

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. We placed excerpts of your feedback into our 2022 newsletter, and here are the complete messages (without names). Your kindness has really touched our team, and we are very glad to be a part of your journey.

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.

There's a clinic that specializes in his care, and as he grows in adulthood and independence, there's a place for him to go where he knows people will care and support him on his journey.

Thank you, Dr. Bassett, Radhika, Lisa and everyone else on the team!

- Mom of a 22 cutie

The Dalglish Family 22q Clinic has been an incredible resource for us along this journey. Every member of the team has impacted us with their kindness, sincerity, and ongoing support. 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.

Congratulations on 10 years! ❤️

- From a mom with an adult son with 22q

My daughter [name] has been a patient of Dr. Bassett for I am gonna say 20 yrs. ..or more..since we found out she has 22q..with the fish test..we have always had a great experience.. very helpful.. and have learned a lot..

[Name] 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..

Thanks

Our family has been connected with the Dalglish Clinic since its very beginning. 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

Our family was introduced to the Dalglish Family 22q Clinic at a time of crisis in our lives and it was completely by chance - quite a miracle actually. The staff at the clinic were welcoming, informative, professional and most of all kind. We felt like they gave us and our daughter a soft landing in the midst of a very troubling and challenging time. 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 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.

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.

The follow ups are great. Finally health professionals who are looking out for our adult child. There are no words powerful enough to say THANK YOU for your work which is so necessary.

Our family is so blessed to have had the Dalglish Family 22q Clinic in our lives for the past 10 years. Our adult daughter and her teenage son both have 22q. There are many challenges that they encounter, as does our family in indirect and direct ways. 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. Thank you, Dr. Bassett and Staff.

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. We were worried that once our son became an adult that it would be harder to get 22q support but the Dalglish Family 22q Clinic allayed our fears and in fact we feel comfort knowing that they are there to help our son live a healthy, meaningful life.



The Dalglish Center has empowered our family to make sound decisions for our adult daughter [name], who has 22q11. Prior to her diagnosis, we acted based on norms for her age. We did not know that doing so put her at risk.

Once we had a diagnosis for [name] at the age of 25, we learned more about this condition by attending the 22q11 conference in Whistler BC and by [name] becoming a patient of Dr Bassett. Since that time the Dalglish Center has studied [her] condition in relation to what is known about people with 22q11. The information we have about 22q11 and [her] medical state is now supporting us all and her medical team back home in making appropriate decisions with [name]. We have received guidance on medication, sleep hygiene, diet, social topics, psychological issues, and planning from the Dalglish Center.

I don't like to think about what could have happened to [name] without the knowledge and support we have gained from the Dalglish Center. [name] was diagnosed with 22q11 when she was in psychosis. Without the Dalglish Center available to provide [name], 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.

We now only require annual online checkups with the Dalglish Center. These checkups may lead to tweaking [her] medical and life skill direction. [Her] life is fairly stable now. She has things to look forward to and her family can rest assured that if things change, we have the Dalglish Center to lean on for support.

Best Clinic Ever

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.

Every member of this profound team goes over and beyond, with exceptional support and care. They arrange for those involved to be followed by top specialists and work closely with them cover all needs.

They truly are amazing and I am in awe in which we are treated, with so much love and compassion. They are like a perfect family in which they work in sync bringing the patient and their families into the fold.

Many thanks! Love this clinic!

10 Years!! The Dalglish Family 22q Clinic Celebration!!

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!

We know as parents this journey would be more difficult without all of your love and support for our adult child and ourselves.

We, as a family, are so proud and fortunate to call you family.

From the bottom of our hearts, We Thank You, today and always.

At the age of 39 I worked at a Retirement Residence as a Personal Support Worker, and was injured on the job while lifting a resident.

I dislocated my clavicle, injured my neck and back preventing me from returning to the Personal Support Worker position; a job I truly enjoyed. (Or any other job for that matter.) Frustrated and upset about why my injury was not healing, my family doctor, at the age of 47 sent me to a genetics specialist who conducted several different genetic tests including a blood test called FISH and the results came back that I was born missing a piece of the 22nd chromosome.

At the age of 49 I became a member of the 22q Dalglish Family Clinic. (now age 53)

Since I have become a member of their team, 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!

