

# PORTRAITS OF --- DIABETES

**10**  
**YEARS**  
2007—2017  
ALBERTA DIABETES INSTITUTE

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## Bringing the Best Together

The University of Alberta has a remarkable legacy in diabetes research that extends from the first clinical use of insulin nearly 100 years ago to leading the world in islet transplantation today.

**Our ultimate goal is to improve the lives of people living with diabetes and to find the cure.**

## Working Together Under One Roof

The Institute brings together some of the world's leading diabetes researchers from disciplines that range from cell biology to nutrition/metabolism and physical activity to population health.



# PORTRAITS of DIABETES

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# PORTRAITS OF DIABETES

World Diabetes Day — 14 November 2017 — marks 10 YEARS of the Alberta Diabetes Institute opening its doors at the University of Alberta.

Portraits of Diabetes is a celebration of this milestone.  
A portraits series offering a glimpse into what it's like to live with diabetes  
— the highs and the lows.

One million people in Alberta have diabetes or prediabetes.  
With 1 in 10 deaths in Canada attributed to this disease.

**There is no cure right now.**

But progress is being made through diabetes  
research happening right here at the Alberta Diabetes Institute.

Portraits of Diabetes is a reminder of the importance of continued diabetes  
research and understanding the impact diabetes  
has on the lives of a million Albertans.





# KEISHA

Keisha Cardinal holds the blanket that's been a source of comfort to her since the age of 10, when she awoke in a hospital bed feeling scared and vulnerable.

She had been visiting her grandparents, who had a stomach flu. When she came home with similar symptoms, her parents didn't realize the traumatic situation that was unfolding. She had undiagnosed type 1 diabetes and her severely high blood-sugar level resulted in a coma that lasted two days.

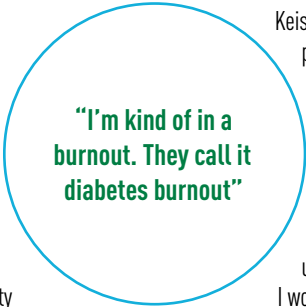
While Keisha was in the hospital recovering, a woman came to her room to comfort her and gave her a homemade blanket. Later, Keisha's family tried to find the woman to thank her, but nobody who worked at the hospital knew who she was and the family never did track down the mystery visitor.

Now 21, Keisha—a member of Swan River First Nation—receives comfort and support from her family and community, from whom she's rarely felt any judgment due to her diabetes. Every year her family—including her dad, Cory, a police officer—offers community presentations, where they tell their story and share facts about diabetes with the goal of educating as many people as possible.

Becoming an adult has brought a huge shift for Keisha; when she was a child, her parents took care of her disease, but now she has to take the reins. Monitoring her blood-sugar levels on a strict schedule requires constant vigilance. Managing diabetes is like working a full-time job without any breaks, which has resulted in Keisha feeling overwhelmed and unmotivated. "I'm kind of in a

burnout. They call it diabetes burnout," she says.

Four years to the day after Keisha was diagnosed, her younger brother Steven was told he also has type 1 diabetes. But father Cory says the circumstances of the two siblings' diagnoses were miles apart. "Keisha went through this really traumatic experience—we all did. And then when she came out (of the hospital), we were really on edge for a long time. I think we put fear into her when we didn't have to," says Cory. But with her brother, they had been looking for the symptoms for a long time and were very prepared once the diagnosis was made.



**"I'm kind of in a burnout. They call it diabetes burnout"**

Keisha's outlook is becoming more positive, with plans to continue improving her health. When she was first diagnosed, both Keisha and her parents went through training to learn about the disease, but because she was so young, she doesn't feel like she really understood the information. "And so I would like to do the training for myself so I know, because [my parents] know more than I do," she says. She believes that information and professional support would help alleviate her burnout.

And Keisha has other plans for her future. After completing academic upgrading she would like to become a registered nurse so she can make an impact on others the way the compassionate woman with the blanket helped her during her hospital stay 11 years ago.

**The Alberta Diabetes Institute is working towards our ultimate goal of improving the lives of people living with diabetes and finding a cure.**

# SIYAPREET

It was barely the beginning of summer break, but eight-year-old Siyapreet Brar was already preparing for the third grade by collecting the pencils and art supplies she would need for the upcoming school year. Her most recent report card was full of As, including one grade she proudly explains she was able to improve.

But she wasn't just excited about school itself; she was also looking forward to spending more time with her best friend, Sarah, as the two share a special bond. Both eight-year-olds have type 1 diabetes—Sarah was diagnosed a few months before Siyapreet—and they've been able to navigate the difficult experience together, while educating their classmates about a disease that even many adults struggle to understand.

"We're in sync and if ever she gets hurt, I help her. She says, 'If ever you get shaky, just tell me, and I'll bring you right away to the classroom,'" says Siyapreet.

On World Diabetes Day in 2016, Siyapreet was able to show her appreciation for their friendship. After winning the Alberta Diabetes Foundation's colouring contest, Siyapreet asked Sarah to share the reward—and the friends were junior researchers for a day at the Alberta Diabetes Institute. They met world-renowned researchers and even had a chance to partake in some research themselves in a behind-the-scenes look at the institute's cutting-edge facilities.

The support of doctors and researchers has made a huge difference for the Brar family, who were shocked when Siyapreet was diagnosed at the age

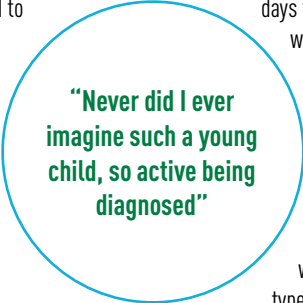
of six. "Never did I ever imagine such a young child, so active [being diagnosed]—there's always the stereotypical thing, where you think it can't happen to healthy people. But it just happened all of a sudden," says Siyapreet's father Raj.

After a routine diagnosis, explains Raj, the doctor immediately admitted Siyapreet to the Stollery Children's Hospital, where she stayed for three days to be treated and monitored. "It was phenomenal to know your whole life was turned upside down, but you have people who can guide you through, walk you through," says Raj.

At the same time, Siyapreet was diagnosed with celiac disease, which can occur in conjunction with type 1 diabetes. Both are autoimmune disorders that are a result of the body's immune system attacking healthy cells. Her celiac disease is severe, which means any type of cross-contamination between a product with gluten and one without can negatively affect her health.

"I even have my own separate toaster and my own frying pan and my own waffle iron, and my own butter. And there's my own section where I put my gluten-free stuff in the fridge and my own peanut butter, and my own jelly and everything [that is] my own," says Siyapreet.

Over the past year, she's gained a great deal of knowledge about both conditions, which is obvious as she lists the many products she can eat and the ways she keeps herself safe, and demonstrates how she can read her blood glucose monitor. "It has a red light, a blue light and a green light," she explains. "Red is for high, blue is for low, green is for good."

