

CASE FOR SUPPORT



THE
CHARLES H. BEST
DIABETES CENTRE

INTRODUCTION

In Canada, over three hundred thousand people live with type 1 diabetes (T1D). Between 2003 and 2014, there was a relative increase of 37.3% in the age-standardized prevalence of diabetes diagnoses, from 5.6% to 7.8%. Although the majority of people with T1D are diagnosed as children, it is not just a childhood disease and one does not grow out of it. In fact, 25% of people with type 1 diabetes are diagnosed as adults. It is the rarest and deadliest form of all diabetes types.

The Charles H. Best Diabetes Centre, affectionately known as the Best Centre, has launched an ambitious \$5 million fundraising Building on the Best campaign to fund an expansion to its current facility located in the Town of Whitby, east of Thicksen Road, north of the 407 ETR.

The Building on the Best campaign is about staying ahead of the curve, to meet the growing needs of T1D patients and those who will soon dawn the doors of the Best Centre. It's about taking full advantage of our prime location which is experiencing growth in population, housing and infrastructure. It's about building awareness around the differences between type 1 and type 2 diabetes, and the fatal outcome of a T1D diagnosis if not managed properly. It's about being here as much as we have been in past, and building capacity for the future. The Building on the Best campaign is about ensuring that the Best Centre is sustained because it is the only centre that exclusively provides specialty care and support to T1D patients in Canada.

IMAGINE this is you,

Your daughter Lisa celebrated her fifth birthday a month ago. Your parents started an education savings plan for her and there are plans for a family vacation near Christmas.

Last week Lisa started to look and feel sluggish. You thought she may be getting the flu –she's looking a lot thinner now and she has become very weak. The next day, she's throwing up and can barely stay awake. Concern turns to panic, and you take her to the emergency department. She looks so small with the tubing in her arm and IV bag hanging high above her.

You're told that she has diabetes. As family arrives, you explain the good news that it's "only" diabetes. Your attitude changes when the diabetes educator comes to visit and explains there are different types of diabetes. Your daughter has the life-threatening kind, type 1. Confusion and panic set in!

The information starts to come too fast now: needles? How many times a day? Finger pricks? In the middle of the night? Carb counting? Coma? Hypoglycemia? Seizures? The instructions come fast – like drinking from a firehose.

Too soon, the hospital has sent you home. But what about tonight?! And the next night? Will she go to school one day? The vacation will need to be cancelled. You do know that you won't be sleeping tonight. The next morning you need to learn how to give a needle. You already feel guilty that somehow, you've given your daughter diabetes. They say it isn't your fault but you feel like it is. Now you look into her eyes and try to explain that she needs the sharp needle. That you're not trying to hurt her. Four times a day... for the rest of her life. What will that life like look like now? School? Love? Children?

It is all too much to process.

There is no other place that does what The Charles H. Best Diabetes Centre does. Not the local physicians, not the hospitals, not the walk-in clinics nor community health centres can provide physicians, can provide the care that the Best Centre does. The Best Centre specializes in type 1 diabetes. The Best Centre is a registered charity serving the community, providing exceptional healthcare, without a fee to any patients. We provide frontline healthcare that is above and beyond the care model supported under the usual Ontario Health Insurance Plan and related legislation, that covers all other healthcare access, like hospitals and community medical offices. Since its inception, the Best Centre has been fundraising since 1989 just to keep the doors open. Despite receiving some support directly from the Ministry of Health, we remain at risk for losing that funding as each year passes. Simply put, our services are free to all who look to the Best Centre for support. Without our generous donors and partners, the Best Centre would not be here. We need additional funding for the much needed expansion with support of our donors and partners.

