

Happy 10th Anniversary

22q & Friends

2022 Newsletter

Greetings from all of us at the Dalglish Family 22q Clinic!

Time sure flies – We are celebrating the 10th anniversary of our Clinic. Our official [opening was on December 11th, 2012](#) and we began to see patients in early spring 2013. Our team is privileged to have shared the past 10 years with all of you – through good times, complex challenges, and even a prolonged pandemic. We have enjoyed all of the anniversary messages you have sent (pages 3-7). We are honoured that you place your trust in us. Together we are advancing the understanding of our adults with 22q and how to maximize health and wellness.

The Dalglish Family 22q Clinic is a medical hub of expertise for patient care, education, and research. Its philosophy empowers patients and delivers care to patients and their families by a team of experts at one location devoted to adults with 22q11.2 deletion syndrome: a paradigm shifts with global impact!

Dr. Erwin Oechslin
Congenital Heart Disease Cardiologist

Our team continues to be world leaders, with experience caring for over 500 adults with 22q. We maintain our high quality of care to both patients in follow-up and those new to our Clinic by using the full range of in-person and “virtual” care options. We have also prioritized seeing as many of our new 22q patients, and their parents and caregivers, in person as possible. There is no substitute for that!

The Biennial International 22q11.2 Meeting in Split, Croatia, was a highlight of the year. I had a lead role organizing this event, and our staff, students, and trainees had prominent roles presenting their work at this international meeting (delayed from 2020 due to the pandemic). Other high-profile events during the year were also important in helping to raise awareness about 22q and our Clinic.

Enclosed in this newsletter you will find an update of our accomplishments as well as your messages. On behalf of the entire team at the Dalglish Family 22q Clinic, thank you for letting us be part of your journey.

Yours sincerely,

Dr. Anne S. Bassett
Clinic Director



Our Clinic Team

A big thank you to all of our patients and families - these past 10 years would not have been possible without you all! We are so lucky to get to know each and every one of you over the years. To all of our team members – we truly do have the best team of caring and knowledgeable professionals. Congratulations to our 22q family on this milestone!

Lisa Palmer
Social Worker

Thank you to all of our wonderful patients and family members! It has been a pleasure getting to know you all. I am so grateful to be a part of our incredible team members and our 22q Clinic. Congratulations to our 22q family on this amazing 10 years!

Radhika Sivanandan
Patient Care Coordinator

My team members' level of dedication is truly inspiring, and I have learned so much from them. I am also honoured to be a part of our patients and families' journey. Happy 10th anniversary!

Joanne Loo
Education and
Communication
Officer

Please see page 1 for Dr. Anne Bassett's message.

I consider working with the dedicated and caring group of professionals at the Dalglish Family 22q Clinic a privilege.

The opportunity to be involved in the care of our patients and families is a true honour.

Thank-you all for your dedication, trust and support and congratulations to the Clinic for a magnificent 10 years!

Dr. Maria Corral
Consultant
Psychiatrist



To all the patients and their families, I am forever grateful for all the data that you have gifted to our clinic. Trust us to continue to use it to make new discoveries that will benefit the 22q community. To all the staff, it's a pleasure to work with such a dedicated and intelligent group of individuals. Here's to another 10 years!

Tracy Heung
Research Analyst

What I cherish most are the wonderful relationships I share with our team members and our patients. I'm so happy to be part of this 22q family.

Samantha D'Arcy
Registered Dietitian

Another year has come around and I am honoured to be part of such a compassionate team of aces. Our efforts here at the Clinic would not be possible without the support from all our families that have joined in on our research pursuit. Warm welcome to you all that have joined our clinical and research family this past year.

Cheers to the upcoming holidays, stay warm!

Joanne Ha
Research Analyst

Note: The photo was taken in January of 2020. Now we wear masks in the hospital to keep you safe.



What Our Clinic Means to You

As we celebrate our 10-year anniversary, we asked for your thoughts. Thank you very much for all your responses. Your kindness has really touched our team, and we are very glad to be a part of your journey. Here are some excerpts from your many contributions. More complete excerpts are available at <https://22q.ca/aboutus/our-newsletter/>.