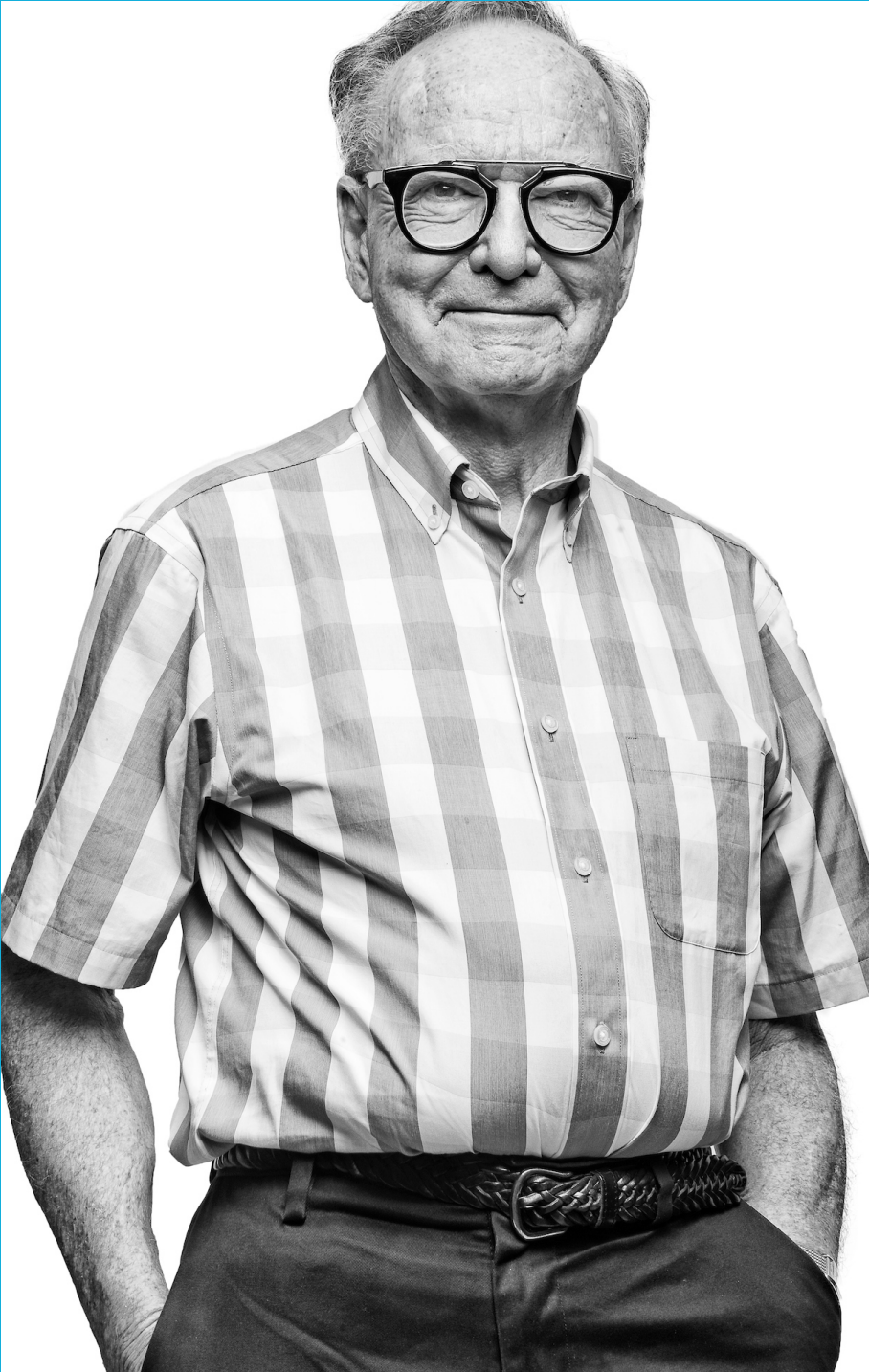


**"Never did I ever imagine such a young child, so active being diagnosed"**

**The Alberta Diabetes Institute continues its relentless pursuit of the discovery of new therapies and methods to prevent, treat and ultimately cure diabetes.**







# BOB

On the sixth floor of the Alberta Diabetes Institute, Bob Teskey looks out a wall of windows at the expansive view of the University of Alberta campus.

New structures intermingle with the original buildings and pathways that Teskey traversed years ago as a young student of the arts, and later law.

He walked those routes every day, but sometimes he wouldn't reach his destination. Instead, he'd wake up to the familiar faces of ambulance attendants whom, he laughs, he was getting to know on a first-name basis.

At 14, Bob was diagnosed with type 1 diabetes, an autoimmune disorder in which the body attacks insulin-producing cells in the pancreas, often resulting in irregular blood-sugar levels. While some people with diabetes can tell when their blood sugar dips—they sweat or feel weak or nauseated—Bob would feel fine one minute and be unconscious the next.

"One of the strategies you have is that you don't let it be all consuming," says Bob. "You carry on with your life."

Bob did that by becoming a lawyer, managing his diabetes alongside a demanding professional schedule until he got a call from his endocrinologist in 1999. The doctor told him his undetected low blood-sugar levels made him eligible to be one of seven to take part in the clinical trial of the Edmonton Protocol. Donor islets—cells within the pancreas that produce insulin—would be transplanted into his liver with the hope they'd produce insulin.

For Bob, it wasn't a question of whether he should do it; he simply asked where and when he should arrive. "When I was diagnosed, I was told there weren't any


days off, there weren't prospects for cures. So when I was given the opportunity to participate it was really like a miracle," says Bob.

Islet transplant research at the U of A began in the 1970s, and the university performed Canada's first islet transplantation in 1989. By 1999, nearly 270 patients had undergone this procedure, but only 10 per cent maintained insulin independence beyond a year.

With the Edmonton Protocol, all patients remained insulin independent after one year and many reached five years of independence. Bob achieved four years of insulin independence with his first transplant, and another four and counting now with the second. The procedures dramatically improved his quality of life.

Results of the trial were published in the *New England Journal of Medicine* in 2000 and have set the international gold standard for islet transplantation—more than 500 have been performed to date.

"Most of the health advances are a result of hard work done by research scientists who have good ideas and are quite prepared to spend days or weeks or years testing those ideas," says Bob. "I don't think most people fully appreciate that. They just assume that if we put our mind to it we can solve almost any problem, but the number of false starts and blind alleys we have to go down before we get to the finish line is really quite remarkable."



**"One of the strategies you have is that you don't let it be all consuming"**

**The Alberta Diabetes Institute has been built upon the remarkable legacy in University of Alberta diabetes research leading the world in islet transplantation today.**

# ANISSA

In 2016 Anissa Gamble had just started as a master's student researching diabetes at the University of Alberta when she experienced first-hand its impact. She observed an islet transplantation that would mean a patient could live without insulin injections for some time.

"I kind of had a tear afterwards. It was just phenomenal and amazing to see the research and progress going on here in the Alberta Diabetes Institute," she says.

