

# EPILOGUE

Unless you or someone you care for has been diagnosed with Crohn's Disease or Ulcerative Colitis this might be the first time you've heard the term IBD. But Inflammatory Bowel Disease affects the lives of approximately 233,000<sup>1</sup> Canadians, both children and adults, every single day. Living with IBD can be frustrating; it can be lonely; it can even be embarrassing to some. But it doesn't have to be.

It shouldn't have to be. These stories came from people of different genders, ages and backgrounds, and yet each has a very similar message: IBD won't stop me. You are not alone. Emotional and medical support is available. Treatments are available. Ask questions and explore your options. Living with IBD isn't always easy, but that doesn't mean it has to define your life.

## References:

1. [www.isupportibd.ca/pdf/ccfc.ca-impact-report-fast-facts.pdf](http://www.isupportibd.ca/pdf/ccfc.ca-impact-report-fast-facts.pdf)
2. [www.isupportibd.ca/pdf/ccfc-ibd-impact-report-2012.pdf](http://www.isupportibd.ca/pdf/ccfc-ibd-impact-report-2012.pdf)



THE CANADIAN CHILDREN INFLAMMATORY BOWEL DISEASE NETWORK:  
A JOINT PARTNERSHIP OF CIHR AND THE CHILD FOUNDATION



# IBD doesn't define me

PERSONAL STORIES FROM PEOPLE  
LIVING WITH CROHN'S DISEASE &  
ULCERATIVE COLITIS

# INTRO- DUCTION

Ask  
Questions

Explore your  
treatment options

You  
are  
not  
alone

Fight  
back

It's possible to feel  
like yourself again.

## Have you recently learned that you have IBD?

If so, you're not alone! Roughly 1 in 150 Canadians<sup>1</sup> live with inflammatory bowel disease, or IBD, every day. In fact, Canada has among the highest frequency of people with Crohn's Disease (CD) and Ulcerative Colitis (UC)—the principal types of IBD—in the world.<sup>2</sup>

IBD affects children and adults alike, but symptoms can vary from person to person. What doesn't change are the cramping pain, fatigue, sudden weight loss and worry that can turn your whole life upside down. But as you're about to read, once diagnosed with CD or UC, it's possible to feel like yourself again. Proper treatment—and the support of a caring team of friends, family and health care professionals—can help.

You're not alone. Ask questions. Explore your treatment options. Fight back. You might have to live with IBD, but that doesn't mean IBD has to define how you live.



# A LETTER OF HOPE

Dear Newly Diagnosed Person with Crohn's,

**A**t times Crohn's may seem like a scary disease—but hopefully soon you will find the treatment that works and will make you better. I know how you feel. When I was really sick in the hospital, I thought the stories people were telling me about going into remission couldn't be true. I could barely walk. I felt like there was not one thing that could fix me. But there are so many treatments now—there is probably one that will work for you.

You may not realize it, but there are good parts to having Crohn's. If you get a treatment you have to get by IV, you may be thinking No, because of the needle—but keep in mind that you will get to watch movies while missing a day of school. That's pretty good, right? Your parents may worry about you catching something if there are contagious diseases going around your class, so that could mean more missed school!

Another good thing that happened to me because of Crohn's is I've met professional athletes, including one who has Ulcerative Colitis and plays pro football. They gave me very cool autographed stuff—an NFL football and helmet, an NHL hockey stick, and I got to go into the BC Lions dressing room, and on the field one time after a game. I hope to be an NHL goalie one day, so it inspired me to meet those guys. Someone who has IBD can still become a professional athlete. It doesn't have to hold you back.

Crohn's may be bad, and the times you're really sick may feel bad, but if you can take all of that, it makes you a stronger person. And there may be some surprising good things about it that you don't even know yet.

Aiden, 11

## LIVING WITH MY SHADOW

**I**BD is scary. It's like a shadow—stuck with you forever, whether you like it or not. While there are days you barely notice it, on others it is pretty hard to miss. But shadows don't cause stomach pain, fevers, weight loss, diarrhea and other uncomfortable symptoms. I think we'd all prefer an annoying shadow than a chronic illness. Yet also unlike shadows, having IBD makes you a stronger person.

