

# LEGACY ACTION



Edmonton  
Community  
Foundation

## UP WITH DOWN SYNDROME

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Grassroots organization  
helps families touched  
by Down syndrome

p10

### HELP FOR YOUNG PARENTS

Terra Centre empowers moms and dads

p14

### OPEN ACCESS

ECF blazes a trail in open data



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Salma & Dr. Zaheer Lakhani



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A large background image showing a group of young girls in blue soccer uniforms playing on an indoor green turf field. The girls are in motion, some running and some looking towards the camera.

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Cover photography by Adam Goudreau



“We thought we could do something that stretched beyond the day-to-day and set something in place so these organizations could have longer term funding and something that will outlive us,” says Denise.

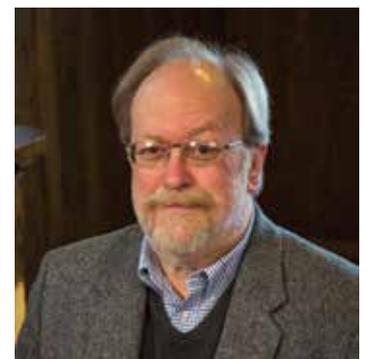
You can read more about the Van Weelden Family Fund on [page 9](#).

We’re also lucky to work with charities that support families of all kinds in our community.

In this issue’s cover story you’ll visit the Edmonton Down Syndrome Society. Through an ECF Community Grant, this parent-guided organization hired a family support liaison. The liaison helps families with children born with Down syndrome navigate the complex network of services available in the city. On [page 6](#) you will meet a few parents who are benefiting from this service.

In our feature story you will learn how ECF’s Single Parents Independence Fund is helping parents at Terra Centre overcome barriers to financial independence. Matt Smith is one such single parent and on [page 10](#) you’ll find out how Terra Centre is helping him achieve his goals.

Welcome to the Winter 2016 issue of *Legacy in Action*.



Martin Garber-Conrad

Families are the foundation on which our communities are built.

In this issue of *Legacy in Action* you will meet families that are making generosity an integral part of their lives — including the Baher family ([page 12](#)).

The Bahers established an endowment fund at Edmonton Community Foundation (ECF) as a way to give back to the community that helped them during their own time of need.

Their goal is to support organizations helping people find stability in their lives, including Youth Empowerment Support Services and WIN House. Both agencies provide assistance to women and children fleeing domestic abuse.

“We want to help people become good, fruitful, productive citizens,” says Ken Baher. “And the goal is that they’ll pass those traits and that support along to their descendants. Helping people like this creates a snowball effect.”

The Van Weelden family also holds giving as a key family value. Denise and Hank Van Weelden have been volunteering at several inner-city charities for years and made sure that this value was instilled in their children (now adults) at a very young age. The Van Weeldens established their family fund at ECF last year as a way to ensure their tradition of generosity continues in perpetuity.

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Kerri DeLuca

## Honouring love.

The 26BG1234 Family Fund was set up at Edmonton  
Community Foundation in memory of my parents.

26BG1234 was a secret code my parents used to mean "I Love  
You" in cards and letters to each other for almost 50 years.

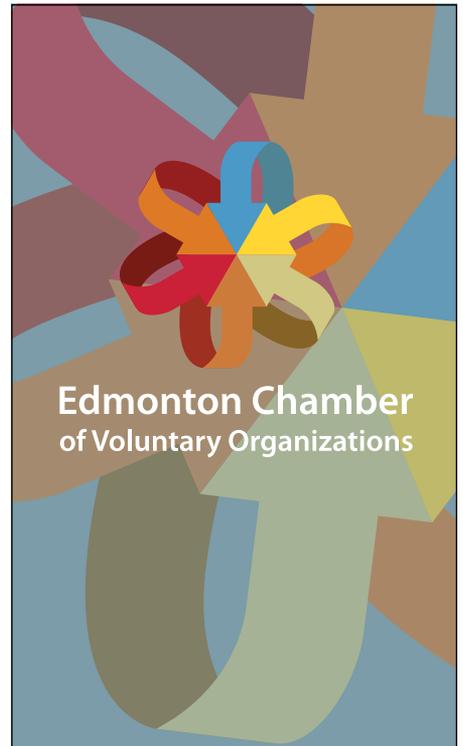
Involving my children made this legacy something old and  
something new. *The Fund supports charities my parents  
cared about and that my children feel are important.*