Today, she stands at her work station in front of a test-tube holder marked with the name Shapiro. James Shapiro, Anissa's supervisor, is one of many Edmonton researchers known internationally for their work on the Edmonton Protocol, a procedure whereby healthy islet cells are transplanted into someone with diabetes.

This year marks 10 years after the Alberta Diabetes Institute opened its doors. Here, advances like the Edmonton Protocol have put the province on the international map, leading towards newer research that includes work done by students like Anissa. She's looking at how different cell types could help islet transplants become even more successful, and while her work is still in the trial stages, she's already witnessing the progress of type 1 diabetes research.

For Anissa, the work is especially meaningful due to the diagnosis she received at the age of eight. She had to leave a school field trip to go to the hospital, where she stayed for a week before being released on Christmas Eve with the knowledge she had type 1 diabetes. It was scary and emotional news for her, as diabetes had already impacted her young life—before she was born, Anissa's grandmother had died from the disease.

But Anissa was determined to be as healthy and positive as possible in the face of managing the disease. She's a talented hockey player, and on the ice she must continuously monitor her glucose levels. She always has a juice box at the ready in case her blood-sugar level dips, but she has come to believe

her challenges have actually put her at an advantage.

"I think that throughout my life, focusing on hockey has allowed me to have really good control in the sense that to do really well in hockey, I have to have really good glucose management," she says.

That focus became essential 10 years ago, when at age 15 Anissa moved from her home in Fredericton, New Brunswick to Oakville, Ontario, to attend boarding school while playing competitive hockey. She had to learn as a young teen to manage her diabetes on her own. Later, as an undergraduate student at Robert Morris University in Pittsburgh, Pennsylvania, Anissa played Division 1 NCAA, the highest level in university hockey.

At that time, she generally did not speak about her diabetes and did not know many people with the disease, which meant she often felt alone and unsupported. But a lot has changed since then.

At the end of August, Anissa was a part of the Connected in Motion 2017 Adventure Team. She was one of 13 North Americans with type 1 diabetes to participate in a fundraising backpacking trip along Vancouver Island's North Coast Trail; the goal was to challenge misconceptions of what diabetes means while connecting with others. The group managed to overcome many difficult challenges on the trail while raising \$25,000, which will help others with type 1 diabetes participate in activities and learn about their disease.

Anissa has also volunteered in research at the Alberta Diabetes Institute, taking part in studies that look at how different forms of exercise can impact blood-sugar levels. Throughout her life, she's benefited from diabetes research and now she's part of making a difference for others.

"I think it's a great motivator to see other people living and doing incredible things—this gives a sense of community. You're a product of your atmosphere and if you're surrounded by positive people, you'll do positive things," says Anissa.

**The Alberta Diabetes Institute provides an optimal training environment for trainee researchers, ensuring the continuity of diabetes research and development.**





# JAMIE

In 1997, Jamie Burke planned a diabetes charity event that his workplace hosted annually, where attendees had the chance to have their blood-sugar levels checked. As a test pilot, Jamie discovered his own blood sugar was at an abnormally high 24.5 mmol/L, a level that can lead to serious health issues. The next day, when he tested his blood again, it was at an even higher level. One of the volunteers doing the testing told him he might have type 2 diabetes. A doctor later confirmed it was true.

"It was the minor prick of the finger that told me. But prior to that, there were indications, like I would have dreams there was glass in my feet and I found I was looking closer to my computer screen at work. I went to see a podiatrist and they had no insights. I went to an eye doctor; he didn't find anything," says Jamie.

At the time, Jamie was working as a community investment adviser and attending parties every week, indulging in rich food and drinks at corporate events. He did not worry about how his lifestyle might affect his health. But everything changed after his diagnosis—for a while, he felt like he'd been handed a death sentence. He started to self diagnose by searching his symptoms on Google, where the variety of misinformation led to panic and confusion.

He had a health-care team consisting of a doctor, pharmacist and dietitian, who provided him with knowledge that eventually changed his perspective from fear to hope. He realized his diagnosis was not a death sentence at all; instead he now chooses to see it as a positive change in lifestyle.

"It's not even just for people with diabetes, it's for anyone. Know what you're putting into your mouth," says Jamie. "Eating like someone with diabetes, it's not rocket science. It's literally eating healthy and that's all there is to it."

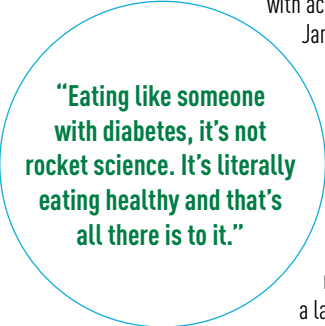
Jamie ended up changing his lifestyle completely—he went from drinking pints on public patios three nights a week to spending time on his own private patio, tending a vegetable patch full of organic lettuce, tomatoes and cucumbers.

While Jamie's diabetes management has gone well over the years, he has noticed a problem with access to medication. Nowadays,

Jamie works with charities and organizes events as an independent contractor, which means he has to get coverage for his medication through a personal health insurance company. Unfortunately, his plan only covers a small portion of his medical costs for the year, leaving a large bill at the end of each month.

Finally, his doctor told him about a free prescription savings card available to Canadians and funded by participating pharmaceutical companies.

Using this service has worked out for him, but he says it's frustrating the amount of research and digging people have to do to determine ways of getting medications without exorbitant costs. The difficulty can mean some people fall between the cracks of the system. And not only are many people continuously bombarded with conflicting health information, they also have to wade through the many different ways of trying to cover the cost of their treatment.



**"Eating like someone with diabetes, it's not rocket science. It's literally eating healthy and that's all there is to it."**

**The Alberta Diabetes Institute performs clinical research studies in vital areas that impact the onset and management of diabetes, which is a critical step for translating new ideas into proven therapies in patients.**

# RICHARD

When Richard Siemens was five years old, in the summertime he would fall asleep on his parents' lawn after eating dinner. It wasn't until he went into a coma one evening that it became apparent he had type 1 diabetes.

It was the late 1950s, when treatment involved insulin injections using a syringe sharpened with a stone and a glass barrel that had to be boiled after each use. One of the devices Richard recalls using most was the Dr. Busher's Automatic Injector, patented in 1932, which allowed a child to quickly inject insulin with just one click.

"Because if kids try to do it slow and shaky, it doesn't work. So I had that thing for years—it was an ugly little contraption," says Richard. "Everything was ugly in those days." Today, improved treatment options range from much smaller needles to a pump that regulates the amount of insulin secreted to the patient throughout the day. There are also advanced surgeries that can result in insulin independence.

By 2005, doctors said Richard would need dialysis due to kidney failure. Since 1972, he'd been working as a photographer, a passion he'd had since the age of nine, and he didn't want to postpone his work while getting treatment. That meant that for three and a half years, three days a week, he would work until around 5:30 pm, then go to the hospital and dialyze until around 11 at night.

