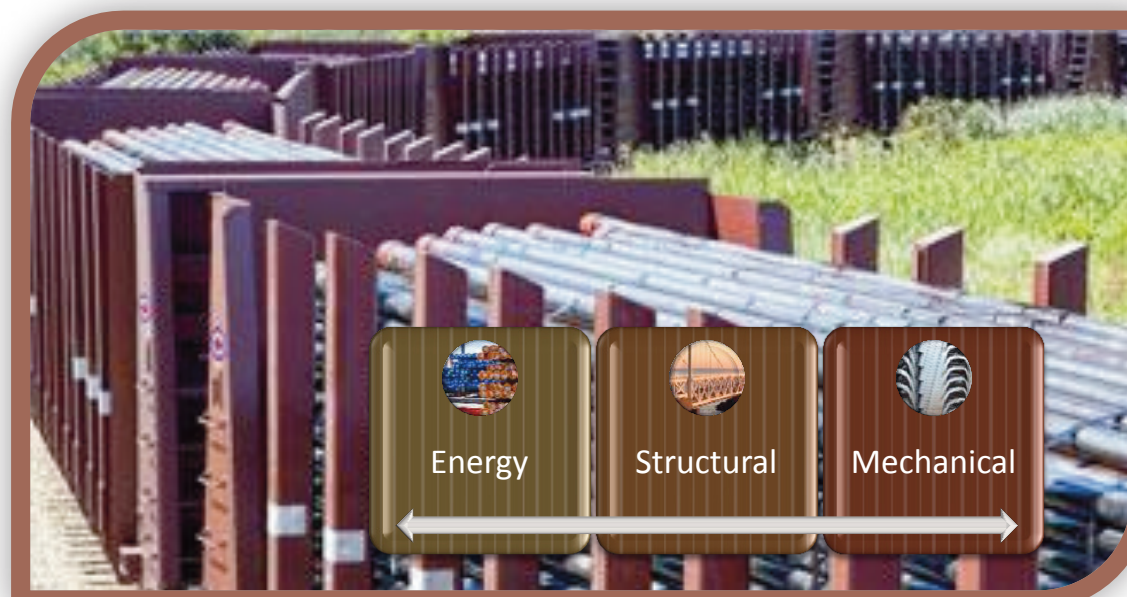




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The holistic approach to 22q

A world-first facility treats the complex, multisystem health needs of adults with this little-understood genetic disease

By Renee Sylvestre-Williams

"I really like going because you can get all your tests done in one place," says Genevieve Dalglish. "I'm treated like gold. I like my doctors very much." Ms. Dalglish is talking about the Dalglish Family Hearts and Minds Clinic for adults, at the Peter Munk Cardiac Centre (PMCC).

Unlike traditional clinic decor, there is very little metal. Instead, when you walk in, the foyer looks more like the entranceway of

a home. There is carpet on the floor, and the waiting room looks more like a living room with a light-grey leather sectional couch. The lights are warm, not harsh, and the reception desk is neatly tucked away. Add some warmth with wood accents, and the Dalglish Clinic feels more like a comfortable, well-appointed condo than a medical clinic.

The first of its kind in the world, this integrated clinic is

dedicated to the adult treatment and research of a little-known genetic disease called 22q11.2 Deletion Syndrome (22q11.2DS), colloquially known as 22q.

It was previously known as DiGeorge Syndrome or velo-cardio-facial syndrome, and it's caused by a missing piece (the "deletion" in 22q11.2 Deletion Syndrome) on chromosome 22. As a result of this deletion, patients with 22q can have

numerous health issues, including palate problems, congenital heart defects, psychiatric issues such as anxiety and/or schizophrenia and learning disabilities. It affects one in 2,000 infants, and, until recently, trying to get a diagnosis, especially for adults, has driven families into a tailspin of years of doctors' visits before getting an accurate diagnosis and a treatment plan. But, instead of the patient going to see different doctors in different locations on different days, the doctors come to the patient and do all their tests and checkups at the clinic.

"We call it the diagnostic odyssey," says Dr. Anne Bassett, Director of the Dalglish Clinic. She explains that it can take years or even decades before patients and their families are given a diagnosis of 22q. For adults with 22q, there was a desperate need for a centralized place to work with patients and families.