The Dalglish Family 22q Clinic truly cares about every aspect in the wellbeing of those involved and their families in this clinic. Never have I felt so supported and cared for physically, mentally and personally ...

My daughter ... is now 38 yrs old..so we are thankful every day for the help and knowledge that has been shared...

Between [her] tetralogy of fallot with pulmonary atresia to her many surgeries and all things 22q...we have appreciated all the help and wisdom shared ...

... Your insight and recommendations to improve the health and quality of life of my son and sharing the latest information on 22q is greatly appreciated ...

When we joined the Dalglish Family 22q Clinic, a few months ago, it was the first time in 18 years that we truly felt understood and supported. Now we don't feel so alone ...

What a caring and helpful team doing their best to explain what 22q is and to encourage us in the process!!

I am a mother of a daughter with 22q. The Dalglish Family Clinic has help us a lot. The clinic has Psychologists, Nutritionists, Social Workers, Researchers. They can recommend you if you need a specialist.

...The clinic has been a comforting place to find voices of understanding, regarding many aspects of life with 22q for our daughter and family. We appreciate their health care advice and guidance navigating obstacles, educating, giving hope, support, and connecting us with others through the years. Thank you.

you guys came into my life when I was 16 years old I was having trouble at school then I did the study with you guys and now I don't have trouble doing any kind of school work.

What Our Clinic Means to You (Continued)

... Quite frankly without the wonderful staff at the clinic we would be lost. Their knowledge of what our daughter is experiencing is spot on and so helpful while we navigate through our journey. While our challenges are big and ongoing, we know we can reach out to the fine people at the clinic at any time and will encounter people who understand and can provide the kind of support we are needing. Absolutely the best care, the best there is. We are so grateful.

... The multi-faceted approach and services provided at and through the clinic help all of us to improve our daily lives. Dr. Anne Bassett's leadership sets a tone of welcoming care, concern and support amongst all staff members. We look forward to visits in the clinic since we are made to feel that we belong and are part of the whole 22q family network ...

We, as caregivers of our son with 22q, are extremely grateful for the Dalglish Family 22q Clinic. We have found that all the staff at the clinic is responsive and caring. We have always been able to make an appointment in a timely manner to discuss issues related to 22q. We appreciate that the staff is up to date on the current 22q research and treats the whole person – mind, body and emotions ...

The Dalglish Family Clinic is a safe place to talk about issues and challenges and the staff at the clinic understand where you are coming from. We appreciate their support, expertise, and knowledge about 22q deletion syndrome.

... Knowing that I have a one-shop place to go to for all my son's needs is invaluable. The support and guidance the past ten years has been life-changing ...

My son is 34 yrs old today, we didn't know very much about the 22q. I would have loved so much to have had information to deal with all the symptoms he had. I thank you today to have a clinic who gives help to the patient and parents.

What a blessing it has been to find the Dalglish Family 22q Clinic! They have proved to become an integral and reliable source of knowledge and care for my daughter. Thank you so much!!

What Our Clinic Means to You (Continued)

... Thank you to Radhika, Lisa, Dr. Corral and the rest of the team - we are so thankful for all of you. You always take the time to listen to our concerns and provide thorough care. It is peace of mind knowing that our family can rely on specialized, professional, expert care as we navigate through this journey of life with 22q!

Not sure how long we have been visiting the clinic, but it has to be 10+ years. Our family's experience has been a very positive one; every time. All staff are extremely professional, knowledgeable, compassionate, friendly, and are always willing to assist when needed!! ...

... Our family was so thankful when you started this clinic. Our son loves the staff there. They helped us learn so much about 22q. We are able to help other people learn about 22q + physician. Our hearts go out to everyone there. Fantastic job.

I am grateful for the Clinic and the support it has given me. I don't know of another place I can reach out to when I have questions or concerns about my daughter's life. I feel less alone and more informed as a result ...

After the stress of getting a new diagnosis, it was such a relief to find the Dalglish clinic. We feel so fortunate to be able to get such expert care!

The clinic has provided information that we hadn't received before. It has been helpful to learn more, and well as hear about the research being done ...