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# FOR PARENTS BY PARENTS

*The Edmonton Down Syndrome Society helps families raise happy, healthy kids*

**D**anielle Barnes was getting ready to put her daughter Mia into Grade 1, but every time she thought about it, her hands shook. She was a teacher herself, but the idea of sending her own child to school was scary because she knew Mia would require more support than many of the children she taught. Mia has Down syndrome and while Barnes knew there were many ways to facilitate her daughter's learning, she didn't know how they would work in a classroom.

Barnes went to a workshop held by the Edmonton Down Syndrome Society (EDSS), and that's when things clicked. She learned how to envision what interactions would work best for her child. "I wrote what I wanted for her, and gave it to her teacher. It was powerful, because her first teacher didn't know how to do this either. But if I hadn't had that first piece, I wouldn't have known where to start," says Barnes.

Her plan involved having the school see Mia's abilities, having children include her in their day, and having an adapted curriculum suitable for her learning style. Now, at eight years old, Mia is thriving at school, interacting with children of all skill levels. >



BY: CAROLINE BARLOTT  
PHOTOGRAPHY: ADAM GOUDREAU

Since that time, the EDSS continues to be a support to the Barnes family, as it is for many families from Red Deer, north to the Territories. Established in 1988 by Edmonton parents, the organization has grown from a very small playgroup with just four families to a non-profit that provides support in all areas of life—from health to education to socializing—from infancy to adulthood. EDSS is run by a governance board of community members along with a steering committee made up of parent volunteers who represent each age group.

Barnes is presently the co-chair of the steering committee and also sits on the governance board. Parent involvement is encouraged in the organization with opportunities to share information, ideas, and to help fundraise for the cause. “We want to be a parent-guided organization. We want to really address what our community needs and wants and not just be told what we need by someone sitting behind a desk,” Barnes says.

As a result, there are social groups for parents, children and adults, musical theatre groups, arts programs, a bowling league, speech pathology classes, and yearly fundraisers. The organization was even able to help put two health clinics into place for children and adults with Down syndrome.

In 2007, the EDSS funded a pilot project to develop a clinic for kids with Down syndrome at the Stollery Children’s Hospital, which involved hiring a full-time nurse for two years. The pilot was so successful it resulted in full, permanent funding through Alberta Health Services and now helps more than 400 children. Then, in 2015, the EDSS and The Down Syndrome Clinic formed a partnership with the Oliver Primary Care Network to create an adult medical clinic with the goal of expanding throughout the city.

Rosalind Mosychuk, chair of the EDSS steering committee, says these clinics are incredibly important due to health challenges faced by those with Down syndrome. Heart defects, respiratory infections, thyroid disorders, and hearing and vision issues are more common among those with Down syndrome; therefore, having specialists who understand the population is better both for the patients and the health care system.

Mia, and her brother, Aiden, who also has Down syndrome, are both patients at the pediatric Down syndrome clinic. “The staff are really on

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””

top of their game, and you don’t have to worry about whether they’re being thorough because this is their expertise. And they can also connect you with other things in the community, so they can help you access other supports and refer you to programs,” says Barnes.

In fact, the amount of community information requested started to become overwhelming. Meanwhile, many people would call the EDSS office also asking for information, so it became evident that more community support was necessary. With a grant from Edmonton Community Foundation (ECF), EDSS created a family support liaison position two years ago. That position was filled by Julie Boucher, who helps connect families with assistance of all kinds, whether education, health or social.

