

## Welcome!

If you are reading this, then you, like all of the contributors to this booklet, have a child with Crohn's disease or ulcerative colitis (also called Inflammatory Bowel Disease or IBD). This booklet has been created by parents participating in the ImproveCareNow Network, who are 'Empowered by Kids', as a reminder that we are not alone.

Each letter or story in this booklet is written by a child with IBD or a parent. While each letter comes from an individual with their own experiences, beliefs, opinions and backgrounds, all share a common thread – we are not alone. Some of us are fairly new to the world of IBD – a world that is filled with new symptoms, medications, tests, doctors' appointments and whole new vocabulary. Others have been on this journey for quite some time. We each bring a personal and unique story to the table, but we all share a common need to hear the words "me too."

As parents, we all understand how important it is to see our kids feeling well and living a normal life, in spite of IBD. Yet we can easily become consumed with worry about our child's diagnosis and feel trapped without the ability to help. ImproveCareNow is providing parents an exciting opportunity to roll up our sleeves and get involved as part of the team, to share our unique insights and collaborate to improve care and health for children with IBD. Parents are involved locally with their care centers and nationally within ImproveCareNow. The results speak for themselves – remission rates up from 50% to 77%.

As the parents of children with IBD, we are all in this together, and together we will make life the very best it can be for our IBD kids and the IBD kids of the future. Together we are going to make a difference for every child living with IBD.

Best wishes to you and your family,

The Parent Working Group of ImproveCareNow



You are invited to sign up for CIRCLE, an eNewsletter published by ImproveCareNow that connects you with information about IBD, tips for managing health at home, news on health care innovations and progress the network is making. <http://improvecarenow.org/subscribe>

Reach the parents who contributed to this booklet at:  
[info@empoweredbykids.com](mailto:info@empoweredbykids.com)

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To say we live, eat and breath the existence of our children is an understatement. Our children fill our world with so much joy and happiness. We provide a platform for them to flourish and assure them that the possibilities are endless to what they can be and do. We want to protect them from everything. Then the day comes we can't, but we can help provide them hope.

How do you explain to your child who has just been diagnosed with Crohn's that all will be ok? When in reality your heart is so broken and your head is scrambling to make any kind of sense from what you have just been told. I was there-six years ago, and what a journey it has been.

You are not alone, you are at the beginning of your journey. You will find your way. Today, put your new plan into effect. With the help of your Doctors/health care providers, local support groups and talking to others it's amazing to learn how many others share your story. Our children become the remarkable strong ones from this journey, they become our heros! They will flourish and their possibilities are endless, we just travel down a different road.

:: *Julia* parent of a child with Crohn's

Finding out your child has an illness that may be lifelong is like walking through a door that you cannot pass through again. You're in new territory, stepping across a border that marks the time before Crohn's or Colitis and now, permanently, the time after. As the parent of a young child with Crohn's, I have made this crossing and, having been here awhile, can share plenty of advice on doctors and treatment, school accommodations and nutrition. But, more significantly and importantly, I offer you this: **Knowledge = Power.**

Become powerful. Learn, read, and speak to smart people who know what they are talking about. Be active and not passive. There is much we do not know about pediatric IBD and you will need to partner with a trusted medical provider to make some tough choices. Do so, not by hiding in the back seat, but by plopping down in the passenger seat. Such involvement is not easy. It takes time and can be overwhelming. The temptation to give up and let the people in the white coats do all the driving can be hard to resist. But, remind yourself (and sometimes others) that the most important person in your child's health is you.

**Knowledge = Power** and your power coupled with your love is as critical as the best medicine. *Use it as directed.*

**David** - Parent



I remember when I was first diagnosed with Crohn's. I was happy to finally figure out what was wrong with me, and how to help it. After a couple of weeks my medicine started to kick in and I felt like a normal kid again. Crohn's may seem scary but it really isn't, so don't be afraid.

Yeager, age 13

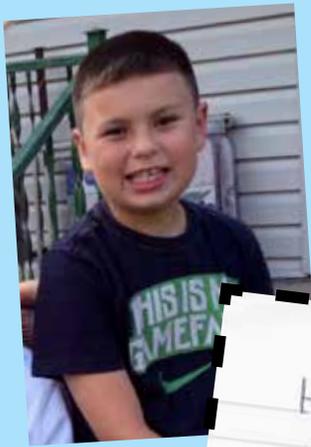
My daughter was just 58lbs and 12 years old when we got the diagnosis from the doctor. Nicole had Crohn's Disease. I knew something was wrong but I had no idea it would be this. I was devastated with the news. All I could think about was how sick she was and wonder what the rest of her life would be like. The doctor explained to me that Nicole would have to be on medication for the rest of her life because there was no cure for this disease. For the first year after her diagnosis things were difficult emotionally for her and the whole family. Our lives were changing, and we were always worried about our little girl. My daughter is now on Remicade infusions every two months to keep her disease in remission. She just started high school and loves it. She's making new friends and is even on the crew team. She feels much better! Of course there are days that are bad for her but she can deal with it. As for me, I am so much better. All I want is for my little girl to be happy and healthy. She is now 93 lbs and gaining. I still worry about what her life will be like in the future but she is strong and Crohn's is just one thing that is part of her life. She is determined that this disease will not define her. She inspires me.