"I'm always my own test subject, so I have a visual diary," says Richard. "And sometimes I look back and go: 'Really? You were working full time when you were going through that?' It does amaze me."

One of his photography projects at the time involved capturing images of individuals with diabetes for the Alberta Diabetes Institute opening in 2007, including a self-portrait that now acts as a reminder

of the challenges he faced. In the photo, he wears a protective boot because a small cut on his foot had developed gangrene, resulting in a toe amputation. Those with diabetes are at risk for amputations, especially in the legs and feet, as conditions such as peripheral neuropathy can deaden the sensation of pain, resulting in infection from the continued pressure of walking on the injury.

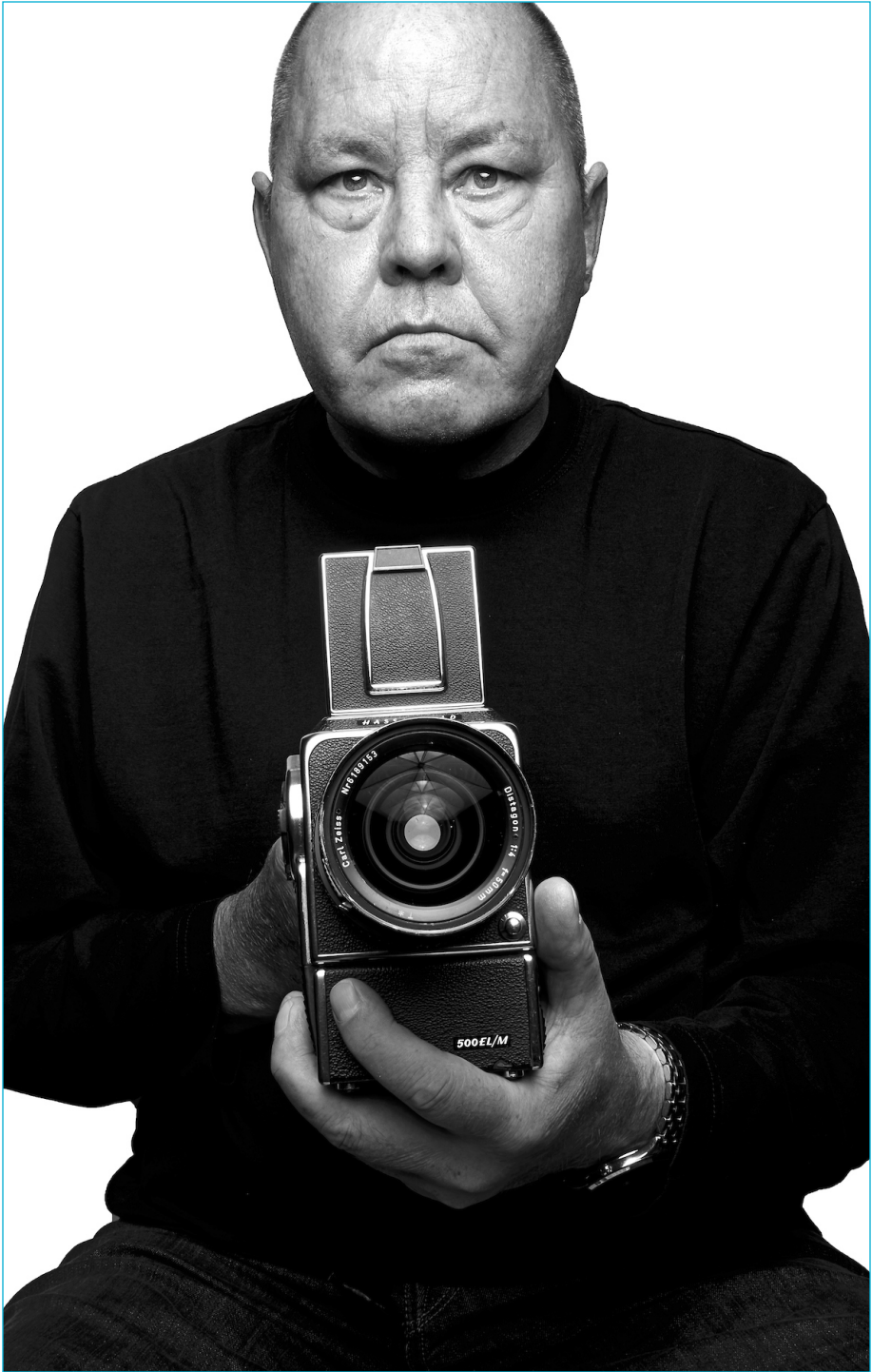
In 2009, he had to have both a pancreas and a kidney transplant. He spent four months in the hospital facing an extensive recovery, overcoming the physical hurdles that small, everyday tasks had become. Taking a shower meant wrapping part of his body with plastic wrap to protect the IV and needles needed to maintain his health. And, to regain his strength, he had to lift weights and walk stairs each day, under the guidance of physiotherapists, whom he jokingly called "physioterrorists."

When he was released, he still had sutures and he had to be careful traversing the 13 steps within his 1910 character home. Since the transplant, Richard has done well. He'll take immunosuppressant drugs indefinitely and now his doctor recommends injecting a small amount of insulin daily just to give his pancreas a break.

People with diabetes don't want to be seen as victims, he says; the disease is just another part of their existence. "The media tends to go on about 'poor little Johnny has to take 40,000 injections in his life.' Ultimately insulin is what keeps those with diabetes alive, as does exercise and diet," he says. "It's all about balance. Mostly, it's a pain in the butt, but it could be worse. Hemodialysis is the same, but on the next level. Yeah, nobody wants to do it, but it kept me alive. Insulin, pumps, pills, transplants—they're all just treatments that for some lucky ones might keep them alive long enough for a cure."

**The Alberta Diabetes Institute plays an important part in the continuity of research and development providing scientists with direct access to services that allow cutting edge diabetes research.**







# KAILAN

Kailan Siegel sits with her mom Christine discussing her future. Ten years ago, Kailan had her photo taken for the grand opening of the Alberta Diabetes Institute at the University of Alberta on World Diabetes Day, November 14. Then, she was six years old and her mom was managing her diabetes with insulin injections and glucose monitoring day and night.

Now, she's having her photo taken again—this time to celebrate the 10 year milestone—and a lot has changed in her life. At 16, she will soon have to navigate her diabetes management on her own with less support from her mom and even the health-care system. Next year, she'll move from pediatric care to the adult system, where there is far more responsibility placed on the patient.

It's a move that weighs heavily on Christine's mind, as she knows the difficulty of managing the disease. There have been times when she's had to give Kailan a needle in the middle of the night without her daughter even waking up. While Kailan usually sleeps through those moments, she does remember when she first started receiving insulin injections. For the first three months, she had to be pinned down for each needle.

"I remember hiding under my bed," says Kailan, who has never really overcome that fear of needles.