The 22q Dalglish Family Clinic has truly become a part of my family!

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!

- Caregiver of adult with 22q

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

Hello, I am a mother of a daughter with 22q. I always felt very lucky to have had my daughter in Toronto versus Montreal, where I am originally from. Because of the amazing Hospital for Sick Children and my daughter's early diagnosis , I had a bit of an idea of what the hurdles could be. With the guidance and expertise of the doctors and the team that makes up the 22q clinic at Sick Kids, I always felt supported, informed and extremely grateful. 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. Thanks to all of you and Happy 10th Anniversary!!

Having 22q clinic one city away has made a world of difference for me. 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. Caring for someone with 22q is not easy. It is a comfort to have this first in the world clinic for adults with 22q close by. I honestly don't know what I would do without it!

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.

Our son's life and our family's life has been considerably improved by the 22q clinic.

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. Even in the medical field the syndrome was not well known, but we have been able to assist our sister with appropriate health care and excellent doctors to aid her in living a fulfilling life. Our sincere appreciation to The Dalglish Family 22q Clinic and congratulations on your 10 year anniversary!

Dr Bassett's 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.

- Mother of a 41 yr old

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.

My Son [name] has diagnosed with 22q deficiencies, he then got referral to The Dalglish Family 22q Clinic. 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.

For our family, it provides access to specialists that are knowledgeable and experienced in this area. We are not dealing with an individual but a team of professionals (Doctors, Nurses, Social Worker, & support staff) rather. We are very thankful for the 22q clinic and appreciate the support and work that all staff do for people with rare conditions. It is clinics like these that really make an impact on people's lives for the better.

Thank you for everything the clinic does! Much appreciated!

Congratulations to the Clinic 10-year anniversary! And many more years to come! Well deserved!

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!! Happy Anniversary and thank you!!!

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]. Our genetic team play such an important role in our lives, we can't imagine what we would do without their help.

Years ago, many Drs. painted a bleak picture of what life would have been, we were told he probably would not live until adulthood, and when he was a teenager, due to his difficulties, we were told our only option was to place him in a facility which he would constantly be sedated.

Thankfully, we found Dr. Bassett and her wonderful team at the Dalglish Family 22q Clinic.

[Name] now lives a very active life, he has been working at the same job for over 10 years, loves bowling, bicycling, kayaking, playing drums, playing pool, swimming, and is a pro at playing video games. It amazes me what he has accomplished over the years. [Name] loves going to the 22q zoo, not because of the animals, but because he loves to see his genetic specialists.

We are eternally thankful for the Dalglish Family 22q Clinic.

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.

We love you all. Hard to put to words how great you all are.

Time has gone by so fast. "10 years" hard to believe. 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.

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.

I am a grandmother and caregiver of a now 27 year old male. We were concerned when he turned 16 wondering what would happen after the excellent care at Sick Kids. Just at that moment, The Dalglish 22q clinic opened and the care continued. 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.

Happy 10th year anniversary
Dalglish Family 22q Clinic!

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!

- Caregiver of an adult with 22q

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

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

Our son was diagnosed with VFC before age 5 when not much was known about this syndrome. All his medical conditions were resolved by his teens and we never gave that diagnosis another thought. It wasn't until he was in his 30s that other medical issues arose leading to a 22q diagnosis, and us to the Dalglish Clinic. As older parents, it is a comfort to know he has access to an organization which understands all the different problems that can arise with this syndrome.

- Parent of an adult with 22q



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 Daglish family and hearts and 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.

We do so appreciate that you
are there for [name] who has
been to your clinic one time .
We know you are there to
meet future needs . We
appreciate the doctors and
other specialists who
specialize in caring for people
with 22 q and in [her] case her
heart condition truncus
arteriosus also. Was so nice to
meet you Dr. Coral and others
on the team.

- Grandmother of an adult with
22q

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. My only problem is that
we live so far away:(

PS. Radhika is ALWAYS
friendly and helpful.

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. My daughter wrote
an article on the clinic and 22q
and said it is more prevalent
than Huntington's, yet people
are not familiar with it. The
awareness would be good for
not only the general public but
also for health care providers.
Thank you!