“There was also funding coming from other supports, so it was a sense of us being part of the puzzle and helping leverage those other funds for a much needed service,” says Craig Stumpf-Allen, director of grants and community engagement for ECF. “They had support letters from other organizational partners and parents of those with Down syndrome expressing the importance of the support.” ECF also operates a designated fund for the EDSS, which was started by a family in support of the organization. Every year, the society receives money from the fund that can be used at its discretion.

Arden Playford says wading through piles of information, paper work, and various resources available for parents is incredibly challenging, even overwhelming. He knows first-hand as his 28-year-old son, Tyler, has Down syndrome. Tyler is very involved with the EDSS—he participates in many social gatherings, is part of a musical theatre group, and acts as an ambassador at various events around the city. The whole family has been involved with the organization since Tyler was seven years old. Both Playford and his wife, Jackie, were chairs of the board and remain very involved with fundraising events.

The addition of the family support liaison to the team, says Playford, has already made a difference for his family. Recently, the couple wanted to find a respite facility so that when they go away on holidays, they can rest easy, knowing their son will be looked after. ➤

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**A \$40,000 Community Grant from ECF** helped the Edmonton Down Syndrome Society hire a family support liaison. To learn more about applying for a Community Grant visit [ecfoundation.org](http://ecfoundation.org).

Government supports are available through Persons with Developmental Disabilities (PDD), but going through PDD had not yielded results. However, thanks to EDSS's family support liaison, Boucher was able to find three potential places within 48 hours, including one within walking distance of the Playfords' home.

There are now more than 80 parents who have asked for support, says Boucher, pointing to her filing cabinet full of information she has collected for the families. She sees her job as connecting people with the information they need, rather than doing the work for them. She provides them with choices and they can make the best one for their family. Recently, she helped a single mother who was struggling because she didn't have a place for her three-year-old to go after playschool. While working and going to school, the mother really needed help and Boucher found several daycare options near the playschool. Meanwhile, she connected a rural family with an aide who could communicate with their young child in sign language, something the school had not been able to do. She also got the child into the community hospital for free speech therapy. Another family had a five-year-old who wasn't able to talk or walk. After their family connected with the right resources, their son quickly became more mobile and vocal.

As their children grow, different supports are needed, and the organization is set up so it can cater to each stage. The EDSS provided support for Playford's son, Tyler, as he enrolled in Concordia University, taking a Bachelor of Arts with a drama minor. Tyler is a natural performer who often dances to Michael Jackson's *Thriller* at relatives' weddings; he also held a small role in an episode of the locally filmed TV series *Fear Itself* in 2008.

"There was 100 per cent support when he went to university—he was assigned to a worker who has an office at the university and every morning, he'd report to her and she'd take him to class. She found a coach student to work with him, and they helped modify the curriculum," says Playford.

When Mosychuk gave birth to her daughter 37 years ago, few medical professionals—never mind the general public—were well versed in Down syndrome. The medical books had maybe one line devoted to it, and it might have been

“  
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”

mentioned briefly in a genetics class at university, she says. As a result, doctors did not even realize the potential of people with the condition.

While she had a very positive experience with her daughter, others faced many challenges. But now, she feels excited by the breadth of resources available and an ever-increasing ability to access them. Her own daughter, Tanya Ponich, is an advocate for those with Down syndrome—she's been a Global Woman of Vision, is very involved with the Canadian and American Down Syndrome Societies, helps organize conferences, and gives motivational speeches across North America.

"It's so wonderful for our children that things are changing; there is more information, more awareness. Our children are a very important part of the make-up of any community and they give back so much more than many people realize," Mosychuk says. ■



Danielle and Mia Barnes



The Van Weelden family (left to right): Angus, Carmen, Hank, Denise and Willem

*The Van Weelden family created a donor-advised fund to give back in perpetuity*

BY: CAROLINE BARLOTT PHOTOGRAPHY COURTESY VAN WEELDEN FAMILY

**D**enise Van Weelden doesn't like the word 'philanthropy.' While she and her husband, Hank, are ardent believers in giving back to their community, the word seems far too fancy for the contributions they make. The couple is passionate about supporting "unglamorous" charities that help marginalized and vulnerable populations in the city and may struggle to raise funds. They see their support not only in the funding they have been blessed with the ability to provide, but also with time, effort and energy. They are regular volunteers at organizations like the Edmonton Native Healing Centre (ENHC), which empowers Aboriginal people, and Crossroads Outreach, which helps street-based sex workers.