When Kailan was diagnosed at the age of four, her mom realized she had already been worrying subconsciously about the diagnosis for years. Christine recalls a recurring dream she had as a child, in which she was being held down and someone was giving her needles. But the day when she walked into Kailan's pediatric room and recognized it as the setting of her childhood dream, she realized it had actually been about Kailan.

Because of those dreams, today she believes that the deep concern for Kailan that consumes her daily life now was hard-wired into her subconscious even before she gave birth to her. And while Kailan may be scared of the needles, Christine is more afraid of what they symbolize—the constant vigilance needed to ensure her daughter's health.

Kailan is now on an insulin pump, a device that delivers basal insulin continuously to maintain blood glucose levels between meals. The pump can also be programmed to dispense a larger amount of insulin during meal times as needed. This form of treatment is generally considered more precise than insulin injections, but still requires a lot of monitoring and adjustments to perform properly.

But Kailan is confident she can manage it, especially with the support of friends with diabetes she's met through summer camps. "The friends I have—one goes to a different school—she'll text me every time at lunch asking what are my sugars and did I check. So I have my friends to help me. I'm worried financially [about being an adult with diabetes] but not otherwise," Kailan says.

"What about site changes?" asks her mom, referring to the small needle attached to an insulin pump that needs changing every few days. "There is that one," admits Kailan. "How about trying to figure out the pump on your own?"

"Doctor," comes her immediate response.

"I'm worried now," says Christine, "because a girl who was diagnosed close to the same day as she was—she's an adult now and she's been hospitalized twice because she doesn't take care of things and it's minimal support. I've heard through the adult clinic." And she has other stories—another young adult is in early-stage kidney failure, and another's blood-sugar levels are erratic due to infrequent doctor visits.

Despite the challenges that will come with managing her diabetes independently as she becomes an adult, Kailan is excited about the idea of starting university in a few years. Currently, her interest is in the field of kinesiology, and she anticipates she will remain in the province while studying so she can continue being insured for her pump through the Alberta government.

**The Alberta Diabetes Institute researchers are deciphering the mechanisms leading to secondary diseases with a focus on developing clinical treatments to reduce diabetes-related complications.**

# KIRA

Kira Heck was just 19 years old when she found out she had type 2 diabetes.

In her Grade 12 year, Kira gained 60 pounds and was exhausted much of the time. Then, in her first year of classes at Concordia University in Edmonton, she developed large welts on her body. The symptom baffled six different specialists, who believed the welts may have been allergy related.

After six months, Kira was accurately diagnosed with hypothyroidism and while the welts started disappearing, the extreme lethargy remained. One of the doctors thought maybe she had narcolepsy. The delay of her type 2 diabetes diagnosis may have been because she was so young.

When the correct diagnosis was finally made, it not only surprised Kira, but also defied statistics. Type 2 diabetes is usually diagnosed later in life, often after the age of 40.

According to the Public Health Agency of Canada, all cases of diabetes in young people in the past were believed to be type 1, so much so that type 2 diabetes used to be called adult onset diabetes. But in the last two decades, with risk factors including ethnicity, being overweight and inactivity, the incidence of type 2 diabetes in children has increased dramatically.

After her diagnosis, Kira drastically changed her lifestyle. She went from rarely eating vegetables to trying to incorporate them into her diet every day, being more active and trying various medical

treatments prescribed by doctors. Some medicines made her very ill, while others have been helpful in managing her blood-sugar levels.

She works in a job that allows her to be active during the day and she tracks her daily exercise using a step counter. "My exercise specialist said, 'Park far away...' or 'Don't take the groceries in all in one load.' Like, do two loads because it's the extra walking," says Kira. "Just changing very small things about your life. Things that you wouldn't normally think about."

But even now, a few years after her diagnosis, she says management of her diabetes is not easy and is constantly shifting. Part of the problem is that it's a relatively new challenge for many doctors to navigate

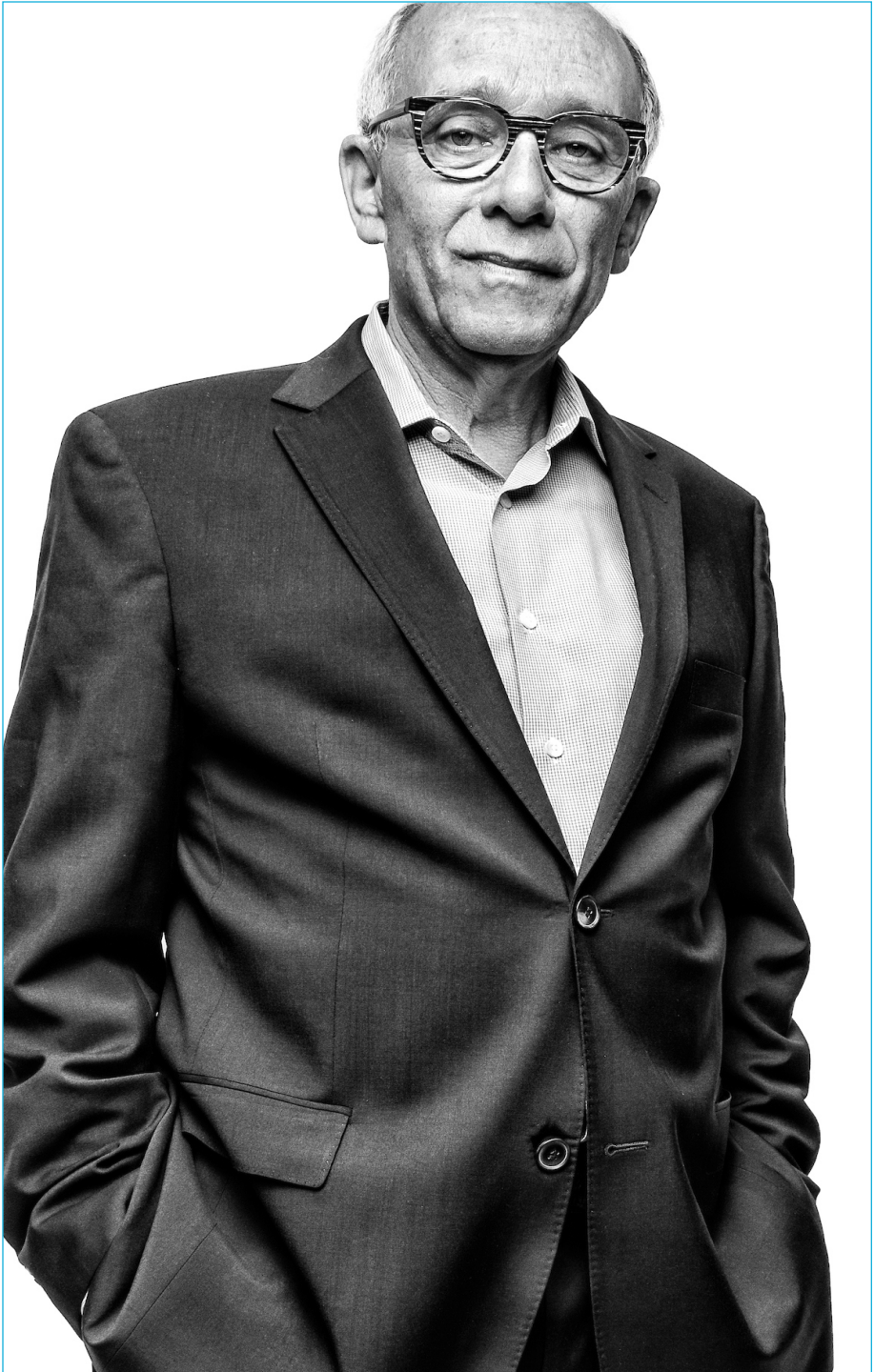
issues associated with type 2 diabetes specifically in young people. For example, there are challenges with helping women with type 2 diabetes maintain a healthy pregnancy, as research on this is relatively new. Kira would like to start a family, but finding support for her health issues has proven difficult.