Type 1 diabetes is **NOT** preventable, its cause is unknown and there is **NO** cure. Insulin is required to survive and it must be injected everywhere every day. Insulin injected into one's body via needles or pump is not a cure. **WITHOUT INSULIN, DEATH IS CERTAIN.**

T1D is the leading cause of non-traumatic amputations, kidney disease, heart disease and blindness. This life-threatening chronic illness can strike children or adults at any age. In fact, 25% of T1D is diagnosed in adulthood and the 75% that are diagnosed as a child will grow into adults with T1D. They do not outgrow the disease or manage without insulin. A person living with T1D will test their blood sugar level by poking their finger with a needle, up to 8 times per day and will need to inject insulin before they eat – this amounts to at least 5,100 needle pokes every year for life. But, some would say the more difficult part of having T1D is how it consumes your mind. The thoughts and fears of “Did I take enough or not enough insulin? Will I eat the amount I think I need? Will my activity change?” are real.

On any given day, managing this disease forces patients to make upwards of 50 decisions over a 24-hour period, that is more than TWO per hour! It is painfully hard to imagine this reality but this is why The Charles H. Best Diabetes Centre is here.

There are 2 major types of diabetes; type 1 and type 2. The most common is type 2 and it is estimated to account for 95% of all diabetes worldwide. It is not unusual for the general public to think diabetes is not a “big deal”, to think it can be fixed with changes to diet and exercise, to think that kids will outgrow it. That may be true for type 2, but this is type 1 diabetes. T1D management is a never-ending, overwhelming and exhausting series of decision-making tasks that add enormous stress and feelings of isolation and frustration for the entire family.

T1D is the leading cause of amputations, kidney disease, heart disease and blindness

Marlene Grass, RN, founded the Best Centre in a trail-blazing effort to help T1D patients and their families. She could see a great deal of resources were being given to support the more common type 2 diabetes, a non-fatal disease. With the support of a few families and no government funding Marlene set out to help families living with devastating T1D. In 1989, The Charles H. Best Diabetes Centre opened to help those forgotten by the healthcare system. Early in Marlene's nursing career, she met so many parents who had no option to get more help (after the teaching at diagnosis was done) other than visiting their local hospital where they were turned away. It was not feasible for families to continue to travel long distances to the children's hospital, often funding overnight stays leading to loss of work and school time. All this effort to have long waits to see their specialist and educators for the all too brief, twenty-minute appointment every three months. In between these visits, there was very little support or opportunities to expand their knowledge.

“Early in my nursing career, I had encountered many patients who developed awful medical complications due to T1D and I didn’t want to see that happen to these kids. The only way I could see a way forward at that time (in the mid 1980’s) was to step outside the traditional system as there was very little chance that the system would improve in time for these kids. There was no path to follow so I had to make one.”

- Marlene Grass, RN

As the staff and volunteers continued to help more and more families cope with the challenges of T1D, The Charles H. Best Diabetes Centre became leaders in the expertise and management. The Best Centre has garnered an excellent reputation in Ontario and across Canada. If a T1D diagnosis became a reality for you or your family; every effort should be made to receive treatment and care at The Charles H. Best Diabetes Centre. The Best Centre prides itself on their mission:

To keep our children, youth and adults living with type 1 diabetes healthy until a cure is found.

The Best Centre’s bold **vision** for the future is, **as an esteemed leader in type 1 diabetes expertise, we will provide exceptional community-based services driven by our patients and their need for lifelong care, education and support.**

As Marlene reflects on her many years working with families and patients, she laments “*T1D is silent and invisible, there are no vacations from this diagnosis. It is a 24-hours, 7 days a week, 365 days per year disease*”.

WHAT DOES THE BEST CENTRE DO?

Most people do not understand the impact of a T1D diagnosis. It has often led to fractured families in a variety of ways including separation, stress-related illness, school and career failures. It can be a source of constant conflict between parent and child, culminating in mental health illness and distress. The Charles H. Best Diabetes Centre, in the early years, was leaps and bounds ahead of the curve by recognizing the importance of interdisciplinary care and the need for proactive support to prevent mental anguish and poor medical outcomes.