The Van Weeldens have a long history of giving back to the community. Twenty-five years ago, they started Trail Youth Initiatives, a charity providing support and intervention for inner-city children, in Ontario. Since then, they've raised their three adult children with a similar desire to give back including volunteer time with the organizations they are most passionate about. In 2014 the family decided to create a donor-advised fund through Edmonton Community Foundation (ECF). The fund is set up so that it can run in perpetuity with the goal of funding front-line staff — who the Van Weeldens say are heroes in the inner city — of charities dealing with marginalized individuals.

"We thought we could do something that stretched beyond the day-to-day and set something in place so these organizations could have longer-term funding and something that will outlive us," says Denise.

Donor-advised funds require a lump sum up front that can be added to at any point; the principal grows through investments with a percentage being granted out each year. Every year, the family can decide where the money will go.

"So, instead of supporting a particular charity year after year, it can go to any charity in Canada and they choose depending on what priorities

come up for them or the community that year," says Craig Stumpf-Allen, director of grants and community engagement for ECF.

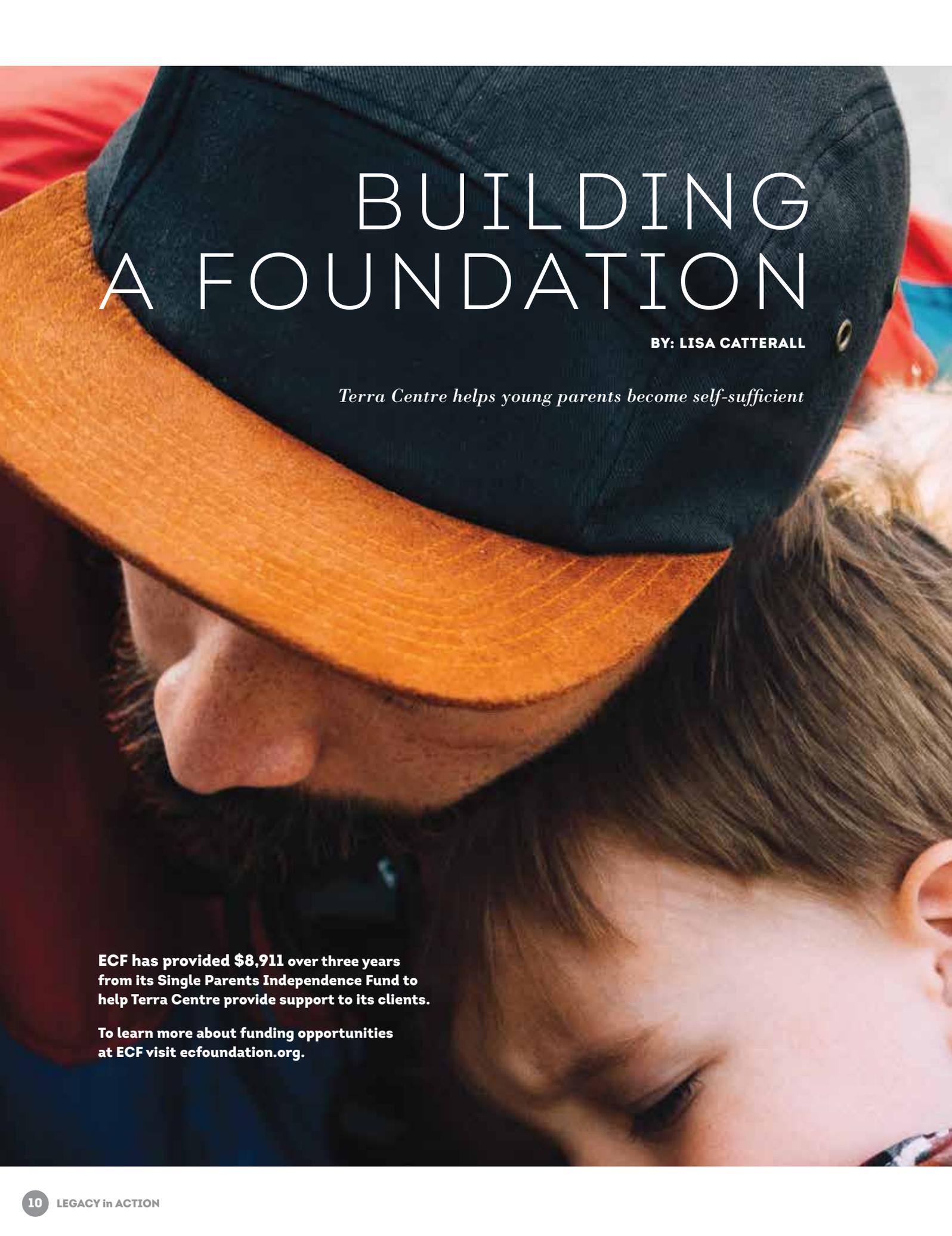
"For long-term sustainable funding, ECF is a beautiful vehicle for that," says Hank. "There's great wisdom in guiding and drawing out our wishes and passions." The Van Weeldens' fund has been set aside solely to fund charities that will fulfill those wishes, which to them means "working with marginalized populations." There are many great organizations to choose from, says Hank, including E4C's Cross Roads, iHuman, Mustard Seed, and ENHC.