~ **Dana** (Parent)

I guess if you are reading this then you got some news that you weren't expecting to hear! I know you are probably scared and honestly you probably have no idea what it all means! My son, Anthony was 10 years old when he was diagnosed as IBD indeterminate. To say this was a shock is an understatement! Upon receiving the diagnosis in March 2012 we didn't even know what questions to ask as we were completely clueless about IBD. But we are learning as we go! Our son has a whole new life now and he is thriving with his new medications. Most of the time you don't even know anything is even wrong with him! WooHoo! And let me tell you, we have an ACTIVE son! He plays travel baseball and he is always on the go! So this does not have to change your child's whole life! You will be amazed by how much better your child will feel now that they know what is going on and they get on the right medications! So keep a positive attitude and never be afraid to ask questions, no one knows everything about IBD! Good luck as you begin this new journey in your life!

Lucretia (Parent)





## BELIEVE ME. I HAVE GOTTEN BETTER.

Hi! My name is Colson.  
I have crohn's.  
Crohn's is hard and  
scary. But it get better.  
Believe me. I have gotten  
better. I do lots of things  
and I have crohn's. I walk  
home, play sports, and ride  
my bike. I was four  
When I got it. I was scared.  
I had to get lots of  
IV's. But now I'm used to them.  
Also you get to go to  
crohn's camps which are fun!

**Are you serious? And Why Me?** We still remember the day when we were taken into that little room and the doctor told us our lives would never be the same. Our little girl's life would be forever changed, she would endure pain, tears and heartache and there was absolutely nothing that we could do to help her. I can assure you that eventually the numbness wears off and you will move forward. The pain turns to courage, the tears turn to "yes, we had a good day" and the heartache turns to strength that you and your child find inside yourself.



The last two years have been filled with so many emotions and so many peaks and valleys. But the one thing we have learned is how remarkable these kids are. My grandmother used to say, "Special people have to deal with special stuff". That statement embodies how our daughter reacts with love, hope, optimism and courage to the circumstances that surround her. She, and all of the other kids who suffer, inspire us. We learn more from watching her courage than she will ever know.

We offer you hope, inspiration, encouragement and strength that you are not alone in this wave of life, just ride the wave as it will get better. We hope you look for opportunities to love and learn. It makes the journey much easier.

**Justin and Robyn, parents of a daughter with Crohn's**

I didn't really understand about Crohn's disease at first. "Then one day I asked my mom, "When will my Crohn's go away?" When I found out it will stay forever, I cried.

It helps that my mom tells my teacher at the beginning of the year that I have Crohn's disease, in case I need to go to the bathroom a lot. And my doctor gave us some papers that explain Crohn's disease, so we can give them to my teachers. So I think this helps them understand me better.

If you want to know one thing to help a kid like me with Crohn's disease, it's not to give them a hard time if they're picky about food. Lots of foods hurt my stomach, so I don't like to try new things. I don't mean to be picky or rude. Once I had a sleepover and in the morning my friend's dad wanted me to try his omelets and hash browns, and I was embarrassed because I didn't want to. But I also didn't want to hurt his feelings. But then my friend's mom told his dad that I have Crohn's and lots of foods hurt my stomach. Then he understood and he didn't keep asking. So I would say, if you're a parent or a kid, make sure people know about your disease.

Now I've learned to live with Crohn's disease. It helps to go to the support group for kids with Crohn's and colitis because I have fun there with kids like me. It helps that I'm not the only one. I know that I'm not alone.

## Michael age 8

**H**aving a child diagnosed with a chronic illness is devastating and the maze of figuring it all out can be overwhelming. When our son was diagnosed five years ago, we had no idea where to turn. Once the initial shock wore off, we reached out to friends and our physician to help us navigate the best way to treat his illness. Having a doctor that not only our son is comfortable with but we also can talk to has really supported us on this journey. We visited several doctors to make sure that this doctor/patient relationship was the best for not only our son but us. Joining a support group also gave us the comfort we needed to help him the best we could. Realizing that we are not alone and listening to other people's stories has been supportive for us.