To complicate matters even further, says Kira, there are varying levels of severity in type 2 diabetes, meaning that what will work for one person may not be effective for another. "Nobody has the right answer for you, unless you're one of those people who falls into the textbook [definition of diabetes]. So you have to ... just do what makes you feel best," says Kira.

**"Nobody has the right answer for you, unless you're one of those people who falls into the textbook definition of diabetes"**

**The Alberta Diabetes Institute brings together scientists from multiple disciplines in a collaborative fight against the complex disease of diabetes.**





# STEPHEN

When Stephen Mandel was mayor of Edmonton, his mind was occupied with more than attending countless meetings and making important decisions for the city. He was also watching his blood-sugar levels and maintaining his health, since just a few years prior he had been diagnosed with type 2 diabetes.

Even though he was very busy, treatments worked well for him and his management of his condition through the years has gone smoothly with a consistent focus on an active lifestyle. Being physically active has always been important to Stephen, who is now the chancellor for Concordia University of Edmonton: He plays tennis three mornings a week, works out three days a week and has played baseball on a slo-pitch team for as long as he can remember.

But he's quick to point out that it's not easy for everyone.

"For many people with diabetes, it's a life-controlling disease. I have many friends who are people with diabetes and are far more careful than I am, and it has a major impact on their lives," says Stephen.

Now, 10 years after the Alberta Diabetes Institute opened its doors, Stephen says he's proud to see the role Edmonton has played—and continues to play—globally with regards to diabetes research.

"You know, there's far more being done than us lay people know. And the evolution in the next phase of controlling diabetes—Edmonton is right in the centre of it," he says. "I'd like to see more invested in it."

Stephen says as mayor he deeply believed in the work that was happening at the University of Alberta, and saw it as a driving force in the community. It's

why he made sure the city and the university had a strong relationship. "As a matter of fact, when I was no longer mayor, I went and spoke with a bunch of university professors about co-operation between cities and universities and I was shocked to hear it isn't the norm—that most cities and universities are in conflict."

In 2014, he became health minister for the Alberta government—a position he held for a year—and in his role, he says, he saw investing in research of all kinds as fundamental. While he's impressed by the diabetes research done in the last 10 years, he anticipates the next decade will hold surprises that he can't yet imagine.

He believes there may be a cure, but he also hopes to see more measures to promote healthy lifestyles—especially those focused on physical fitness—put in place.

Stephen worries that younger generations are losing the desire to be physically active and hopes society will see a shift back to more active days. "I think we have to change how we do things and there's a real need to begin to socialize young people into putting their phones down and going to the big baseball field. I think that we've really lost sight of physical education and physical fitness," says Stephen.



**"...the evolution in the next phase of controlling diabetes—Edmonton is right in the centre of it"**

**The Alberta Diabetes Institute continues to push the limits of what we know, while our population health research drives us in the direction of new approaches for preventing and treating diabetes.**

# DANA & ROSS

After Dana Kanerva was diagnosed with type 1 diabetes at just three years old, her parents had to give her needles throughout each day and sometimes even in the middle of the night. It was a difficult learning curve for everyone involved, never mind a toddler.

But Dana adjusted well and understood from an early age the importance of monitoring her disease. "She suddenly had to be the most responsible three-year-old. She had to grow up at three; she didn't get to have a regular, carefree childhood," says Laurie, Dana's mom.

By the age of 10, Dana was a nationally ranked competitive diver, often travelling on her own and spending time at the pool without her parents. She enjoyed competing, but a complex schedule of training and maintaining her health led to diabetes burnout.

While burnout can happen to anyone with diabetes, it was particularly challenging for Dana, with the added intensity of her competitions. She decided to stop diving at a competitive level when the pressure became difficult to handle, but now she pursues other passions, including soapstone carving and academics.

Dana is the oldest of three children—Eric, her youngest sibling, doesn't have diabetes, but Ross, the middle child, was diagnosed with type 1 at the age of six. While the family knew what was coming, there was an emotional toll from having to manage the disease, especially the needles, which can be scary for a small child.

"It made me less social and more scared to talk to people. It definitely raised my level of anxiety, and it didn't help my depression," says Ross.

Laurie and her husband Jim also struggled emotionally and mentally, especially when the kids were younger and everyone was still learning about the disease and its treatment. Their experience during the early years after Dana's diagnosis is chronicled in Jim's book, *Dana's Disease*, written while he was director of the Alberta Diabetes Foundation.

Laurie says now the challenge is watching as their adult children learn to manage on their own — 20-year-old Dana is at the University of Alberta studying history and classics, while Ross, 18, is taking environmental science at Lakeland College.

Sometimes, Laurie covertly calls Dana's boyfriend just to ask how she's doing and she often texts Ross to see how his blood-sugar levels are faring.