On Thanksgiving 2015, the family gathered to discuss where to give their first grant. They decided to support the ENHC, an organization the family has been involved with for many years (Denise sits on the board and other family members volunteer). Their gift was used to help fund a health navigator — a staff member to help clients follow through with health goals, whether that means getting to appointments or finding addictions treatment. The role recognizes the importance of health from a preventive approach, understanding that mental, physical and emotional supports are all aspects of overall wellness.

As a nurse, Denise has seen too many patients miss out on proper care because of a lack of health literacy or challenges like addictions or homelessness. People can get lost in the system and relatively minor health issues can evolve into emergency situations.

"Many Aboriginal people I work with say [health professionals] don't hear me, they don't listen to me. The health navigator is able to hear their story, but also support them in seeking and getting care," she says.

The Van Weeldens are getting ready to decide on their next grant, and say they've put their children in the position to make the majority of the decisions, within the framework of the fund that Hank and Denise have set up for them. "So, our whole goal is to make sure our kids learn our thinking and start making those decisions independently of us," says Hank. "And hopefully they'll ensure our grandchildren are smart enough to take care of another generation's needs." ■



# BUILDING A FOUNDATION

BY: LISA CATTERALL

*Terra Centre helps young parents become self-sufficient*

**ECF has provided \$8,911 over three years from its Single Parents Independence Fund to help Terra Centre provide support to its clients.**

**To learn more about funding opportunities at ECF visit [ecfoundation.org](http://ecfoundation.org).**



At age 19, Matt Smith (not his real name) was looking forward to finishing high school. He had been working hard for what seemed an eternity to complete his final classes, and finally, the end was in sight. But in the spring of 2011, Smith received news that would change his life forever: he was going to be a father.

In the span of a few weeks, his life transformed. Although he was young, he took a mature approach to the news. He didn't know what challenges lay ahead, but he bravely prepared for the next chapter in his life.

"My ex and I had split up, so I didn't find out that I was going to be a father until about five or six months along," he says. "But still, there was no question in my mind that I was going to be there for my son."

On a brisk day in March, Noah Smith was born. Seeing his son Noah's (not his real name) precious face staring up from a swaddle of baby blankets, Smith was overwhelmed with emotion. It was a moment of great responsibility and growth. It was the moment that he decided to do everything he could to give Noah the best life possible.

