

22q and Friends

2025 Newsletter

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

In 2025, the Dalglish Family 22q Clinic team stayed the course, contributing both locally and internationally. We continued to care for adults with 22q11.2 differences and their families and caregivers. Mostly we see those with 22q11.2 deletion syndrome (22q11.2DS), but also those with 22q11.2 duplications (22q11.2Dups) or other complex genetic conditions.

We are delighted that Dr. Nikolai Gil D. Reyes, a neurologist specialized in Parkinson's disease and movement disorders, has brought a special research focus on movement disorders. Be sure to read about his awards (page 3) and recent publication (page 6). He and Joanne Loo, our Education and Communication Officer, both contributed significantly to the development of the Brain and Nerves Series for the International 22q11.2 Foundation (page 6).

As always, our Social Worker, Lisa Palmer, our Dietitian, Samantha D'Arcy, and our Patient Care Coordinator, Radhika Sivanandan, have been supporting our patients and families. We thank Shayna Mullings, Kaitlyn Berner, Noushig Bakjajian, and Jocelyn Ngor for assisting while Radhika was away.

Lisa is sharing her tips on managing anxiety on pages 7 and 8. Samantha now offers online group nutritional education sessions, with resources available (as unlisted videos) on YouTube. Check out the videos and the dates of the 2026 sessions on page 10.

On pages 5 and 6, we bring you our recent research findings. These results reinforce our standing as a leader in the global 22q community. We thank our research analysts, Tracy Heung, Joanne Ha, and Alice Macgregor for their hard work, and we sincerely invite you to join our research studies (see page 6).

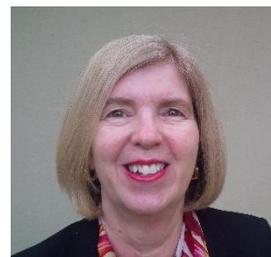
Back in 2023, we led the effort to publish 3 international clinical practice recommendations for 22q11.2DS. Joanne Loo has since coordinated the international effort to translate the 2 documents regarding the care of adults and children with this genetic condition. Each one is now available online for free in 4 languages (English, French, Spanish, and Chinese) across Canada and internationally. You will find the links to the originals and the translated versions on page 9. We also provide an update on 22q11.2DupS.

On behalf of the entire team at the Dalglish Family 22q Clinic, thank you for letting us be part of your journey.

Happy Holidays!

Yours sincerely,

Anne S. Bassett,
CM, MD, FRCPC
Clinic Director and
Inaugural Dalglish
Family Chair in 22q11.2
Deletion Syndrome





Our Clinic and affiliated staff



[Dr. Maria Corral](#)

Psychiatrist (Retired)



[Dr. Anne Bassett](#)

Psychiatrist and Clinic Director



[Dr. Nikolai Gil D. Reyes](#)

Neurologist, Clinical Fellow,
and PhD Candidate



[Lisa Palmer](#)

Registered Social Worker



[Samantha D'Arcy](#)

Registered Dietitian



[Radhika Sivanandan](#)

Patient Flow Coordinator



[Dr. Erik Boot](#)

Physician for people with intellectual disability
Research Associate



[Joanne Loo](#)

Education and Communication Officer



[Tracy Heung](#)

Clinical Research Analyst



[Joanne Ha](#)

Clinical Research Analyst



[Alice Macgregor](#)

Clinical Research Analyst

Please visit the [About Us](#) section of our Clinic website for a complete list of our staff, residents, students, and collaborators.

Awards and Recognitions



Dr. Nikolai Gil D. Reyes is a recipient of the **2025-2026 Ontario Graduate Scholarship (OGS)**, an award based on academic excellence, at the University of Toronto. He also received a **2025-2026 Brain Canada Rising Stars Trainee Award in Parkinson's Disease research**. This award recognizes the excellent research being conducted at Canadian institutions by graduate students, postdoctoral fellows, and medical residents.

Dr. Reyes is a movement disorders neurologist who is pursuing graduate studies at our Clinic. His work aims to investigate potential genetic risk factors and diagnostic markers of Parkinson's disease, as well as other movement disorders, in individuals with 22q. This work promises to help with the early diagnosis and treatment of Parkinson's disease and other movements within the 22q community and in the general population.



Our Patient Care Coordinator, **Radhika Sivanandan**, is always kind and supportive to our patients, their families, and the whole Clinic team. In early 2025, our team nominated her to be recognized at UHN. She received the **UHN Star Recognition** accompanied by the following: "Radhika consistently shows compassion to our patients, specifically by helping make our patients' journey to their appointments at the Clinic smooth and accessible. She is incredibly understanding of the barriers they face in getting here and is never deterred by challenges such as missed appointments or rescheduling. And no matter what issues arise, she still has a warm smile on her face when patients are here at the Clinic. This is just one of many examples of how Radhika is a compassionate member of the Clinic team, and why patients, families, and colleagues alike recognize how special she is."