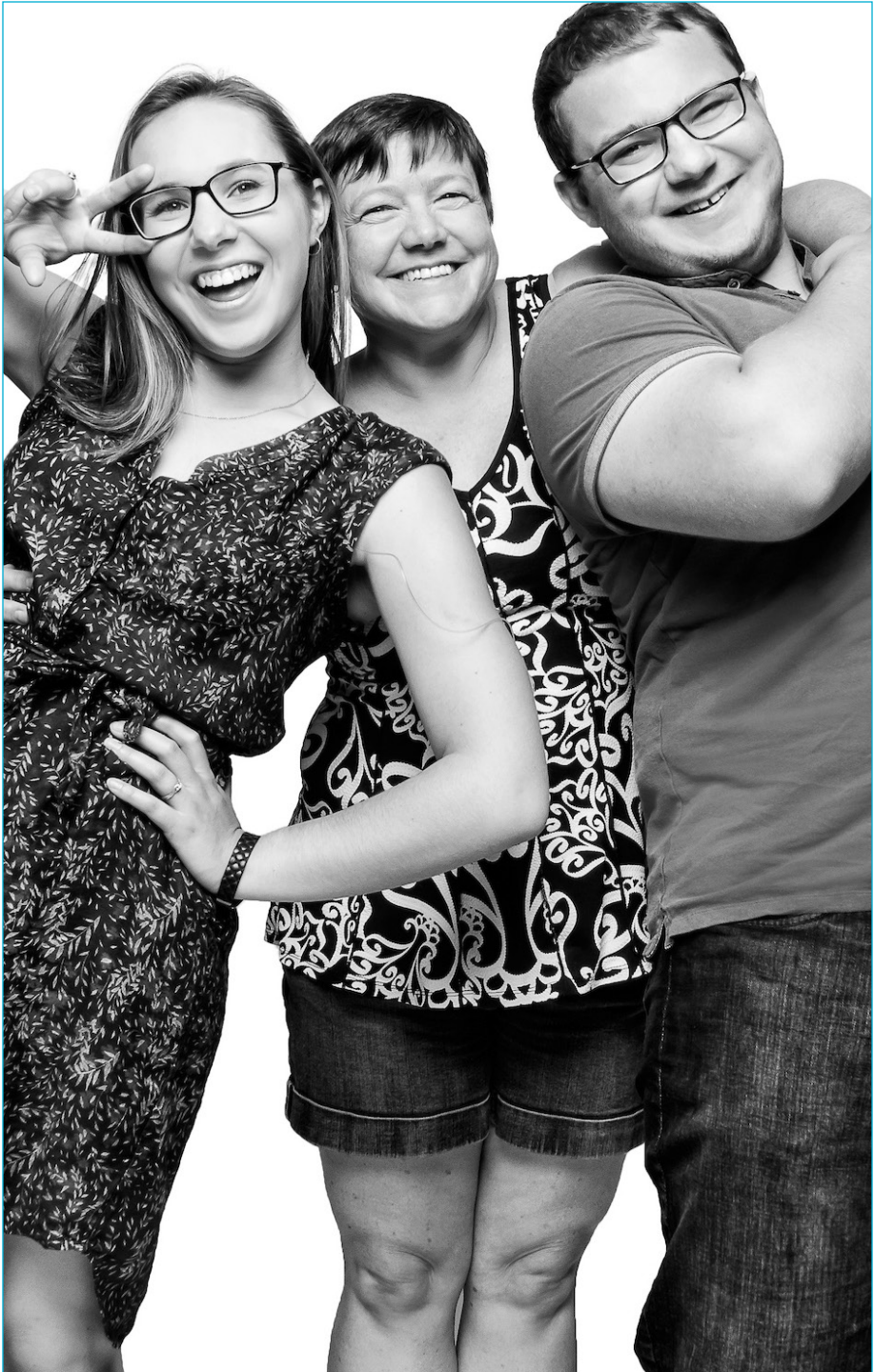
Dana and Ross agree that while they may have balked at their parents' help in younger years, there are times now when it comes in handy. "When I'm at school by myself, I really appreciate the nagging sometimes," says Ross. "Because every once in a while, I just forget to do stuff."

As the siblings grew older, they moved from pediatric care to adult care with some help from a transition clinic and with the years of knowledge passed down from their parents. "And then, when I moved to the adult clinic, I realized I don't need to be perfect and I can't expect that from myself," says Dana.

"All you can expect of yourself is not to give up. Just keep trying," says Laurie.

**The Alberta Diabetes Institute is the largest freestanding diabetes research facility in Canada, providing an environment where research is integrated into practical applications with access to state-of-the-art facilities and equipment.**







# ARUN

Thirteen years ago, Arun Patel was held in a Hong Kong airport for nearly three hours while security questioned him about the contents of his carry-on luggage. The delay nearly cost him his flight connection on the way from India, where he grew up, to Edmonton, where he now lives.

Arun carried a doctor's note explaining that the items in his possession—syringes, insulin, tablets and juice—were all for treating his type 2 diabetes. "And finally, when they found out that legally I can carry all this stuff, then they rushed me to the plane," he says.

Arun, an entrepreneur and owner of two autobody repair shops, received his diagnosis in 1991, and he says that the experience in Hong Kong is just one example of a troubling lack of knowledge he has encountered about the disease.

While the prevalence of type 2 diabetes is rising worldwide, India in particular has experienced a sharp increase. This growth is often attributed to genetic factors that increase the likelihood of the disease, along with the recent decrease in people's physical activity and nutritious food consumption. Many people are unaware of the importance of a healthy lifestyle in diabetes prevention.

But that lack of awareness is not just a problem in India; Arun believes it can follow immigrants to their new home.

After Arun immigrated to Edmonton in 1982 with his family, the cold climate here meant he became far less active than he had been. At the same time, his daily food consumption did not change. He

worries that other new Canadians might face similar problems. "I wish somehow new immigrants would get this kind of education on health initially. In my opinion we could avoid some pre-diabetes conditions for many people," says Arun.

**"When it happens to you, it gives you a shock. I was like: 'OK, it'll never happen to me, and suddenly it does'"**

Arun discovered he had diabetes when he went to the doctor after losing 60 pounds, a symptom he did not realize could be linked to diabetes. "When it happens to you, it gives you a shock. I was like: 'OK, it'll never happen to me, and suddenly it does. Normal life is not going to be 100-per-cent normal. It changes a lot,'" he says.

Luckily, Arun had a lot of support after his diagnosis. His father Govind—also originally from India who didn't speak English at that time—had been diagnosed nearly a decade prior and Arun's wife, Ramila, learned about the disease while helping translate for her father-in-law at his doctors' appointments. Her knowledge came in handy for helping Arun understand what he needed to do to make improvements to his health. He quit smoking, improved his diet and increased his physical activity.

Reflecting on the Alberta Diabetes Institute celebrating 10 years since opening its doors, Arun says if he could go back a decade in his own life, he'd encourage his younger self to be as healthy as possible. And if he could go back even further, he'd change his lifestyle completely in the hopes of preventing his diabetes in the first place. He says the disease can create long-term internal damage to organs and nerves and because so many of its symptoms aren't overt, the gravity of the illness is only now being fully understood.

**The Alberta Diabetes Institute helps to remove barriers that stand between scientific discovery and new health applications that improve the quality of life of diabetes patients.**

# MIKE & JOSH

In 1999, Mike Medicoff spent three restless nights sleeping on a gurney at the Stollery Children's Hospital after his then fourteen-month-old son, Josh, was diagnosed with type 1 diabetes. The first night was especially long and uncomfortable—not just because of the makeshift sleeping arrangements, but because Mike was preoccupied with how his family would handle the coming years. But he felt more at ease over the next few days, as medical staff taught him and his wife Gillian Clarke how to help their son.

Five years later, 40-year-old Mike was told he also had diabetes, though initially there was some confusion as to the type. He was first told he had type 2. For Mike, who had always had an active, healthy lifestyle, it came as a surprise. He didn't realize that while obesity, lack of proper nutrition and a lack of exercise are risk factors for type 2, other influences such as heredity, one's environment and heritage can also play a role. Doctors eventually realized he actually fit into the type 1 category, which is normally diagnosed much earlier in life.