...We know you are there to meet future needs. We appreciate the doctors and other specialists who specialize in caring for people with 22q and in [our granddaughter's] case her heart condition truncus arteriosus also.

Being the mother of an adult with 22q is the greatest task of my life. I felt alone until I met the great staff of the Dalglish Family 22q Clinic. Finally someone understood our daily challenges ...

Dr Bassetts expertise has helped us when our local PEI rural doctors could not. Teleconference connection is so valuable. We are happy to contribute to 22q research and publications.

What Our Clinic Means to You (Continued)

... Once my daughter turned 18, we moved to the Dalglish Clinic which has made the transition to a new hospital and clinic very easy and who have continued to provide the excellent care and support we received at Sick Kids.

... This clinic changed our family's life...we did not know what resources or tools were available before and thought we were the only family experiencing it. After years of misdiagnoses and delays in treatment, the clinic provides people with 22q deletion an opportunity to make friends, be social, participate in activities, and to feel part of a community ...

We would like to thank everyone at the Dalglish Family 22q Clinic for the amazing support we have received over the years. We have been blessed with the professionalism and commitment to excellent care for [name] ...

We are extremely thankful to the 22q clinic. They have been immensely helpful in helping our son and our family to better understand his illness and how to better deal with it ...

The Dalglish Family 22q Clinic has been most helpful to our family in understanding 22q Deletion Syndrome of which our sister was diagnosed when she was in her fifties. Without the Clinic sharing information and research, we would have been lost on how to help her ...

... How to acknowledge such an amazing team of Professionals...All of you are caring, knowledgeable in your perspective fields, determined to advise, suggest and guide us as we navigate this genetic syndrome. While keeping up with your research, meetings, travel....you are our heroes!

... I appreciate the experience of all the professionals involved and we continue to learn new information. It was great to attend the family/caregiver meetings and we learned from others making us feel that we weren't alone.

22q clinic has helped me by understanding and coping with my health and mental issues. The clinic has given me the sense of I am not alone. The friendliness, kindness, respect and the most important is understanding.

What Our Clinic Means to You (Continued)

... Without the Dalglish Center available to provide [our daughter], her family, and medical team with support, our family life would likely be in a mess and [she] would not be getting appropriate medical attention.

Not only did the Dalglish Center save one person with 22q11 from a harsh life but also all the people in her life.

... At the age of 49 I became a member of the 22q Dalglish Family Clinic. (now age 53) ... they collaborate with all my doctors involved, and provide them with their input, it sure makes the appointment less stressful. They also provide me with emotional and social support, and nutrition aspects for 22q. But most importantly;
THEY UNDERSTAND ME!

... As older parents, it is a comfort to know [our son] has access to an organization which understands all the different problems that can arise with this syndrome.