22q at the Zoo – Toronto Event

The International 22q11.2 Foundations' Annual [22q at the Zoo – Worldwide Awareness Day](#) is an international initiative to raise awareness about chromosome 22q differences.

The Toronto event is co-hosted by the [22q Deletion Syndrome Clinic at SickKids Hospital](#) and the 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. Our most recent event took place at the Toronto Zoo on Saturday June 7th, 2025. Our team had a great time (photo on right).



From left: Samantha D'Arcy (Registered Dietitian), Dr. Nikolai Reyes (Neurologist), Lisa Palmer (Social Worker), Alice Macgregor (Research Analyst), Joanne Loo (Education and Communication Officer), and Tracy Heung (Research Analyst)

 Please bring the following when you come to the Dalglish Family 22q Clinic...

This will be really helpful for your appointment!



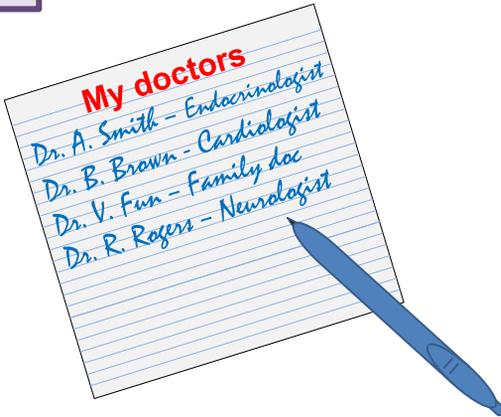
Your OHIP card



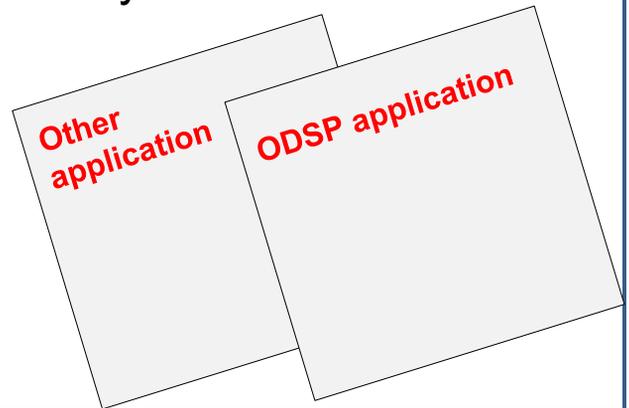
All **medications** (including herbal, natural, supplements, over-the-counter) in their original bottles, packages, or blister pack



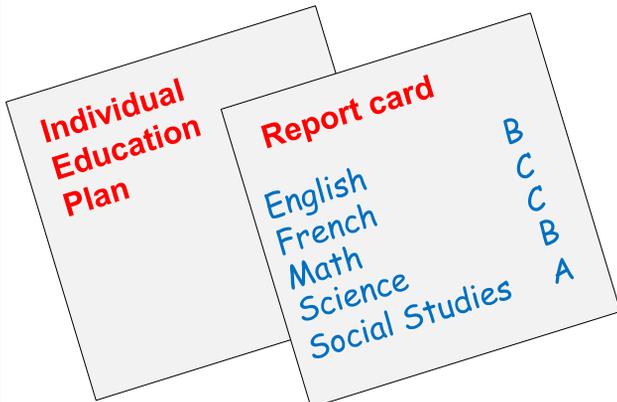
List of doctors



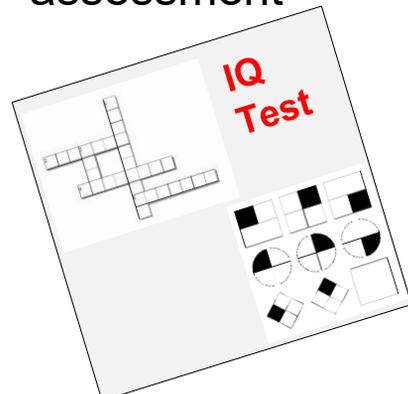
Forms or documents you need reviewed



Report cards, IEPs (if applicable)



Psychoeducational assessment



Our Latest Research Findings

Finding a Way to Check for Metabolic Syndrome

[A non-fasting marker of metabolic syndrome in a high-risk population.](#)

Cancelliere S, Heung T, Blagojevic C, Malecki S, Dash S, Bassett AS.