The new diagnosis did not really change the course of his treatment, but Mike believes it did affect both his perception of his disease and that of others. Some people with type 2 diabetes experience judgment from those who believe the person's lifestyle may have contributed to the development of the disease, even if that is not the case.

Now, Mike's less focused on how he's perceived, and dedicated to managing his disease as well as possible while making smart choices. "I hope Josh sees me [handling] it properly because in all aspects of being a parent, you try to model positive behaviour and hope they pick up a little bit of it."

Josh's sister Sydney is 14 years old, and when asked how diabetes has affected her own life, she simply shrugs, stating it's something that's always been in the background. She doesn't worry about being diagnosed, she says, because she's already seen two of her family

members manage well with the disease. "It's become normalized," explains Josh, now 19.

Along with diabetes, Josh also has celiac disease, a condition that causes an immune reaction to gluten and is more prevalent in those with type 1 diabetes. Over the years, it's meant Josh has to be particularly careful about what he eats, adding another layer of complexity to the management of his health; but he's had plenty of help from his family.

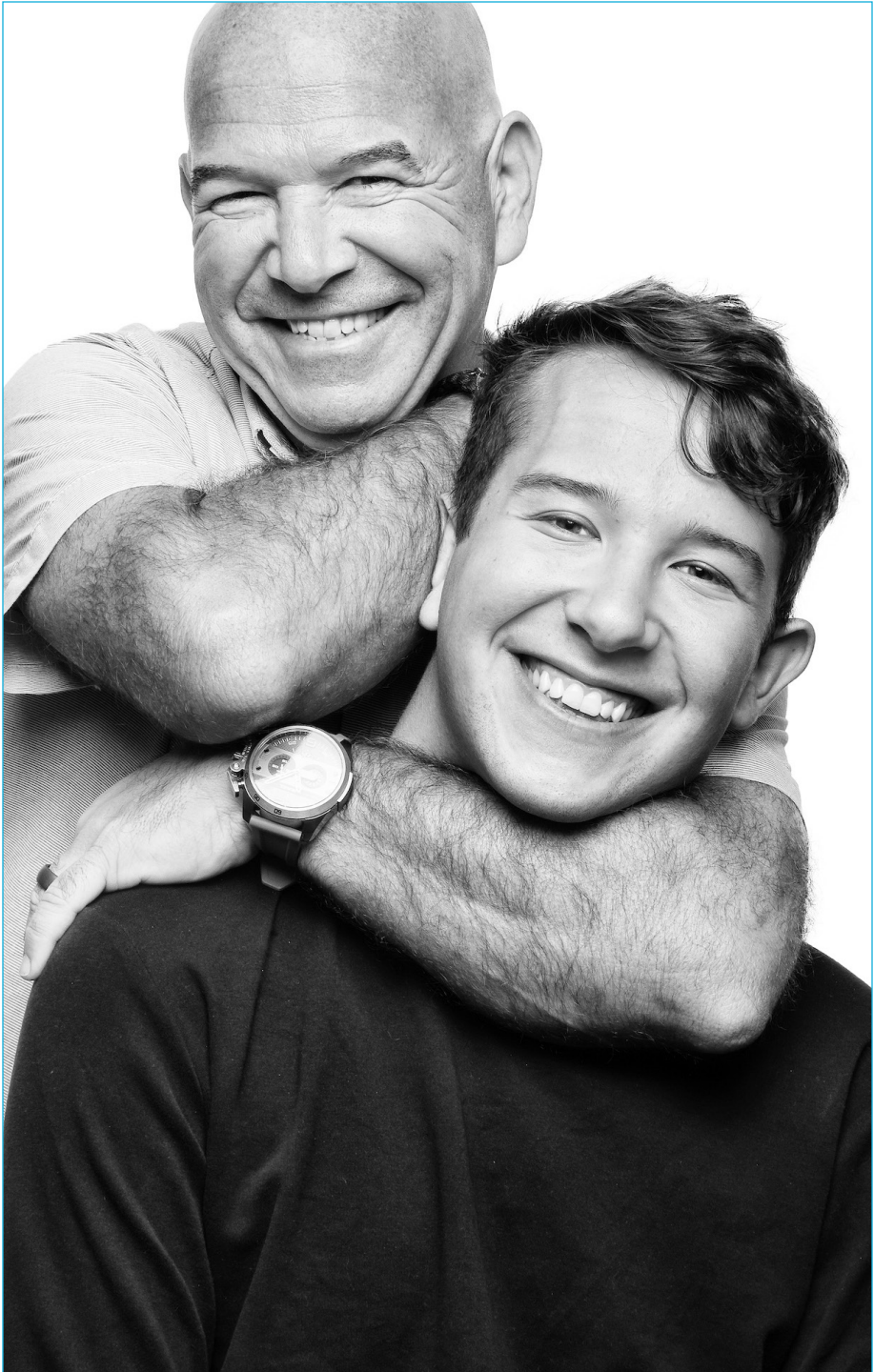
Both Mike and Gillian have modelled a healthy lifestyle while being involved in fundraising for diabetes research. Gillian has a busy career as a lawyer, but finds time to volunteer as chair of the board of directors for the Alberta Diabetes Foundation. She's excited to contribute to the Foundation because of all the international research and knowledge the Alberta Diabetes Institute generates. Gillian has been impacted by the disease her entire life as her sister was diagnosed at a very young age, then her son and finally her husband.

As a child, Josh didn't notice the ways in which his parents were involved both in his own life and that of others with diabetes. But now, it's something he can really appreciate. "They want to see me live and prosper with a better body health and mental health. It's just a way for them to wordlessly explain how much they care about me," he says.

Josh is now majoring in political science and geography at the University of British Columbia and recently went on a month-long trip through Asia. After landing in Vancouver, he drove to Edmonton to visit his parents.

Gillian paid for his phone plan while he was overseas and used an app to track his progress as he drove home. She has worried about Josh's safety ever since the day he was diagnosed, and she anticipates that concern will always linger. But just as Josh works to live a full life without constraints, the whole family is inspired to do the same.

**The Alberta Diabetes Institute spans the spectrum of research with expertise in many forms of diabetes including type 1, type 2 and gestational.**





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As the Alberta Diabetes Foundation enters its 30th year of investing in life-changing diabetes research, we are reminded of the people to whom all the effort is for. Currently, one in four Albertans have diabetes or prediabetes and the numbers are rising. It means we have more work to do, and if it takes another 30 years we won't stop until there is "a world with no diabetes", so that young girls can be princesses, mom's can just be moms and not nurses too, and so that our grandparents can grow old and enjoy their retirement. Only then, shall we rest!

**Visit Portraits of Diabetes online at [www.ualberta.ca/Alberta-Diabetes](http://www.ualberta.ca/Alberta-Diabetes)**

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