While many organizations focus on research, policy, politics and an elusive cure, **The Best Centre’s mission remains steadfast: to keep our children, youth and adults living with T1D healthy until a cure is found.** If you have experienced any chronic illness or disease, you already know the care you receive will be the most important thing to you at that time. The Best Centre is here for those who need us, to improve quality of life and daily self-management. If patients are turned away the outcomes would be dire. It would create an unmanageable stress on the local physicians and hospitals, it would contribute to worsening of hallway medicine and clogged emergency departments. Also, patients would not have access to educators to learn about and access lifesaving technologies (e.g. insulin pumps, glucose monitors, new insulin formulations).

A wide range of programs and services are delivered in a multidisciplinary team environment. The Best Centre offers expert assessment and counselling in:

- T1D technology
- in-school support
- peer support and networking events
- life transitions
- multiple caregiver training

The pediatric program was the centre's first; it does and always will ensure patients and families get all the time they need to learn how to manage T1D well. It includes an after-hours urgent care program that is unmatched across the country. In the beginning, on average, a new patient will need twenty hours of hands-on counselling, education and (on-call) communication with an educator. The cost of caring for one newly diagnosed child is at least \$2,200 for the first three months.

Our impact:

- 24/7 on-call clinical educator service (After Hours Urgent Care Program) for newly diagnosed patients and those with emergent needs; often resulting in avoiding the emergency department and preventing admission to the intensive care units.
- Comprehensive school and outreach programs; including home visits and telemedicine services and the option for live virtual appointments.
- Advanced knowledge translation and education for healthcare professionals.
- Improved quality of life and health outcomes, through extensive patient training for insulin pump and continuous glucose monitoring devices.

The staff at The Charles H. Best Diabetes Centre offer 24 hours a day wrap around support for patients and families. The specialized and tailored approach means the Best Centre has a better understanding of the patient's overall lifestyle and the factors that impact their daily decisions. The team of multidisciplinary experts are then in a better position to provide direct solutions to the management of this very fatal disease.

From Lorne Coe, Member of Provincial Parliament (MPP), Whitby

Self-management is a key component of improving the management of type 1 diabetes. The ability of individuals to self-manage their condition 365 days per year has a powerful impact on their health and well-being. The Charles H. Best Diabetes Centre plays a pivotal role across the region of Durham in improving diabetes care outcomes for thousands of residents living in the region. The programs and services designed by the excellent and caring staff at The Charles H. Best Diabetes Centre help prepare and empower local individuals to assume greater control and responsibility for daily healthcare decisions, and continue to live fulfilling lives.

WHAT MAKES US SPECIAL?

The specialized care offered by the staff of the Best Centre has set it apart from any other healthcare options available to T1D patients. It is the only one of its kind in Canada. It truly is a special place!

At the Best Centre:

- We understand the disease does not take a break so neither do we; patients have access to an educator 24/7 once diagnosed.
- We continue interdisciplinary care into adulthood and senior years, preventing possible medical complications and hospitalizations.
- Care is delivered in the right place and helps to minimize patient stays in hospital.
- All perspectives are considered with a focus on the patient needs in the moment.
- There is no limit to the number of clinical interactions with our team.
- Care is delivered at the right time with the latest technological developments.
- Our intervention reduces emergency visits and admissions to the hospital.
- Our interdisciplinary clinical team includes Physicians, Registered Nurses, Dietitians and Social Workers who provide frontline care and education throughout our patients' lifetime.

WHY EXPAND THE BEST CENTRE?

