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MEDIA RELEASE

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FOR IMMEDIATE RELEASE (Mother's Day feature)

Moms on the March

Why three Calgary moms are walking 100 kilometres for their kids

[Calgary] – Three Calgary moms are taking on the one-hundred-kilometer Kidney March challenge to fight for a better future for their children living with kidney disease.

Kidney March is not your average walkathon. This is the twelfth year of the Calgary based event. It is the largest one-hundred-kilometre walk of its kind in the world fighting against kidney disease and for organ donation. Danielle Sinclair, Laura McKenzie, and Kim Ball are three of the many moms who take part every year. For these moms, kidney disease is a lifelong battle they never imagined they would have to face.

Kids experience unique challenges with kidney disease, and its impacts are felt by the whole family. Danielle Sinclair is marching for her 10-year-old daughter, Teagan. Teagan has a rare kidney disease called Cystinuria that almost went undetected. She was diagnosed at 5 years old and has had 6 surgeries to remove cystine kidney stones. One of which was 5cm in her only 9cm kidney. Due to her disease, Teagan lost her right kidney. Danielle's hope is that Teagan will not need a transplant in her lifetime.

This past year has been particularly hard on moms with kidney kids. It has been especially hard for first-time Marcher, Laura McKenzie who is facing the new diagnosis of her 4-month-old daughter. "Because of the pandemic a lot of people don't even know Penelope has kidney issues, let alone has already had surgery." Laura had to go through a lot of this alone. Due to covid protocols, only one parent was allowed at appointments. "You try to stay strong but ... there is only so much a mother can do on her own without breaking down." Until Laura decided to do Kidney March and share her story, she was afraid to tell family and friends. "No one can really do anything for you... but with Kidney March, they now have a way to help and a way to support us."

One of the greatest things about Kidney March is it reinforces the support of the community for patients, families, and kidney healthcare professionals. People who have had kidney disease touch their lives need a lot of help in their journey. Everyone can rally around the same cause and connect from their shared experience.

"Being part of the Kidney March family really gives me a sense of belonging," explains Kim Ball, Calgary urologist and mother of three. Kim's youngest son Liam was born in 2018 with very low kidney function. Liam now needs a lot of extra care, is on dialysis every night and needs a transplant. "As a mom, we want the best outcomes for our kids, we don't want to see them suffer. So having this opportunity to hopefully better his future means a lot."

Kidney March helps moms turn a negative situation that was once out of their control, into a positive one. It allows them to take an active role in creating change. “Every year, we fund incredible research projects, that improve the treatments of kidney disease and bring us that much closer to a cure,” explains Joyce Van Deurzen, Executive Director at The Kidney Foundation of Canada Southern Alberta Branch and Saskatchewan Branch. “There have been many advances made by our researchers right here in Calgary, and Kidney March is a big part of that.”

Kidney March is going virtual again for 2021 and growing from coast to coast. Kidney March 2020 was an incredible triumph, raising the second highest amount ever for the event. Last year proved that no matter where participants are across the globe, no matter what challenges or opportunities they faced, they were united, marching no matter what.

“The safety of our community is our number one priority. Everyone involved in our event is working hard to protect each other, while doing the most we can do. We are getting creative with ways to raise awareness and funds. Kidney March aims to continue making a historic difference in the lives of all families and individuals impacted by kidney disease,” says Van Deurzen. This year participants will again walk in their own communities while connecting virtually. Unlike some other pop-up virtual walks, participants are not on their own. There is a plan, and event organizers have a line up of fun activities and surprises to keep everyone engaged, while still challenging them to achieve their goals.

There is no age limit to kidney disease. 1 in 10 Canadians has kidney disease. There are also very few warning signs. Up to 80% of kidney function can be lost without any noticeable symptoms. Genetics can cause chronic kidney disease and kidney failure, especially in children and adolescents. Some of these diseases can be rare or even ultra-rare, and a lot is still unknown about them. These moms are marching so that more research can be done to find answers to those unknowns. Not only for their own little ones, but for future families.