"I knew what I had to do – so I just did it. I dropped out of school, and started working to be able to provide for him," he says.

No longer in a relationship with Noah's mother, but determined to be a good father, Smith sought full custody of his son. It was a long and arduous process, but after two years of tireless effort, Smith was granted full custody.

To say it has been a challenging path for Smith would be an understatement. At times, the obstacles he faced seemed insurmountable, with frustrating bureaucracy and red tape around every corner. For some, these challenges would mean giving up, but for Smith, it meant an opportunity to persevere, learning along the way.

"It's challenging because as his sole guardian, I still have to handle everything for Noah, as well as try to provide for [us]. Over the last few years I've learned a lot, but I'm still learning more as I'm going," he says.

Three years ago, Smith was introduced to Terra Centre, a local non-profit that provides support and resources for parents under the age of 25. The organization offers the Edmonton region's only program for young dads, which helps them with both parenting and financial independence. Through the program, Smith received guidance in finding government services, health-care, and housing. The program can also help with employment searches, school enrolment, and navigating the legal system.

"I've struggled here and there because it's tough being a single parent, but Terra Centre has helped me out a lot over the last few years," he says.

Last year, Smith's challenges intensified when the car he was travelling in was t-boned at an intersection. Lasting injuries have left him unable to work for over a year, adding to his financial

struggles. Recently, he needed to request a copy of Noah's birth certificate in order to apply for healthcare coverage. Unfortunately, to get the certificate, he needed photo ID of his own, an added expense that would have been tough to manage on his tight budget.

"For something as small as a piece of ID, people may not think of it as a really significant issue but if you don't have proper identification sometimes you can't move forward to the next steps," says Karen Mottershead, executive director at Terra Centre.

While many funds provide support for continuing education, childcare, or other long-term costs, few provide for one-time expenses that may act as a barrier for young parents to get on the path to financial independence. But thanks to Edmonton Community Foundation's Single Parents Independence Fund, Terra was able to provide funding for Smith's photo identification.

"The Single Parents Independence Fund is invaluable in addressing gaps in available funding from other sources," says Derek Dicks, Smith's family outreach support worker at Terra. "Having valid photo identification removes significant barriers in accessing services not only for the parent, but for their children, as well."

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## I'VE STRUGGLED HERE AND THERE BECAUSE IT'S TOUGH BEING A SINGLE PARENT...

” ”

The fund provides financial support for low-income parents in a variety of areas, including education, childcare, or any related expenses that might be acting as a barrier to their financial independence. Mottershead explains that most other community funds don't help parents with emergency situations or smaller things like damage deposits, registering for classes, or photo IDs. "But these expenses are really important aspects of creating stability. So even though it might be for something small, it makes a huge difference to our parents."

After getting photo ID, Smith was able to get a copy of Noah's birth certificate. It was a small victory, but a victory nonetheless. And though the road ahead is still peppered with challenges and obstacles, wins like this make the young father confident that he will continue to build a better life for his family.

Now Smith is preparing to become a father for the second time as he and his girlfriend are expecting a baby. He credits Terra with helping him become a great parent, and is looking forward to using these skills well into the future with his growing family. "With Terra's help, I've learned a lot," he says. "And it's just getting better from here." ■



The Baher family: Ken and Bernice with son Ed, daughter-in-law Marta and grandchildren Michelle and Naomi.

# A FAMILY AFFAIR

*Ken and Bernice Baher have made philanthropy a family tradition*

BY: LISA CATTERALL PHOTOGRAPHY: ADAM GOUDREAU

In their early years together, Ken and Bernice Baher lived a story that is all too familiar to many Albertans. At 17, after finishing high school, Ken left home in search of a better life for himself and his future family. For years, he worked as a logger, miner, and oilpatch worker as he looked for a career that would provide a comfortable life for his family. After meeting Bernice, Ken was inspired to return to school to earn an engineering degree, laying a foundation that would provide financial security for his family.