It's going to be a tough journey. Different treatments, procedures and flare-ups. People who don't have it will never fully understand what you're going through. But once the really bad part is over, once you start medication or other treatment, things get a lot better. And instead of a diagnosis that ruins your life, IBD becomes a part of who you are. This will be a lifelong journey, but thousands of other people are experiencing it as well. We are all fighting this disease and understand what you're going through, whether you have Crohn's Disease or Ulcerative Colitis. No matter how difficult your life may seem right now, it will get better—I promise.

Kyler, 13

## REACHING NEW HEIGHTS



I was 12 years old when my life changed.

Diagnosed with Ulcerative Colitis in 2003, I had no idea of the battle I was about to face. From multiple hospitalizations to losing my large intestine, the past 12 years have been tumultuous! Despite major downfalls, I always looked ahead and knew no matter what, I would be okay.

In 2005, I was given the opportunity to attend Camp Canada with Easter Seals Camp Horizon in Bragg Creek, Alberta. Camp Canada connected youth living with ostomies from across the nation. After camp, I became an advocate for young people living with IBD and decided to become proactive with life, helping others to adjust,

and to inspire them beyond the confines of inflammatory bowel disease. None of this came easy though. I still underwent multiple hospitalizations as I battled my own health difficulties and lost a lot of time in both my academic and extracurricular activities. That said, I graduated high school on time with honours and snagged two scholarships.

After high school, I joined a non-profit organization called IDEAS, Intestinal Disease Education & Awareness Society. Through this network, I continued my work with youth and children affected with IBD. Although there is no physical cure for the disease, I believe in an emotional and mental cure. Just having someone to talk to, to text, to Facebook or to email, or having someone that will listen when your frustrations reach the roof is more than enough and can help more than anyone realizes.

On August 31, 2014, I became the first person living with a J-pouch to summit the world's highest freestanding mountain, Mount Kilimanjaro in Tanzania. Healthcare professionals were baffled when they heard of my attempts and even more so when they heard I actually did it! This journey wasn't easy though. Climbing was one of the hardest things I have ever done. Not only was it mentally draining, but also the physical toll it took on my body was ridiculous. I suffered, overcame altitude sickness and dealt with constant changes of my health conditions on the 6-day journey up the mountain. In the end though, I showed through my actions that this disease doesn't control me. My name is Kevin Ram and IBD doesn't define me!

Kevin, 24





# Never stop

**W**hen people find out I've been living with Crohn's Disease for thirty years, they are surprised. Although it has affected my life in profound ways, it doesn't define me.

I was diagnosed as a young teen at a children's hospital. I remember the amazing nurses and how they explained everything to me. How they sat up with me in the hallway, backs against the wall, chatting late into the night because I couldn't fall asleep. I remember they taught me how to insert my NG tube for overnight feeds. They reminded me to fill up my feedbag before heading to Marnie's Lounge to socialize with the other teens in the

hospital. They let me sneak into the nursing station and use the pneumatic tube station to send papers and specimens to other parts of the building. And I remember how they held my hand and gave me hope. This disease would help shape me, but not stop me.

I grew up at a Christian summer camp in Muskoka, Camp Kwasind. The summer I was 16, I dragged my NG feeds, my pole and my pump up there, to volunteer as a cabin leader for six weeks. Sitting in the dining hall three times a day watching other people devour camp food while I was enjoying my liquid diet was challenging, but not impossible. Being at camp was home

for me. And being on staff was a dream come true. My life had been shaped by previous cabin leaders, so I needed to become one. I went back for a week at the end of that summer to be a camper during Teen Week. During one of those "small world" moments earlier in the year, my nurse from my children's hospital, Krista, and I discovered she was headed to Camp Kwasind to volunteer as the camp nurse for Teen Week. So there we were in August, talking late into the night, as my pump infused formula via NG tube, with our backs against the wall of an old wooden cabin.

In university, my plans to become a veterinarian changed, since my Crohn's flared up again. Three surgeries later and more missed school, I thought I was being led in a different direction. I graduated from my second degree as a Registered Nurse and headed to the same hospital where I was diagnosed. In winter 2000, my last student placement was on Ward 6A, because of the IBD population. That spring I was hired to work full-time—and I was home.