Funds raised by Kidney March benefit The Kidney Foundation of Canada and fuel advances in kidney research, valuable local patient programs, organ donation initiatives, and much more. Visit kidneymarch.ca to donate to the event or find out more about how you can take part.

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** Photos from Kidney March of the Moms participating in Kidney March and their kids are available for use by media. Contact to Michelle Hofer for specific image requests.*

****An Image of Danielle Sinclair is attached and approved for use by media (photo credit to Kidney March). Danielle is holding up a photo of her daughter Teagan. This image is also the official poster for the 2021 Kidney March representing this year’s theme, ‘We March No Matter What.’***

All Available Interviews - Background info:

Joyce Van Deurzen – Executive Director at The Kidney Foundation of Canada, Southern Alberta Branch, and Saskatchewan Branch. Joyce can speak about Kidney March as an event founder and organizer. She can also speak about the status of kidney disease and organ donation in Alberta and discuss the direct impact and work being done by The Kidney Foundation of Canada as a result of the funds raised by Kidney March. “Kidney March is all about people coming together to make a difference in the lives of others and to create a different future.”

Dr. Julian Midgley, Pediatric Nephrologist at the Alberta Children's Hospital in Calgary is available for interviews to talk about pediatric nephrology in Calgary. Julian has also participated in Kidney March himself over the past 12 years and has been involved in the event since it began. He is the captain of the team, KIDneyKIDs. He marches in support of all the families he has seen throughout his many years. At Kidney March he has the opportunity to walk alongside these families outside of the hospital walls. Although this year is again virtual, the sentiment and value in Kidney March remains the same. He will be walking every kilometre and raising as much funds as he can to continue to do the most he can do for his patients and their families.

The three moms and their impactful stories:

Danielle Sinclair (Calgary, AB) Three-time participant of Kidney March.

Danielle marches for her 10-year-old daughter Teagan. Teagan has a kidney disease called "Cystinuria." She was diagnosed at 5 years old and has had 6 surgeries so far to remove cystine kidney stones. Doctors found a 5cm kidney stone in her kidney which was only 9cm long at the time. Unfortunately, Teagan lost her right kidney from the disease. Danielle's only hope is that Teagan will be able to thrive on one kidney and not need a kidney transplant in her lifetime. Teagan's kidney disease almost went undiagnosed. If the doctor had not done a urine sample to follow up on a slightly abnormal blood test, they would never have known, and things could have been much worse. “I worry for her ... they can't tell me if she will ever start developing a stone in the other kidney.” She will be monitored her whole life and is on a supplement for now. Despite all this, she is a thriving little kid. “I march for my daughter. I just feel so grateful knowing that by marching we help people get better care, better medicine. How good would you feel knowing that one day you helped find a cure?”

Laura McKenzie (Calgary, AB) First-time participant in this year's Kidney March.

“Right now, things are awesome and under control, she is the happiest baby, you would never know she had any health issues at all.” But from the twenty-week ultrasound, Laura knew her daughter Penelope would be facing kidney troubles. Laura's daughter was born with what is called a Duplex Kidney. A Duplex kidney is a developmental condition in which one or both kidneys have two ureter tubes to drain urine, rather than a single tube. In some cases, it doesn't present any issue, but for her, she had a blockage that was ballooning the top of one of her kidneys. She needed surgery at three months old to fix the blockage, but due to complications instead had a right cutaneous ureterostomy. Penelope is now four months old and to this day they don't really know the cause of this blockage. She will still need one more operation when she is two. “Hopefully, she will just need monitoring throughout her life ... but we had a surprise before, and we don't really know what to expect for the future.” Her journey with kidney disease has just begun. "Because of the pandemic a lot of people don't even know my daughter has kidney issues let alone has already had surgery." Another thing most don't