“We both come from very humble backgrounds, but we were fortunate, and were able to be quite successful in our lives,” says Ken.

As time passed, the couple’s hard work paid off. More than a decade after getting married, the couple formed their own private corporation, which is still active today. Now, with two grown children raising families of their own, the Bahers are modest but proud of the legacy they started all those years ago.

“We had some times in our journey where we were the recipients of help,” says Ken. “And we feel that it’s important to pass that back. It’s important to help those who are helping themselves.”

This concept played a major role in the couple’s discussions as they began to explore the future of their legacy. Their children had achieved their own financial independence, so Bernice and Ken began looking for ways to support others in the community.

“We want to help people become good, fruitful, productive citizens,” says Ken. “And the goal is that they’ll pass those traits and that support along to their descendants. Helping people like this creates a snowball effect.”

After researching various options for their legacy project, the Bahers decided to start an endowment fund, and contacted Edmonton Community Foundation (ECF). In 2013, they worked with Kathy Hawkesworth, director of donor services at ECF, to establish the Baher Family Fund. The donor-advised fund allows them to support a

number of different community initiatives at once.

“We love the flexibility of the fund and the resources that ECF provides us to decide which organizations to support,” says Ken. “The biggest challenge we face is that there are so many needs out there that trying to prioritize them is so hard.”

Each year, the couple gathers input from their children and grandchildren to determine which local organizations to support. Although they continue to support some of the same charities each year, they also select new ones with help from ECF. This year, the family’s chosen charities include:

YONA Sistema with the Edmonton Symphony Orchestra, a musical education program designed to promote positive change for youth in Northern Alberta; Youth Empowerment Support Services (YESS), which offers support and resources to at-risk youth; and WIN House, providing assistance to women and children fleeing domestic abuse.

By starting their philanthropic efforts now, the Bahers are able to see the effects of their generosity and encourage their children and grandchildren to get involved in community initiatives.

“Our daughter and grandchildren volunteer, and our son was actually the one who introduced us to the work that YESS is doing in the city. All of us are very much involved in the community,” says Bernice.

“We hope that our children and our grandchildren will feel a connection to the fund, and that they’ll continue the spirit of it even after we’ve passed on,” says Ken.

Recently, the Bahers visited one of the organizations they choose to support, YESS, to better appreciate the impact of their help. The experience was profound.

“It was a real eye-opener. I left there in tears, I was so thrilled with what they’re doing,” says Bernice. “I would just love for us to be able to help them more.”

And through the Baher Family Fund, that’s exactly what they’ll do. ■



# ECF EMBRACES OPEN ACCESS

*Edmonton Community Foundation's Open Access database will help charities, granting agencies, and researchers gather information about funding*

BY: CAITLIN CRAWSHAW ILLUSTRATION: JULIA MINAMATA

While charities are known for doing a lot with a little, finding funding for programs and services is an ongoing battle. “[They] are always struggling for resources and the key way to get resources right now is to write a

grant proposal,” says Alex Draper, a donor grants associate at Edmonton Community Foundation (ECF).

To increase their likelihood of receiving funding from granting agencies, charities do extensive research on the resources currently available in the community and what other organizations have received. It’s a time-consuming, labour-intensive process that pulls staff away from the work their charity was created to do. “It’s a rough system,” says Draper.

While attending a conference two years ago, he realized there might be a way to make this process more efficient. Draper encountered a Montreal non-profit called Powered by Data that was creating a database system to track funding for charities. This would provide a central location for information about grant funds and recipients, useful not only to charities crafting proposals, but also to funding agencies, government departments, entrepreneurs, and academic researchers. By making the database Open Access — that is, accessible to anyone online — the data could even be used by members of the public, as well.

“It’s transforming the non-profit sector from this murky environment where it’s hard to find the information you need, to shining a

light on it and finding out who is working on what and who are they collaborating with,” explains Michael Lenczner, director of Powered by Data.