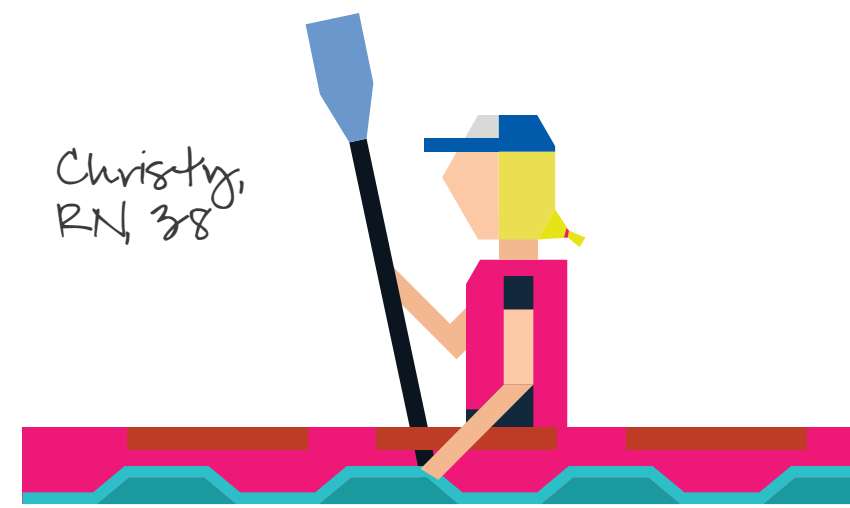
Camp has also never left me. I continued to volunteer as a Cabin Leader at Teen Week throughout university. When I became a nurse, I joined the Board of Directors and was handed the key to the Health Care Centre. I now run this part of Camp Kwasind, ensuring there are volunteer nurses each week at camp, and of course I am there for at least a week myself each summer.

Camp is a part of my soul, and keeping kids safe and healthy in such an active environment makes me happy. (I love to devour every delicious meal in the dining hall!) And, as the "small world" laws continue, I have even had former campers become patients at the same children's hospital, and then bring their NG feeds to camp—other people who would not let IBD stop them from having life experiences.

As an adult, life experiences abound. I have travelled the world. I have a challenging job that I love, and the shift work hasn't beat me. I am active at camp and in my church. I volunteer as the nurse at winter camp retreats. I am blessed with a busy social life. I take care of myself, but live large (all 5'1" of me). And I eat whatever I want.

My choice to be a nurse at the same hospital where I was diagnosed is definitely rooted in my early experiences there. When patients are newly diagnosed with Crohn's or colitis, this is devastating news for the patients and for the parents. I am often asked to meet these families and share my story. And I give them hope. And I tell them—this disease will help shape you, but not stop you.

Christy,  
RN, 38





## Fighting my battle

When you think about it, it's hard to imagine that almost everyone has gone through something that altered everything for them. Here's the experience that changed my life.

In December 2014, I got the flu. I felt sick with a bad cough and sore throat—but I also had a fever every night. My parents recorded the fever to tell the doctor, but after the flu, they noticed I still seemed to get a fever nightly. Another thing I noticed was that everyone in my class kept getting taller but I stayed the same size. I had stopped growing.

By that summer, I was almost always tired, and not very energetic. I spent most of my time indoors because of fatigue. I felt like I had wasted my

summer. By September, I was in a lot of pain. We went to a hospital emergency room in Hamilton. We got there at 8:00 p.m., and I was admitted but didn't get a room until 4:00 a.m. I slept for 2 hours and then woke up to a bunch of surgeons telling me I would have surgery that day!

After undergoing a lot of tests, I was finally set free! I got a doctor who diagnosed me with Crohn's Disease. He put me on a biologic medication, which has me growing again. Now that you know my story, you should be extra nice to everyone you meet. Everyone you meet is fighting their own battle, and most of the time you can't tell from the outside.

Jack

## The guts to keep going

Hi, my name is Emma. I am ten years old, and I have Crohn's. There are many ups and downs but I always pull through. I am trying to take this disease and turn it into something good. This year I am doing the Gutsy Walk to raise money for Crohn's and Colitis Canada. I have sold 134 T-shirts. I also held two barbecues to raise some more money for the walk. So far I have raised \$1,720—and I am not done for the year! Crohn's can be scary at times—and the times that were scary for me were when I had to have a colonoscopy and endoscopy.

It was also scary when I had to have a feeding tube. Now I am feeling better, and I am on a biologic medication that you get in an IV every 2 months for 2 hours at a time. I talked to people about my Crohn's and so I got asked to be the honorary chairperson for the Gutsy Walk 2016.