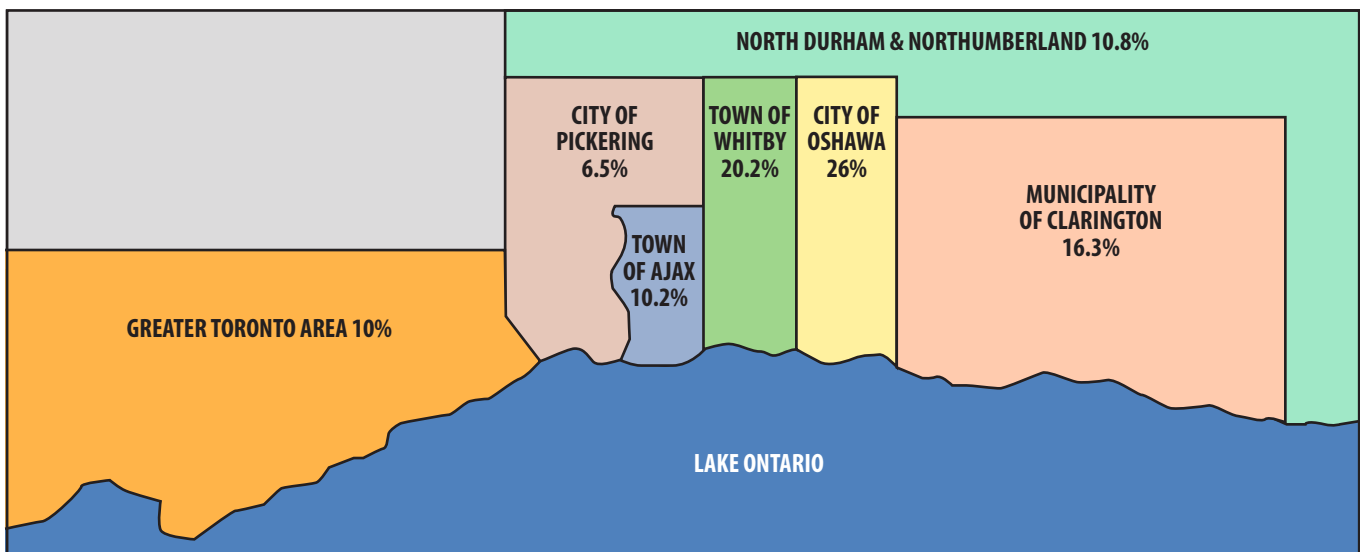
The Charles H. Best Diabetes Centre is located in an area that is the epicentre of Durham Region. We know the region of Durham is moving towards tackling a housing shortage under a comprehensive “Master Housing Strategy”, solving the future of broadband access and working with hospitals to usher in a new healthcare administration. We also know the region of Durham, more specifically, the north centralized area of Whitby and Clarington is the last frontier for suitable building land to get any of the above accomplished. At the centre of this growth is The Charles H. Best Diabetes Centre, which is perfectly located to help the growing number of families that are in the area and surrounding communities.

There is no question of whether there will be more patients, rather a forecast of how many. We are faced with a variety of mitigating factors, many of which drive the demand for proactive education and support for all patients living with type 1 diabetes. The Best Centre must continue to grow in order to support the growing community of people and T1D patients coming to Durham Region.

Today, there are close to 2,000 patients who rely on the Best Centre to receive the care they need and deserve. Eighty-five percent of the Best Centre’s patients come from every corner of Durham Region (see Figure 1), from across the Greater Toronto area and other provinces. We know Durham Region expects an astounding growth in population (up by 75% to 1.2 million people¹) over the next two decades. As such, we must plan for the infrastructure needed, which includes healthcare services and our contribution within the larger healthcare system.

¹ (<https://www.durham.ca/en/doing-business/envision-durham.aspx>)

The demand for our patient services has increased at an annual average of 14.5% over the last decade. Patients and families come from all 8 area municipalities: Ajax, Brock, Clarington, Oshawa, Pickering, Scugog, Uxbridge and Whitby. TAs of 2022, the Best Centre will see over **2,000 patients and conduct over 22,000 interactions per year, the estimated impact is to at least 16,000 Durham residents (families, friends, classmates and colleagues). In fact, the Best Centre will need to double in size by 2027** with an estimated future demand indicating a growth of **93%** over the next ten years.