J Nutr Health Aging. 2025 Jul;29(7):100573.

doi: 10.1016/j.jnha.2025.100573. Epub 2025 May 8. PMID: 40344905; PMCID: PMC12172950.

Metabolic Syndrome

Metabolic syndrome means having 3 or more of the following problems:

- High blood pressure
- High blood sugar (not able to use sugar properly as energy)
- Obesity or too much fat around the waist
- High level of cholesterol or triglyceride (“bad” fats” in the blood)

Metabolic syndrome is a group of health problems that raise the risk of heart disease and stroke. It is becoming more common worldwide. We wanted to know how common metabolic syndrome is in adults with 22q.

In our study of 350 adults with 22q, we found that about 1 in 4 had metabolic syndrome. As expected, it was more common in people aged 40–59 than in those aged 18–39. People with **hypothyroidism** (a condition where the thyroid gland doesn’t make enough thyroid hormone) tended to be more likely to have metabolic syndrome.

We also looked at a simple blood test measure called the TyG index. This uses routine bloodwork results and does not need fasting (no eating before). We found that the **TyG index was strongly linked to metabolic syndrome** and could predict who had it about 77% of the time.

Why does this matter? The TyG index could be an easy way to check for metabolic syndrome early. This means we can help people with 22q to start treatment sooner, lowering the risk of heart disease later.

Next: We are working on finding what treatment works best!

Height and Weight in Adults with 22q

[Influence of polygenic risk on height and BMI in adults with a 22q11.2 microdeletion.](#)

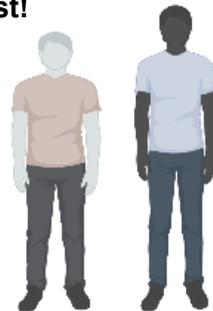
Ying S, Heung T, Morrow B, Thiruvahindrapuram B, Yuen RKC, Bassett AS.

Journal of the Endocrine Society, 2025, e-published 28 June 2025 (pp 1-8).

Doi: 10.1210/jendso/bvaf115. PMID: 40741418 PMCID: PMC12308129

Genetics can affect things like height and weight. For example, a 22q11.2 deletion is associated with shorter height than average by a few centimetres.

In our study of 259 adults with 22q, about 1 in 5 shorter height than most people in the general population, and nearly half had obesity, about twice population expectations. Short stature was less common in those with the rare shorter 22q deletions and in those with no major congenital heart disease. Obesity was more likely in women and in older adults.



We found that, **besides the 22q11.2 deletion, other common genetic factors can also affect height and weight in adults with 22q.** This means that a person’s overall genetic makeup—along with age, sex, and health history—and not just the 22q deletion, can help predict these traits.

Why is this important? Knowing these factors can help doctors give better advice and set realistic expectations for growth and weight management in people with 22q.

Each person with 22q is different. If you have any concerns about your health, please make an appointment to see your doctor.

Our Latest Research Findings (continued)

Movement Disorders in 22q

[Dissecting the phenotypic spectrum and complexity of movement disorders in 22q11.2 deletion syndrome.](#)

Reyes NGD, Grippe T, Callister M, Abkur T, Villanueva EQ 3rd, Heung T, Chen R, Boot E, Bassett AS, Lang AE. Eur J Neurol. 2025 Jun;32(6):e70256.

doi: 10.1111/ene.70256. PMID: 40530538; PMCID: PMC12174967.



We studied in detail the 31 adults with 22q who were seen at the Toronto Western Hospital specialty clinic for movement disorders between 1996 and 2023. The most common problems were **tremors** (shaking that is not part of Parkinson's disease), **parkinsonism** (slow movements, stiffness, and tremor at rest), and **dystonia** (muscle that tense up for a time, often into an uncomfortable position). We also found some other rarer movement problems that had not been reported before for 22q. Whether people were or were not taking antipsychotic medication did not seem to make a big difference.

Most people (77%) had more than one movement disorder - on average between 2 and 7 problems. **The good news:** These conditions can be treated with standard treatments when diagnosed correctly.

This study shows that movement disorders in 22q are more complex than we thought, but they are **treatable**. Regular check-ups with a neurologist can help make sure people get the right care.

To find out more about brain and nerve conditions that affect adults with 22q, check out the **Brain and Nerves Series** of the [Health Conditions Explained](#) feature of the International 22q11.2 Foundation. E.g.:

- [Seizures and Epilepsy](#)
- [Parkinsonism and Parkinson's Disease](#)
- [Other Movement Disorders](#)

Our Education and Communications Officer, Joanne Loo and our Neurologist and PhD Candidate, Dr. Nikolai Gil D. Reyes were 2 of the 3 people who developed this series.