Don't be afraid to tell other people about your disease, because other people need to know what you have and how to deal with it. You should speak to your friends and teachers so they all know and can help support you in your journey.



**You should speak to your friends and teachers so they all know and can help support you in your journey**

Let's make more people aware of this disease so we can fight it and find a cure. I know I have the guts to make it stop—and so do you!

Emma, 10

# STAYING STRONG

Casidy's story

**M**y name is Casidy. I was diagnosed with Crohn's Disease on August 29, 2014. I became sick at the age of 12. I'm 16 now. Those four years were hard—being skeptical about doctors, dealing with pain most people could not handle. Let me tell you about myself. I've never been one to say no to sports or playing with boys. I'm competitive and stubborn. When I'm hurt, I keep going and I don't stop until it's physically impossible. I've played soccer for twelve years and volleyball for four. I'm a farm girl and help my dad in the fields and with the machinery.

This last year has been rough. Over the summer, I lost 25 pounds, and became so sick I could not stand up on my own. At one point, my fever was 103 °F. On August 28, I had high school registration, and a doctor's appointment. Later that day I was lying on a hospital bed in emergency. It took them four tries to get an IV line in, but for someone who was scared of needles and hated doctors, I thought I did pretty well. They kept me overnight and rushed me to a children's hospital the next



afternoon. I missed my first week of high school, but as soon as I got out, I played in a volleyball tournament. I was put on a full liquid diet for eight weeks, Nutren 1.5, nothing else but water. I'm glad I did it—because I'm in remission now and can eat most things.

Always keep your friends and family close and never take anything for granted, even through the hardest times. **Stay positive, it really does help. Never be scared to tell people about your disease, be strong and willing to speak up about it.**

Casidy, 16

# A letter of empowerment

To: Parents of a child newly diagnosed with IBD  
From: A mom of a brave, resilient boy living with colitis since he was three

The day my son was diagnosed with colitis both my husband and I were relieved. He was three and anaemic. But he still played—on the floor—stopping to rest now and then. Luckily, it took only a few months from his first symptoms to diagnosis. He's 12 now.

DON'T BE AFRAID TO ASK QUESTIONS AND ADVOCATE FOR YOUR CHILD

I was a student in the early days of his illness. I recall talking with my classmates about letting him eat cheese when we knew how it could affect his symptoms. I had one classmate who questioned why I would let my then four-year-old make this decision himself. But another classmate supported my approach. She was diagnosed with Crohn's when she was young. Talking to her was very helpful. I understood how important it was to let my son make his own decisions. Only he knew how his body actually felt.

Empowering our son to speak up for himself was one of the best decisions we made. He began letting other adults in his life know what he could and could not eat. At the age of nine, he decided he was done with aspects of his treatment. He felt empowered enough to tell us and trusted that we would listen.

Working with our medical team has also been helpful. Don't be afraid to ask questions and advocate for your child. As a parent, you see how your child's medical care affects their day-to-day living. We've learned to listen to our gut feelings. Trust yourselves and your instincts. Develop a relationship with your medical team—together, you can build a strong team dedicated to what is best for your child.

Samantha

# Looking Toward Tomorrow

My name is Lauren, and I was diagnosed with Crohn's just after my eighth birthday. At first I was really scared and didn't know what was going to happen. Now I am 10, and I feel great. I love to swim and run cross-country and spend time with my family and friends. Try not to worry too much—know that the doctors are amazing and will take good care of you. When I grow up I want to be a doctor and help other kids with Crohn's. My dream is to help cure this disease.

Lauren, 10



# I'm still kicking

You never understand what Crohn's Disease is or how it feels until you are diagnosed with it.

It was at a Greek restaurant in Jasper, Alberta, after a beautiful hike in Maligne Canyon, when I started to experience severe stomach cramps out of the blue. Jasper, being a small town, had a miniature hospital near the restaurant. Trying to get in the car, I vomited my whole lasagna in front of a window at A&W. We made our way into the tiny hospital, but after an assessment, I was quickly transferred by ambulance to a children's hospital in Edmonton. Even with many doses of morphine, the stomach pain would not stop. I stayed there for three weeks, meeting six roommates along the way. After numerous tests, medications, a nasogastric tube and lots of IVs, they

eventually diagnosed me with Crohn's Disease on September 2, 2013. To heal my 42 cm obstruction, I was not allowed to eat or drink for over two months—and somehow made it through both Thanksgiving and Halloween!

