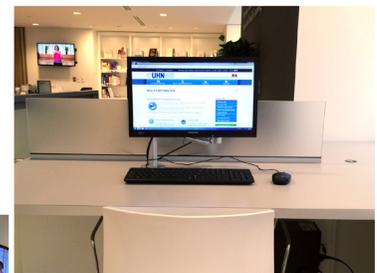
 Website: [www.uhnpatienteducation.ca](http://www.uhnpatienteducation.ca)

## Holiday Hours in the Patient Library

Dec. 19 to Dec. 22      8:30 AM – 4:30 PM

Dec. 23 to Jan. 2      CLOSED

We will re-open on Tuesday, January 3<sup>rd</sup> at 8:30 am and resume our normal hours.



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Please forward comments, questions or submissions to [tgpen@uhn.ca](mailto:tgpen@uhn.ca)

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