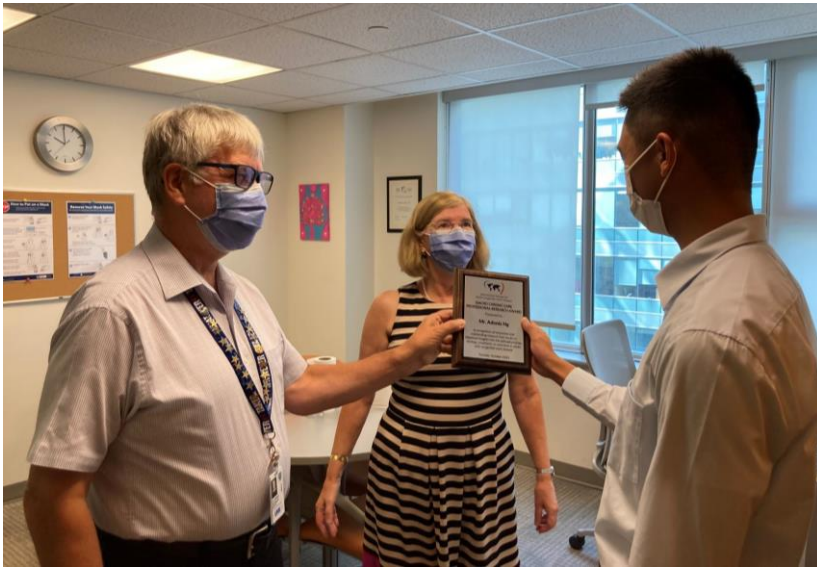
Words to say with 22q Deletion Syndrome

If only I knew!
What I would tell my younger self.
The pressures of my human anatomy,
I would say.
My life is not just a piece of a lemon meringue pie.
But a self paced life,
With all the mental health issues and physical restraints,
With my hole in my heart,
Not contagious, closed when I was a baby.
No cure
But a place found on my DNA diagnosis, 22q deletion
As I found out when I was 20 by
The Dalglish Family Hearts and Minds Clinic,
Doctor Bassett and clinicians from Sick Kids
On the way to adulthood
With the help of the team
The caring from within
The strength and power
I would tell my story
With my endurance, I GREW, my family knowing my condition .
With my loving husband, whom I would not know what I would do without.
I needed
Didn't know what I could control
It's only my thoughts
At the end of the day
What we all want
Family, true love, a job satisfaction
As I've reached to this age of
Almost 40
I could only thank everyone from
The bottom of my heart.
Believe in what you want to do.
Believe in life.
Believe in asking for help when,
All else has failed
As the support is most precious,
A gift that you can receive.

Working Together

Our Clinic team teaches students in medicine and allied health areas about 22q and how to provide the best care possible. We also work with experts from multiple specialties around the world. Together, we do cutting-edge research on 22q in our Clinic and through related programs.

Emily Tjan is pursuing a Master of Science degree in Biomedical Communications at the University of Toronto. She is a medical illustrator and animator currently working with the Dalglish Family 22q Clinic team to create a patient education video that will help patients and caregivers better understand 22q.



Congratulations to **Adonis Ng**, who conducted research with us during his undergraduate years, for receiving the [International Society for Adult Congenital Heart Disease Professional Research Award](#), presented by Dr. Oechslin. The award recognizes innovative and outstanding research that results in important insights into the causes, mechanisms, treatments, or outcomes in adults with congenital heart disease.

Adonis's project title was [Incidence of infective endocarditis in adults with congenital heart disease and diagnosed 22q11.2 deletion syndrome](#). He presented the findings at the International Symposium on Adult Congenital Heart Disease, an online meeting that took place on October 13th, 2021.

Collaborators

To see the complete list of our collaborators, please visit: <https://22q.ca/aboutus/our-staff/>

Residents & Students

Lily Van, MD

Resident in Psychiatry
Clinician Scientist Program
Now on staff at CAMH

Sarah (Voll) Malecki, MD

Resident in General Internal Medicine

Christina Blagojevic, MD

Resident in Internal Medicine

Sabrina Cancelliere, HBSc

Medical student

Brigid Conroy, MSc

Medical student

Grace McAlpine, BHSc

Medical student

Zoë McManus, BSc

Medical Student

Vikita Mehta, B.Arts Sc.

Medical Student

Kanya Rajendra, BHSc

Medical Student

Research & Clinical Fellows

Caihong Ji, MBBS, MD

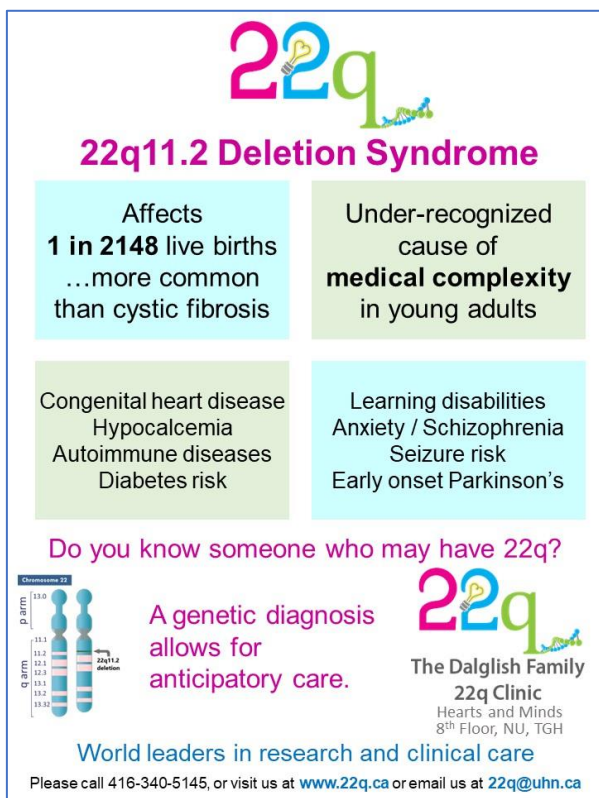
Research Fellow
Epilepsy Genetics Program
Toronto Western Hospital