Help us help others... Join our research!

Over 95% of the adults we follow at our Clinic are helping in our research about 22q. The research findings (pages 5 and 6) as well as the clinical recommendations documents (page 9) would not exist without the participation of our patients and caregivers. Frankly, without your help, we would know nothing about 22q11.2 deletion and the related conditions, or how best to care for people affected by them.

We are one of the very few centres in the world to focus on **adults** with 22q – so every person who participates is precious. **We invite you, your parents, and your siblings to take part.**

Ask us what studies we are working on. We are happy to explain!

Check out our research studies:

- [Our world-first research contributions](#)
- [Summaries of our recent research findings \(2018 – 2025\)](#)
- [List of all our publications related to 22q11.2 deletion syndrome \(2011 – 2025\)](#)

How to Help Manage Anxiety

Tips for Adults with 22q

Here are some general tips to help reduce stress and feel better.

1. Take all medications, including supplements, as prescribed

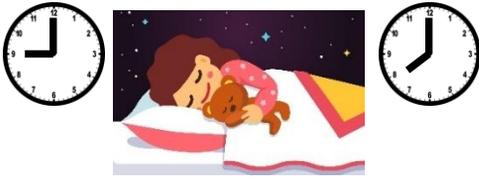


Standard anti-anxiety medication is effective for adults with 22q

2. Set up a routine to provide structure. Include activities that you enjoy



3. Practice healthy sleep habits, such as going to bed and waking up at the same time every day - No electronics!



4. Engage in physical activities



5. Learn relaxation / emotion regulation techniques



6. Connect with family members, friends - people you trust



7. Eat healthy foods as much as possible



8. Limit alcohol, caffeine, and drugs, including marijuana



For more questions about managing anxiety, contact us at the Clinic (416-340-5145) or 22q@uhn.ca) to speak to one of the members of our team.



Helping Adults with 22q

Manage Anxiety

- Some Tips for Caregivers

Our patients and their caregivers tell us that the standard anti-anxiety medications used around the world for the past 30-40 years are well tolerated and very helpful for treating the anxiety disorders that are common in 22q.

We have also found the following strategies to be helpful:

1. Provide consistent structure and routine.
2. Use simple, concrete language, and short, clear sentences.
3. Use a positive and matter-of-fact tone of voice. Use written / visual communication when possible.
4. Only give 1 – 2 instructions / directions at a time.
5. Limit choices to 1 – 2 at a time.
6. Reduce challenging or stressful situations that require more advanced judgment and/or problem solving. Provide support, encouragement and oversight.
7. Reduce negative-focused environment (e.g., social media, TV or other news sources re disasters).
8. Reduce high expressed emotion (e.g., hostility / anger) and as best as possible, use a soft / neutral tone of voice when speaking.
9. Reassure / encourage / support / praise (must be genuine)
10. Encourage positive behaviour change; celebrate successes and achievements.
11. Focus on what the person CAN do.
12. Divert / distract from negative thought processes or behaviour.



Many of the families we see at our Clinic have found the above suggestions to be helpful. For more information about managing anxiety, please contact us at the Clinic (416) 340-5145 or 22q@uhn.ca to speak to one of the members of our team.



Clinical Recommendations for 22q11.2 Deletion Syndrome

Now Available in 4 Languages

The 22q clinical recommendations documents for the care of adults and children with 22q are now available for free in **French, Spanish, and Chinese**, in addition to in English.

Updated clinical practice recommendations for managing **Adults** with 22q11.2 deletion syndrome

- [English \(Original\)](#)
- [French – Français](#)
- [Spanish – Español](#)
- [Traditional Chinese 繁體中文](#)

Updated clinical practice recommendations for managing **Children** with 22q11.2 deletion syndrome

- [English \(Original\)](#)
- [French – Français](#)
- [Spanish – Español](#)
- [Simplified Chinese – 简体中文](#)

Please scan the QR code to go to our website, where you can obtain the pdf files of the clinical recommendation documents.



In addition, the document regarding **Prenatal Screening and Diagnostic Considerations for 22q11.2 Microdeletions** is available in [English](#).

Information for 22q11.2 Duplication Syndrome

People with 22q11.2 duplication syndrome (22q11.2DupS) have an extra piece on chromosome 22 that can affect how the body is formed and may function. There is very little research as yet about this condition in general, especially for adults. This means there are no international guidelines for care.