We can't imagine a world where we turn people away.

The Best Centre has changed our lives. I am a patient and a mom of a patient, and in previous programs I was unable to self-manage my T1D in a way that would prevent organ complications. Now, we are fully supported and a respected part of our own healthcare team where we can manage well every day.

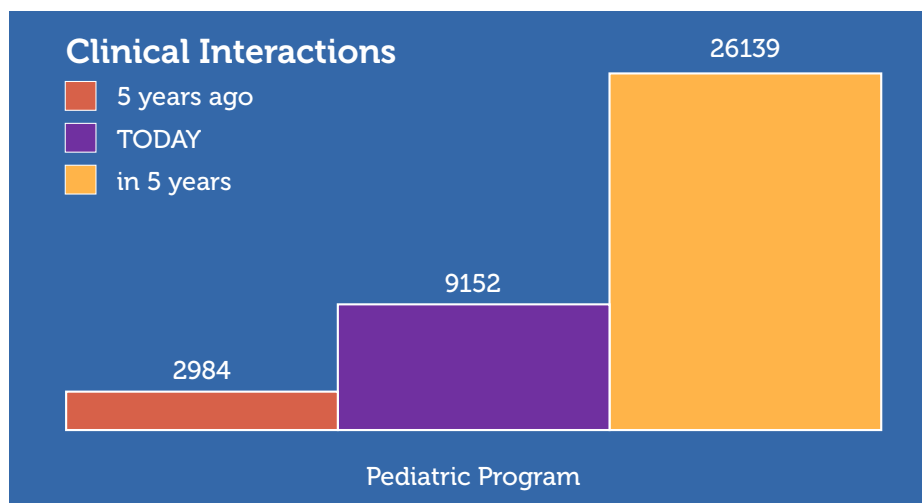
Dr. Chris Montgomery (prominent Durham pediatrician) shares,

I moved to Durham in 2000 feeling a little disillusioned. When I started working at The Best Centre, I found what I thought was an example of how a healthcare facility should be run—truly patient-centred, multidisciplinary and staffed by compassionate and dedicated professionals. Marlene, I couldn't help but be overwhelmed by your fierce determination, wisdom and commitment. I still am. Durham Region is forever in your debt.

THE NEED IS NOW

In the early years of the Best Centre, it was the financial contributions of the T1D community and a few corporate partners that ensured children, adults, and their families had access to expert type 1 diabetes care. However, over the years the Best Centre has become the leader in this care, hence the need for Building on the Best. The need is now. The Best Centre has outgrown its space and must take steps to be prepared for the next generation of T1D patients, while the research continues for a cure. The most recent numbers tell the story. In the past 5 years, there has been a major increase in interactions within the pediatric program, notably a greater than 3-fold increase and a projected need for 30% more year over year in the next 5 years.

A clinical interaction is any communication between an educator and a patient or caregiver including a health assessment and/or counselling, either in person, on the phone, by email or telemedicine. The all-inclusive nature of the centre's care model is such that we have always been available to our patients. The issue we are facing now is that we can't keep up with the demand and growing number of patients requiring our support. This is particularly impacted by the astonishing rate of advances in medical technology like insulin pumps and glucose monitoring devices.



We expect an increase in active patients by **1.7 times** in the next 5 years. Therefore, the need for the campaign is now with a goal to break ground (phase 1) by year end 2022 and the renovation of the existing space (phase 2) being completed the following year.

THE CAMPAIGN: BUILDING ON THE BEST CAMPAIGN

In response to the growth, forecasted demand and need for more type 1 expertise, The Charles H. Best Diabetes Centre has launched the Building on the Best campaign, a capital expansion fundraising campaign to raise \$5 million to meet the needs of a growing T1D community. The Best Centre has outgrown its capacity, requiring professional clinical staff to share offices and treatment spaces.