Nikolai Reyes, MD

Clinical Fellow
Movement Disorders Clinic
Toronto Western Hospital

Raising Awareness

22q is not well-known even among medical professionals. In order to raise awareness, we displayed our infographic about 22q on the computers of the University Health Network (UHN) from November 19th to 26th, 2022 and lit the CN Tower in Red on November 22nd, 2022.



22q

22q11.2 Deletion Syndrome

Affects **1 in 2148** live births
...more common than cystic fibrosis

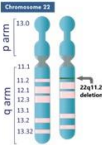
Under-recognized cause of **medical complexity** in young adults

Congenital heart disease
Hypocalcemia
Autoimmune diseases
Diabetes risk

Learning disabilities
Anxiety / Schizophrenia
Seizure risk
Early onset Parkinson's

Do you know someone who may have 22q?

A genetic diagnosis allows for anticipatory care.

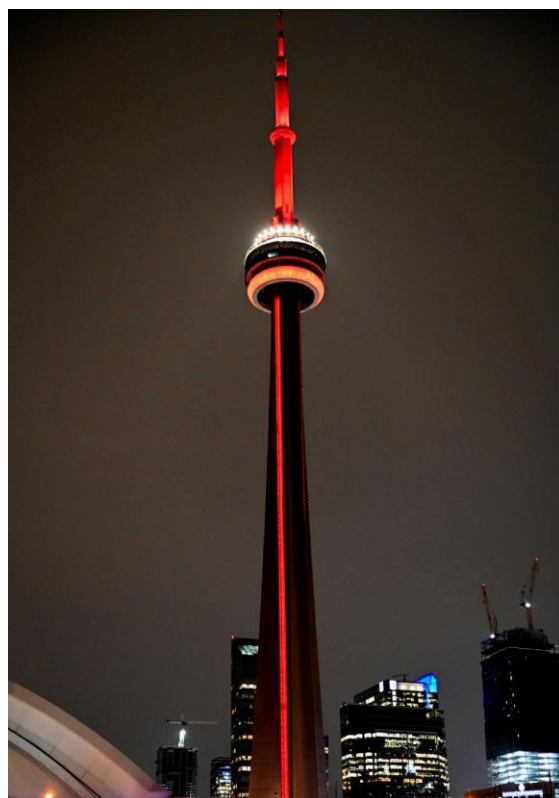


22q
The Dalglish Family
22q Clinic
Hearts and Minds
8th Floor, NU, TGH

World leaders in research and clinical care

Please call 416-340-5145, or visit us at www.22q.ca or email us at 22q@uhn.ca

UHN Infographic



CN Tower lit up for 22q!

Sharing Knowledge



The 12th Biennial International 22q11.2 Meeting took place in person at Le Meridien Lav Hotel in Split, Croatia in July 2022. Our team members presented our recent findings and led discussions in these meetings.

Our team members (from left to right)

Samantha D'Arcy, Registered Dietitian

Dr. Anne Bassett, Psychiatrist and Clinic Director

Dr. Erik Boot, Research Associate & Former Dalglish Fellow

Lisa Palmer, Registered Social Worker

Dr. Lily Van, Psychiatry Resident

Ania Fiksinski, Former Graduate Student

22q at the Zoo

The International 22q11.2 Foundations' Annual [22q at the Zoo – Worldwide Awareness Day](#) (“22q at the Zoo”) is an international initiative to raise awareness about 22q11.2 deletion syndrome. The Toronto event is co-hosted by the [22q Deletion Syndrome Clinic at SickKids Hospital](#) and our Dalglish Family 22q Clinic. The focus of the day is for individuals with 22q, their families and Clinic staff to socialize, network, and raise awareness of 22q in the community. Participants also have the chance to join in fun activities with their friends and families and enjoy a day at the Toronto Zoo.