Expert healthcare providers are currently preparing a paper for publication that will provide detailed information on features associated with 22q11.2 duplication syndrome. In the meantime, the experts recommend using the same healthcare guidelines prepared for

the 22q11.2 deletion syndrome (listed in the above section). Many of the features associated with the duplication are quite similar to those associated with the deletion, just with a lower frequency.

Our Clinic will be in touch as soon as the new paper for the 22q11.2 duplication syndrome is published.

Each person with 22q11.2 deletion / duplication syndrome is different.

If you have any concerns about your health, please make an appointment to see your doctor.



What's Cookin' with Our Dietitian?

Samantha D'Arcy, our Clinic dietitian, has posted online webinars to YouTube with information about nutrition and 22q.

- [All about Blood Sugars and Cholesterol](#)
- [All About Calcium](#)
- [All About Appetite and Cravings](#)
- [All About Healthy Weight](#)

Our virtual nutrition program offerings for 2026 include:

Meal Planning Support Group (for individuals with 22q only):

This group program is about meal planning, with virtual weekly meetings to learn tips and set a meal planning goal for the following week. There will be follow-up meetings after the first month, to help participants stay motivated. **Only 7 spots available in each session.**

Session #1:

- Weds, March 4th, 2026; 7 pm to 8 pm
- Weds, March 11th, 2026; 7 pm to 8 pm
- Weds, March 18th, 2026; 7 pm to 8 pm
- Weds, March 25th, 2026; 7 pm to 8 pm
- Weds, April 22nd, 2026; 7 pm to 8 pm
- Weds, May 20th, 2026; 7 pm to 8 pm

Session #2:

- Weds, September 2nd, 2026; 7 pm to 8 pm
- Weds, September 9th, 2026; 7 pm to 8 pm
- Weds, September 16th, 2026; 7 pm to 8 pm
- Weds, September 23rd, 2026; 7 pm to 8 pm
- Weds, October 21st, 2026; 7 pm to 8 pm
- Weds, November 18th, 2026; 7 pm to 8 pm

Nutrition Information Sessions (for everyone):

- **All about Calcium:** Wednesday, February 18th, 2026 from 7 pm to 7:45 pm
- **All about Appetite and Cravings:** Wednesday, June 17th, 2026 from 7 pm to 7:45 pm

Email samantha.darcy@uhn.ca to register.

Please scan the QR code to go to our website and click on the video links.



The CN Tower was lit up in red for 22q!

The CN Tower was lit up in red to raise awareness for 22q11.2 deletion and duplication syndromes on November 22nd, 2025! We chose this date (“22/11”) as a play on the name of the conditions. We do this as part of the “Luces por el 22q/Lighting the 22q” international awareness movement that began in Spain in 2018. Thank you to our team members and patients for sharing the photos.





In Memoriam...



These are the members of our 22q family we have lost over the past several decades, including two individuals in 2025, one at age 70.

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.

We are grateful to have known each and every one - and their loving families.

They are beacons of light that will forever shine!



Please Support Our Work

The [UHN Foundation](#) manages all donations and you can direct your gift to our Clinic. Just a reminder that we receive no Ministry of Health or institutional funding support **for our educational, outreach, and other activities (e.g., our website) for patients with 22q and their families.** Many families (and friends) have kindly made donations to help our Clinic.

Please write **22q Deletion Syndrome Fund for Excellence** in the gift designation field online or the memo field of your cheque. **Thank you** for your support - every gift helps us help those with 22q!

3 Ways to donate to our Clinic

[Online](#)

By mail / fax (use this [form](#))

Via UHN's [Honour Your Hero](#) program

The Future of our Clinic...

The support for Dr. Anne Bassett's role as Dalglish Family Chair in 22q11.2 Deletion Syndrome ended in 2024, and Dr. Maria Corral retired in 2024. In our newsletter last year, we mentioned that the hospital is searching for someone to become the new Dalglish Family Chair, supported by a generous donation from the Weston Family Foundation.

Unfortunately, we do not have any updates on this situation. No one in our Clinic is involved in the search process for the new Chair. Dr. Bassett, together with Dr. Reyes and our small but mighty team continue to provide clinical care, and we hope to keep you posted as we learn more about possible changes.

Contact us

The Dalglish Family 22q Clinic Toronto General Hospital

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Fax: (416) 340-5004
E-mail: 22q@uhn.ca

Visit our website at www.22q.ca

Please call or email us at 22q@uhn.ca for an appointment if we haven't seen you in a while!



Room Number Change

In September 2025, our Clinic's room number was changed to "**Room 897**".

We have not moved! We are still at the same location. This is just an internal change at the hospital for way-finding.

To download a digital copy of this newsletter or previous newsletters, please visit:

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