Camilla Dalglish, who spearheaded the donation



02



03

01 Genevieve Dalglish (left) and her mom Camilla praise the positive, friendly atmosphere at the clinic.

02 Christine Grant holds a picture of her brother Henry. She says the clinic may have saved his life.

03 Dr. Anne Bassett, seated at the right and pictured here with her team, saw the need for a centralized place to work with families and patients with 22q.

symptoms, even in the same family, which can make it very difficult to detect and treat. “We think this is because of the complexity of the condition and the variability of the condition and the lack of recognition by doctors,” says Dr. Bassett.

This lack of knowledge can harm undiagnosed patients. Christine Grant knows this first-hand. Her older brother, Henry*, now 51, spent 20 years in and out of hospitals. He was diagnosed with schizophrenia, had corneal transplants and intermittent stuttering and dragged his left foot. Ms. Grant said that in the 20 years of trying to get a diagnosis for her brother, many doctors thought her brother’s symptoms were behavioural versus medical.

“It took a long time to get specialist treatment,” she says. “Some physicians were completely ignoring his needs.” It wasn’t until she met Dr. Bassett at a conference in 2010 that Henry got a genetic workup, with Dr. Bassett, that revealed a diagnosis of 22q. Henry became a patient when the clinic opened at Toronto General Hospital. Ms. Grant has seen improvement and feels the clinic, the team and the treatment may have saved her brother’s life. “I truly believe he would have died by now.”

While the Dalglishes were on their personal journey with their daughter, Mrs. Dalglish asked Dr. Bassett what they did at the Hospital for Sick Children (SickKids). Dr. Bassett replied that while SickKids diagnosed and worked with children and their families with 22q, there was a need for an adult clinic. Thanks to the Dalglish family, the clinic officially opened two years ago. What makes the clinic the first of its kind is the integrated treatment it provides to its patients and the ability for them to transition from children to adults without loss of care.

“We’ve developed a wonderful transition program with the Hospital for Sick Children. They start out over there, and our staff members go over there and walk them across the street to Toronto General,” explains Dr. Bassett. The new patients, who are

often 17 years old, get to see the clinic, are welcomed by Radhika Sivanandan, the Patient Flow Co-ordinator, and are offered a healthy snack. They are examined by Dr. Erik Boot, a clinical and research Fellow from the Netherlands and a physician for people with intellectual disability. “They get a chance to know each

other [from SickKids], which, I think, is a benefit because they know they’re not alone, and that is really good,” says Dr. Bassett. “For their next visit, they know where to come, they’ve seen everyone once and there’s some development of familiarity. It’s much more likely they’re going to come to their appointments

“We’ve developed a wonderful transition program with the Hospital for Sick Children. They start out over there, and our staff members go over there and walk them across the street to Toronto General.”

Dr. Anne Bassett,
Director of the Dalglish Family Hearts and Minds Clinic

here, after they leave SickKids, because they’ve met the person who is going to talk to them on the phone.”

The clinic also provides social workers, a registered dietitian, psychiatrists, endocrinologists, neurologists and genetics expertise for the patient and their family. Everyone is able to talk with each other face to face, and all the patient files are under one roof. This creates a holistic approach to treatment, not just for the patient, but also for the caregivers.

“Families are overwhelmed,” says Pam McFarlane, a social worker with the clinic. “It’s hard to do your own research, and we can help with developmental and financial resources.” This personal touch extends beyond the monthly or yearly appointments and family meetings. It’s not unusual for patients to e-mail or call the clinic to check in. Ms.

McFarlane and colleague Lisa Palmer will e-mail and speak with patients, sometimes on a daily basis. Registered dietitian Samantha Cooper works with the family and patients on dietary plans, part of the preventative treatment of 22q. This includes ensuring patients have enough calcium and vitamin D (calcium deficiency is a symptom of 22q) to prevent seizures.

For Ms. Dalglish, the experience has been positive. “It’s less stressful. I can make friends. I met my best friend at the clinic.”

There is still a lot of work to be done, says Dr. Bassett. “To this day, we just don’t have a ‘What is 22q’ message for the public. And a lot of education is still needed for doctors and trainees. It’s better than it was 20 years ago, but it’s still an uphill battle.”

**Name changed upon request.*

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