Toronto’s 2022 event took place on **Sunday July 17th, 2022** at the Toronto Zoo.



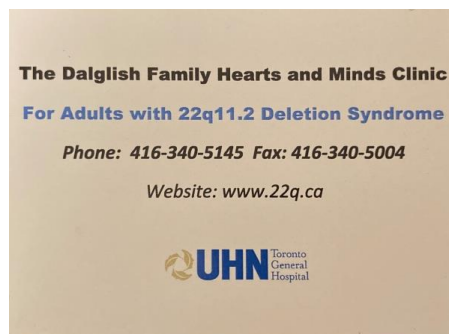
At the registration area: (Left to right) Joanne Loo and Samantha D’Arcy from the Dalglish Family 22q Clinic along with Andrea Shugar from the 22q Clinic at the Hospital for Sick Children



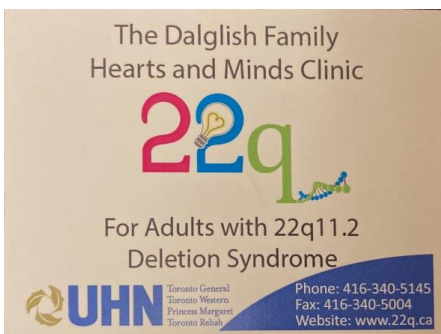
At the table of the Dalglish Family 22q Clinic: (Left to right) Dr. Anne Bassett and Joanne Loo from the Dalglish Family 22q Clinic

Remember These Magnets?

One of the earliest ways that our Clinic used to spread the word about 22q and our services was through the distribution of magnets. Take a trip down memory lane with the 3 magnets we have been giving out in the past 10 years. Our current magnet has been in use since the name change of our Clinic in 2016.



2013



2014 to 2015



2016 to present

Our Latest Research

Does having 22q increase the risk of having high lipid levels?

Hypertriglyceridemia in young adults with a 22q11.2 microdeletion

Blagojevic C, Heung T, Malecki S, Ying S, Cancelliere S, Hegele RA, Bassett AS.
European Journal of Endocrinology 187:91-99, 2022; PMID: 35521712. [\[PubMed\]](#)

- **Triglycerides** are a type of lipid (fat). Your body stores and releases energy as triglycerides in fat cells.
- **Hypertriglyceridemia** means having too high a triglyceride level in the blood.
- Hypertriglyceridemia increases the risk of:
 - Obesity
 - Diabetes
 - Heart disease
- Our team performed a study of 7,060 non-diabetic Canadian adults to see what factors could predict hypertriglyceridemia.
 - Age range: 17 to 69 years old
 - 267 of the 7,060 adults have 22q

The 22q11.2 deletion may be a risk factor for a high triglyceride level. But...we can lower the triglyceride level with exercise / activity, and with eating and drinking fewer sugars & simple starches. Here's to healthy eating!



Main Findings

- Predictors of hypertriglyceridemia:
 - **22q11.2 deletion**
 - Being male
 - Certain ethnic groups
 - Older age
- NOT a predictor of hypertriglyceridemia:
 - Use of antipsychotic medication
- 75% of the individuals with 22q who have hypertriglyceridemia are **under 40 years of age.**

Coming Soon: Updated Clinical Guidelines for Children and Adults with 22q

22q Guidelines: Our Involvement

Dr. Anne Bassett

Leader & Senior Author,
Together with Dr. Erik Boot

Lisa Palmer

Author (Guidelines for Adults)

Joanne Loo

Screeener of Research Publications
Coordinator of Article Retrieval

Grace McAlpine

Assistant Coordinator of Article Retrieval

Article Retrievers (Toronto Team)

Sabrina Cancelliere, Brigid Conroy,
Joanne Loo, Grace McAlpine,
Aarabi Thayaparan, Gladys Wong,
Shengjie Ying

22q is not well-known, even among healthcare providers. To help medical professionals care for children and adults with 22q, international experts including our Clinic staff published clinical guidelines for 22q in 2011 and 2015. We have since learned a lot more about 22q.