The architectural design plans for expansion of our current site include:

- an impressive end-product of 18 patient counselling rooms (up from 7)
- a new large event and education space
- 6 leadership, education and healthcare spaces and an additional clinic room with play areas
- full 1st floor accessibility
- improved privacy and layout of new addition (Welcome Area/Reception) that will connect the two original structures

The Charles H. Best Diabetes Centre's Building on the Best campaign is critical to meet the needs of a growing T1D community. The campaign will ensure our one-of-a-kind organization with a variety of educators including nurses, dietitians and social workers will continue to provide direct care, education and support to patients and families coping with type 1 diabetes. The donor dollars from the Building on the Best campaign will enable us to expand and renovate within our current site. People have often commented on how lost they would be without The Best Centre. After more than 30 years of success, the centre has garnered national respect within the type 1 community, as a unique, specialized and unmatched diabetes education team.

The Building on the Best Campaign is about staying ahead of the curve to support self-management of this fatal and dreadful disease. It is about growing alongside a growing region which finds itself in an unfortunate scenario. With growth comes untapped opportunity, however, growth also brings the need to ensure those coming to the region have the services they deserve. The Building on the Best Campaign is about expanding a centre that is ready to provide the level of multidisciplinary care our patients and families have relied on for over 30 years.

The new Best Centre will be a full site upgrade to ensure services can be delivered without compromise for the next generation of T1D patients. The expansion now means families dealing with T1D can have:

- Access to more counselling services by exceptional medical experts in order to continue their wrap around support model families have become accustomed;
- An event space to host educational workshops, seminars and conferences located at the epicentre of Durham Region;
- A place to bring their loved ones, to keep them away from an emergency department; to contribute to the goal of ending "hallway medicine".
- The after-hours urgent care program is very busy with about 450 care interactions per quarter.
- The estimated savings to the healthcare system is \$180,000 per annum for hospital admissions avoided.

The Building on the Best campaign is about building towards the future and being ready to meet the demands of a region that is growing. Many from across the province will make their way over to Durham Region to take advantage of the last real frontier of growth and opportunity in Ontario. Building on the Best campaign is about being ready to welcome and support the many T1D families we know will be part of that wave of new residents to the region.

FINAL THOUGHTS

There is work to be done. There are families waiting, devastated by the news of a T1D diagnosis and its life-threatening complications. The phone is ringing and the Best Centre staff must continue to answer the call; they are the only ones who do this work.

The staff make type 1 diabetes their specialty so patients and their families don't have to worry about getting the right information, from the right people, at the right time. The Best Centre is here for patients and their families, to teach them, to help them cope, to make the best of every day---the centre is here to help patients and families sleep at night. Patients learn what they can do, not what they cannot do. Our staff are here to fully support all patients and teach them how to avoid devastating outcomes of this potentially fatal disease.

A new diagnosis can occur anytime and anywhere. With a call from your family physician or from the intensive care unit, no matter where the call comes from, our staff will work to ensure families get the care they need now and throughout their lifetime.

The Charles H. Best Diabetes Centre, and the real-time support it provides, is a vital service. The cost of doing nothing is unimaginable. The local hospitals are not equipped to provide type 1 diabetes expert care to the residents of our communities. The provincial insulin pump program oversight would fall by the wayside, making it impossible for patients to get the funds they deserve to live well with this fatal disease. The patients, their families and the T1D community would suffer.

Financial contributions will ensure children, adults and their families living in the region of Durham and beyond, have access to expert type 1 diabetes care. The Building on the Best campaign will help The Charles H. Best Diabetes Centre achieve its goals. The Building on the Best campaign is about building to meet the future together. It's about delivering **frontline** care to patients and families who are waiting for a cure. Ultimately, it's about building on the care.

By Building on the Best Centre of the future, we are building on specialized care for T1D patients by shining a light on this national beacon.