I am now 13 and enjoy playing the piano and accordion. I also play soccer as a goaltender and enjoy Ukrainian dancing. I attend grade seven at École Secondaire Saint Marguerite d'Youville where I am learning my third language. Taking many pills daily, and infusions every six weeks, I am able to manage with the support of my family and GI team. I struggle every day—but I think of a goalie facing a breakaway, and have promised myself to never give up.

Demetrius, 13



I am now 13 and enjoy playing the piano and accordion. I also play soccer as a goaltender and enjoy Ukrainian dancing.



# WHY ME???

To have constant stomach pain as a 12-year-old child was frustrating. So many visits to the ER, family doctor and specialists—only to be told they couldn't find anything, or that it was just a pulled muscle. The pain was like a gut-wrenching punch to the stomach, and a burning sensation in my throat and chest every time I took a breath. Being told by my friends I was faking, or looking for attention or just didn't want to go to school—it hurt. To be asked by my doctor if there's a problem at school, at home or if I was throwing up after a meal—you start thinking it's all in your head. But the pain was so excruciating it really drove me crazy. This pain kept

me awake at night, so I was a zombie by day. I couldn't go to school since I couldn't concentrate. I sat in the house for four months. I didn't want to talk about what I was going through. When I couldn't take the pain anymore, I told my mom "shoot me now." That's when she took me to see a GI specialist.

It didn't take long to be diagnosed with Crohn's. I had ulcers from throat to ileum. Now let me tell you, prednisone is the best steroid pill ever. After taking it, I couldn't believe how the pain went away. Unfortunately I also couldn't believe how much weight I gained—I was always hungry. We tried two different medications until the third one, a biologic medication,

put me in remission for three years. We then moved on to injections of a different biologic medication, once a week, to keep me stable. There were times I needed a tutor to keep my grades up, but I passed all my courses. Throughout, the constant fatigue was hard to handle. I finally had to listen to my body and rest when I couldn't go on. When I wasn't well, I always asked myself, *Why me?*

Now that I'm almost 18, I'm finally comfortable talking to my friends and family about this terrible disease. I've found that no two people with IBD have the same symptoms or can eat the same food. You can eat something one day



Take it one day at a time and do your best

and be okay, but the next time, you're in pain. Take it one day at a time and do your best. If you have good friends, they will understand when you have to cancel plans and just want to stay in and watch a movie. Reading about this disease helped me understand what I was going through and gave me ideas to help cope. I hope a cure is found—it can't come soon enough for me!

Brianna, 17

# NOTHING WILL STOP ME

When people first look at me, they see my NG tube. The second thing they see is my smile. And to them, it just doesn't add up. How can someone who looks so sick be smiling and happy? To them, happy means healthy. To me... well, I'm still trying to figure that out.

The journey to my diagnosis wasn't easy. I had the misfortune of some not-so-great doctors. I ended up in the hospital for a week. I lost 40 pounds. Exercise and food were the devil—all I wanted to do was sleep. I was miserable. I laugh about it now, but it took a lot out of me—and my family.

Eventually, we were referred to a children's hospital in London. That was the greatest thing that ever happened to me. I got a great team of GI doctors, a dietician, a nurse practitioner and a social worker—who I affectionately referred to as "my squad." They helped me accept my diagnosis and

understand what has happened and how things have changed. I consider this my new normal. Because normal is relative. Now, back to the real question. How do I stay positive?

I don't let myself be sad—I've decided to laugh about my disease, and educate others because that is a much better use of my time and energy. I will answer any questions people have about Crohn's or IBD. I've made YouTube videos for people who are too shy to ask, sharing my experiences and struggles with the world.

My life isn't perfect. I take medications daily, and I often give people older than me medical advice. My journey is just beginning, and I can't wait to see what happens next. Crohn's may have slowed me down, but it will never stop me.

Storm

# Continue à jouer



**C'était très difficile pour mes parents, mais ensemble nous avons pu nous soutenir mutuellement et rester positifs.**

**J**e m'appelle César et j'ai 14 ans. J'ai reçu le diagnostic de maladie Crohn quand j'avais 11 ans. Au début, j'avais très peur car je n'avais aucune idée de ce qu'était la maladie de Crohn. Tout s'est passé très vite. Je suis allé à un rendez-vous régulier chez un médecin et quelques semaines plus tard, je suis devenu un patient atteint de la maladie de Crohn. Mon jeune frère, Nicholas, a été également diagnostiqué avec la maladie de Crohn en même temps que moi. Il avait 7 ans. Il m'aide beaucoup parce qu'il comprend exactement ce que je vis régulièrement. C'était très difficile pour mes parents, mais ensemble nous avons pu nous soutenir mutuellement et rester positifs.