This struck Draper as a great concept, “but it was kind of a big, unruly idea.” For one thing, a critical mass of funders would need to be on board, as the system would rely on funders inputting their organization’s data. And for the charitable sector in Canada to move to

a new way of managing information, people would need to see it working well in one region of the country.

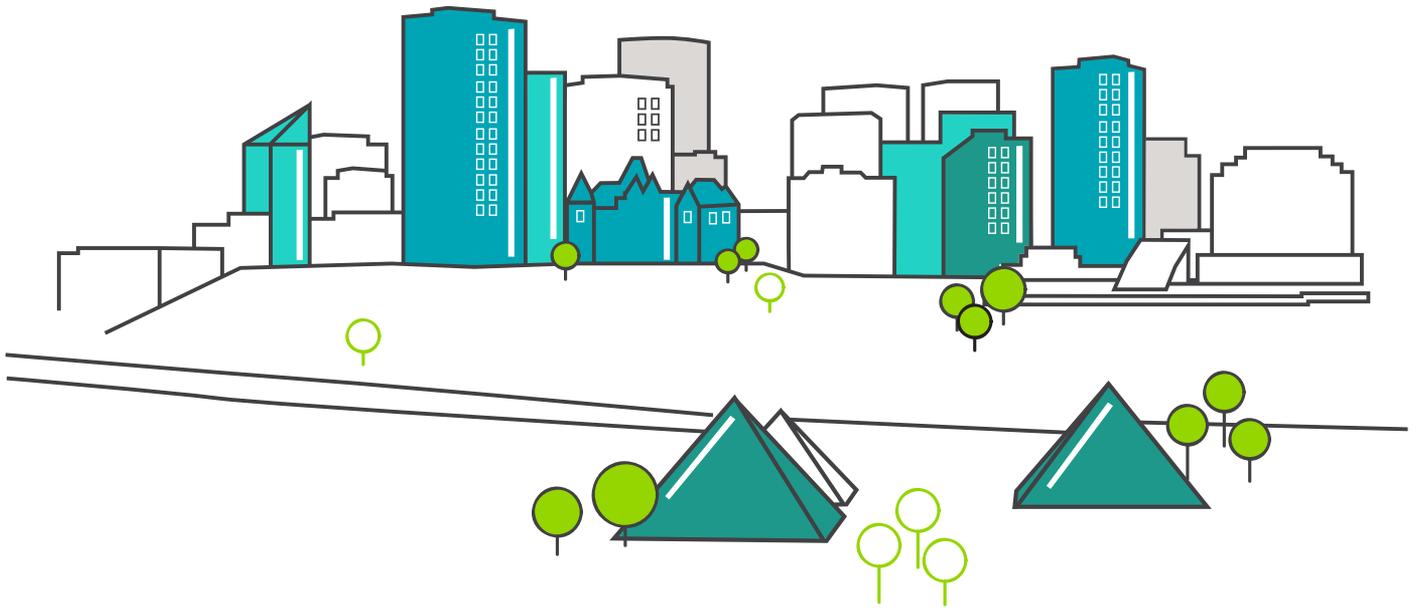
Draper figured Edmonton would be a great place to test-drive the idea and successfully applied for the Community Foundations of Canada’s inaugural Community Philanthropy Fellowship, which includes a sabbatical project. In collaboration with Powered by Data, Draper has spent the last year working on getting a database up and running in Edmonton, to get a complete picture of the city’s charitable funds and recipients.

It’s a good time to be doing this work as the Open Access movement is growing in Canada. A growing number of Canadian governments have been opening up their data to the public — including the City of Edmonton, which won awards for its Open Access initiatives in 2015 and 2016. However, Draper notes that most governments haven’t yet made funding data public.

“It makes sense in that they’re public institutions and having data available to the public is in everyone’s best interest,” he says. But there’s a practical element to this, too:

“It gives people the opportunity to come up with creative solutions to complex problems.” ■





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