To share the most up-to-date medical knowledge, the [22q11.2 Society](#) led the effort to update these guidelines. This major project involved expert 22q healthcare providers from 10 countries, covering >20 specialties, as well as 8 patient advocacy groups representing over 7000 families.

22q experts combined data from over 2300 studies with their collective patient-care experiences, as well as the patient advocate survey results. The two consensus clinical guidelines (one for children, one for adults) were critically reviewed and revised. We are delighted to let you know that **both documents have now been accepted for publication in the journal, Genetics in Medicine!** As soon as they are published, we will place links to them on our Clinic website.



In Memoriam

Joel

Elise

Lisa

Trevor

Susanne

Michael

Thomas

Glen

Ari

Jennifer

Jeffrey

Jesse

Genny

William

Daniel

Amanda

Patricia

Jim

Melinda

Neil

Melissa

Gary

Andrew

Susan

Stephane

Kerry

John

Sharon

Heather

Adam

Helen

Shirley

Joshua

Patrick

Jayde

Karen

Murray

Grace

Colin

Tina

Claudette

Denise

Christine

Dale

Dianne

Gisele

Wendy

Peter

Lara

Philip

Amber

Kathleen

John

Kim

These are the members of our 22q family we have lost over the past 25 years, including six individuals in 2022.

They will never be forgotten, and remain close to our hearts.

Their research contributions live on.

Through the knowledge generated, they continue to help others with 22q.

They are stars that will forever shine!

We Welcome Your Donations!

While the Ontario Ministry of Health supports the basic operations of our Clinic, we receive **no funding for the education, outreach, and many other things we do for patients with 22q and their families.**

The [UHN Foundation](#) manages all donations for our Clinic.

Please [Donate](#) and support our education and outreach efforts.

Thank you.



Three Ways to Donate

Donate online

- Please visit our [Donate](#) page (<https://22q.ca/donate/>) to donate online.

Donating by mail or fax

- Please download the form from our [Donate](#) page (<https://22q.ca/donate/>)
- Make the cheque payable to the **UHN Foundation**
- Be sure to write **22q** in the memo field of the cheque.

The [Honour Your Hero](#) program

- Honour a hero (a staff member or a care team) by making a donation.
- The hero will receive a certificate and a thank-you message from the donor.
- For “Direct my gift to”, please select “Other”
 - In the “Other gift designation” box, type in **Dalglish Family 22q Clinic.**

UHN Foundation's Honour Your Hero program enables patients and their loved ones to thank their care team, while making a gift to support research, education and the enhancement of patient care at UHN.

Say thanks with a gift today.
honouryourhero.ca

UHN FOUNDATION | Toronto General
Toronto Western
Toronto Rehab
Michener Institute

Thank you for helping us help the 22q community!



Let's Take Part in 22q Research!

Your most precious gift is helping with our research to understand 22q!

Over the years, **hundreds of our patients with 22q** – and others around the world – have helped doctors and scientists to learn about 22q.

We are one of the very few centres to focus on adults with 22q – so every person who joins in is precious. Your participation will improve the lives of those with 22q, now and in the future!

What do I have to do to take part in research?

If you have not signed up, a research analyst will invite you to take part in research related to 22q. He/she will tell you about the study and answer your questions.

Why do we ask family members to join in the studies?

Family members are the very best comparison group. We would like to recruit moms, dads, brothers, and sisters whenever possible.

Please let us know if you would like to find out more about our research.

We are happy to answer your questions, and we welcome your input.

And, please let us know what questions you would like answered about 22q!

Thank you.

To download a digital copy of this newsletter or previous ones, please scan the QR code to reach:



<https://22q.ca/aboutus/our-newsletter/>

Visit our website at

www.22q.ca

Contact us!

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E-mail: 22q@uhn.ca



The Dalglish Family
22q Clinic

Please call or email Radhika for an appointment if we haven't seen you in a while!