Au début, j'avais peur que la maladie interfère avec l'école et

mon hockey. J'avais tellement peur de ne pas être en mesure d'aller à l'école ou que mes amis se moquent de moi. Heureusement personne ne s'est moqué de moi. Mes amis ont été très gentils et m'ont accepté comme avant. De plus, je jouais au hockey depuis cinq ans lorsque j'ai reçu le diagnostic de maladie de Crohn. Le hockey est ma plus grande passion. J'étais terrifié, mais 3 ans plus tard, je joue au hockey et je joue mieux que jamais!

Alors oui, la maladie de Crohn provoque un malaise et ça change certaines de vos habitudes alimentaires, mais en fin du compte, ce n'est pas si mal. Au début c'est un peu difficile, mais par la suite, vous ne remarquerez même pas que vous l'avez! J'espère que tout ira bien!

*César, 14*

# Crois en toi

**L**es gens à mon école étaient aussi très généreux et compréhensifs jamais ai-je eu un commentaire négatif à propos de mon tube. Aujourd'hui à l'âge de 16 ans, je suis très heureuse avec le progrès que j'ai fait et je suis très confiante et confortable dans ma peau. Je continue à suivre un horaire d'école plutôt chargé au BI complet, et je continue de suivre ma passion pour la danse depuis l'âge de 3 ans. Je trouve qu'il est important de se trouver une passion du genre où tu peux échapper à la réalité pour même quelques moments. La danse pour moi m'a aidée à surmonter mes plus gros défis, comme il y a quelques mois quand j'ai été diagnostiquée avec l'arthrite juvénile.

Mes expériences m'ont menée à la réalisation que la clé pour surmonter des défis du genre est simplement de persévérer et de croire en soi-même. C'est ainsi que j'ai atteint le bonheur; en me faisant confiance et en suivant mes passions, malgré tous les problèmes que je dois surmonter.

*Véronique, 16*

# RESTER POSITIF

**E**n 2011, j'ai été diagnostiquée d'une colite ulcéreuse sévère. J'en étais à ma deuxième maladie auto-immune. Je ne comprenais pas pourquoi on s'acharnait sur moi. Je suis une fille très sportive, toujours

avec le sourire aux lèvres et énergique. Cela a pris beaucoup de temps avant que mon médecin diagnostique ma maladie, car je suis super dure envers mon corps. La colite n'a jamais été contrôlée. Avec tous les jours d'école que

j'ai manqués c'est vraiment difficile de croire que j'ai réussi mon secondaire avec succès et à jouer au soccer 5 fois par semaine, mais j'y suis arrivée. J'avais la détermination et l'assurance que la colite ulcéreuse ne me mettrait jamais

au tapis. J'ai pris tous les médicaments qui sont reconnus pour contrôler la colite ulcéreuse, mais ils n'avaient aucun effet sur moi. Mon corps est cortico-dépendant. À chaque fois qu'on essayait de se débarrasser des médicaments

temporairement je retombais en crise, c'était immanquable. Mon dossier à voyager à travers le monde.

Un jour, mon médecin a voulu essayer un médicament qui sortait de la recherche chez les adultes. Malheureusement, les

recherches n'avaient pas été effectuées chez les enfants. Le gouvernement et la compagnie du médicament n'acceptaient pas que j'aie ce médicament. Après presque 3 mois d'acharnement ils ont enfin accepté! J'ai été la première

patientel'hôpital à recevoir ce médicament biologique par voie intraveineuse. Mon médecin a créé un protocole pour moi et nous avons lancé le mouvement. Grâce à ma persévérance et à celle de tous mes médecins, de l'hôpital et de mes parents

plusieurs enfants auront une meilleure qualité de vie avec ce nouveau médicament. À ce jour, je suis à mon meilleur. Il ne faut jamais lâcher prise. Gardez l'espoir, restez positif et vous verrez la lumière au bout du tunnel.

*Nbemi 18*