realize is because of covid protocols Laura had to go through all of this alone, her husband couldn't come to the specialist appointments as only one parent was allowed. Being delivered the news without any personal support, at those moments would be hard for any mom. During Penelope's first surgery, Laura had to drop off her tiny 3-month-old daughter and wait all by herself. "It was so hard. You try to stay strong but when her one-hour surgery ran into complications and ended up being four-hours... there is only so much a mother can do on her own without breaking down." Thankfully, the care team was amazing and helped her through. "Even if you don't need the services forever, you want to raise money and support so everyone can have the same care experience you had and better outcomes." Until she decided to do Kidney March, and share her story, no one in her circle knew what they were going through. In a way Laura, was afraid to tell family and friends because she did not want a 'pity party.' "No one can do anything for you, no one can help, or meet you for coffee. But through Kidney March, they now have a way to help, and a way to support us. We are so excited to participate and spread awareness." Kidney March is giving her a vehicle to share what is going on in their lives in a positive way.

Kim Ball (Calgary, AB) Two-year participant, for both our Virtual events.

Kim Ball is a urologist nurse and mother of three young kids. Her youngest son Liam an adorable little boy with bright eyes and a charming smile, was born in 2018 with very low kidney function. Now at just over two years old, Liam has undergone many surgeries, is on growth hormones and peritoneal dialysis. Right now, they are struggling with Liam disconnecting himself from his dialysis, "kids being kids" and it can be hard to get him to understand why he can't keep doing that. He will need a transplant soon and likely more than one in his lifetime. Liam's father (Kim's husband) is just starting the process of testing through the donor program as he is the best potential match for Liam. They are hoping Liam will be big enough soon so he can receive a living kidney donation by the end of this year. He is a bit of a daredevil despite everything he is going through and your typical two-year-old troublemaker. "Being part of the Kidney March family really gives me a sense of belonging. Dealing with all of Liam's extra care, the dialysis we run every night and now looking towards transplants. As a mom, we want the best outcomes for our kids, we don't want to see them suffer. So having this opportunity to hopefully better his future means a lot. We know one kidney transplant won't be enough for his life, they last 20 – 25 years and he's only 2. We are really pushing for research and better outcomes for these kids." Says Kim. During Covid, the organ donor wait lists are longer and things are starting to get backed up and surgeries are being put on hold. Getting appointments can be hard and they are trying to book as many appointments as they can in advance, because they don't know how long they will have to wait.

More information about Kidney March 2021: KidneyMarch.ca

- 2021 event dates: kick off August 9 and Kidney March weekend is Sept 10 – 12, 2021
- Kidney March has raised over \$9.5 million to change the lives of kidney patients and their families since it began in 2010.
- Around 400+ participants typically take part every year and they come from across Canada and beyond. Participants have been from as far as New Zealand, England, Austria, USA and more.
- Marchers are asked to walk 100km and raise a minimum of \$2200 each.
- This year the March is broken into two parts for their safety. In part 1 participants will walk 70km of their 100 km's between August 9th – and September 9th. Part 2, the final weekend of Kidney March participants will walk a minimum of 10km per day for 3 days to complete their

final 30 km of the march. There will be opening and closing ceremonies, along with nightly inspiration and some virtual entertainment. Participants will also get special packages for different stages of the event.

Some stats about kidney disease:

- In many cases, the signs of kidney disease are not noticed until the kidneys are close to failure. The Kidney Foundation promotes Kidney Health to help raise awareness about the warning signs and risk factors associated with kidney disease to encourage early detection.
- Kidney disease is often linked to other conditions, including hypertension and diabetes but can also be genetic.
- More than 45% of people with kidney disease are under the age of 65.
- Out of pocket costs for kidney disease treatment can be 12.5% of a patient or family's income.
- The average dialysis patient spends 13.5 hours a week receiving dialysis treatments.
- In 2019 in just southern Alberta, with the majority in Calgary, roughly 2455 children and adults were on dialysis. With many thousands more of Albertans living with Kidney Disease in various stages of illness.
- 1 in 10 Canadians has Kidney Disease and it is the 10th leading cause of death in Canada.
- There is no cure for kidney failure, dialysis and transplant are treatments. Until there is a cure for kidney disease, a transplant is often the best available therapy for many kidney patients, but the demand for donor kidneys far exceeds the supply. 77% of those waiting for an organ transplant are waiting for a kidney.