It has also shown us that no matter how bad we think we have it, unfortunately there is always someone in a worse situation. As cliché as it may sound, keeping a positive attitude is the best way to help your child. Always remember that you are doing the best you can with the situation you have been dealt.

~ Liz [Parent]



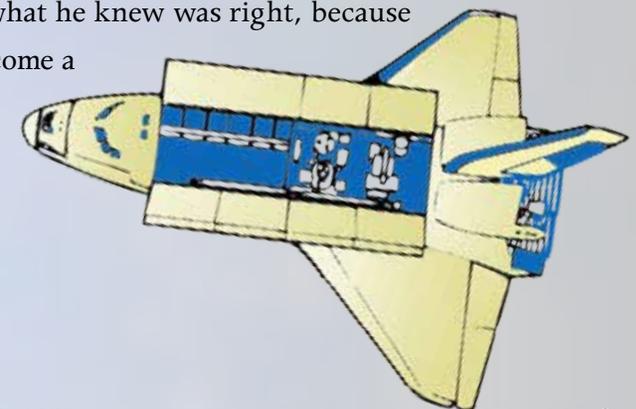
This is a story about a boy that loved outer space, playing outside, and most importantly his family. He never thought much of tragedy, never thought anything terrible would happen in the world, let alone to him.

## BECOMING AN ASTRONAUT



Then one day he began to experience disabling stomach pains. He was diagnosed with Ulcerative Colitis, and suddenly everything that he loved had vanished. His dream of becoming an astronaut could no longer happen. After what seemed like forever, he was tested, treated and he was back on his feet in no time. However, he had many flare-ups and was hospitalized numerous times, including an entire summer. The one reason he never lost hope, was because every time he was sick, he had gotten better. Realizing how bad his life could be without the proper care and treatment, he began volunteering with whatever was needed, whether it be at school, in the community, or the hospital itself. Then the boy began playing contact sports again, stayed in school even when his stomach was hurting, and still found ways to do what he knew was right, because one day he will become a doctor and fulfill his new dream of helping a child similar to himself.

## Kolin, 17



To all the siblings,

I was so young when my brother was diagnosed that I don't remember him ever not having Crohn's Disease. I want you to know that YOU are an important part of the family too. Sometimes it feels like the sibling with IBD gets all the attention but I have learned it's not really true. Your brother or sister needs you! They just want to be a regular kid, like you, so don't treat them any different. Learn as much as you can about IBD so you understand what's going on when they are sick, getting tests, in the hospital, taking medicine, missing school and feeling good. Sometimes family plans change when they are sick, but don't get mad because they don't want to be sick. Always have their back and they will have yours. This disease affects the whole family so be strong, be patient and always be there for them.



- Kyle

Hi I am Anthony and I am eleven years old. When I was first diagnosed with Crohn's disease I was very scared. But then I realized if I eat healthier and take my medicine I would feel a lot better. It has been almost two years since I found out I had Crohn's and it doesn't limit me to what I can do. I still play travel baseball year round. I am on the swim team in the summer and I get straight A's in school. This goes to show Crohn's may be a roadblock but it doesn't stop me from going where I want to go.

Good luck,  
Ant



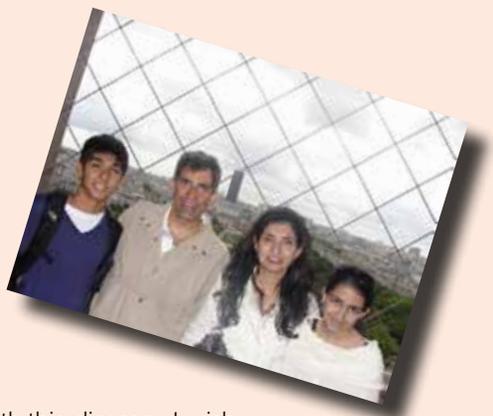
When I was young I was very very sick. When I was in kindergarten I got sick. I think people called me names like Chubby because of my medicine. I was in kindergarten so I had no clue what they said. When I got into first grade, I went to the nurse a lot just like kindergarten. I went to the nurse every day. I have ulcers. It is a problem that makes your stomach hurt and it hurts a lot. I missed a lot of school and it was hard to catch up. Second grade was better. I did not go to the nurse as much twice a week but that year was great! It was my first healthy year. I got a cake one day to celebrate. I do a walk every year. Last year I walked the whole way! It was my first time walking the whole way. I was so proud of my self. Now I'm great!

Jimmy, age 8



**Dear Parent,**

I am the father of a son who was diagnosed with Crohn's disease at the age of 12 (2008) and a daughter diagnosed with Crohn's disease at the age of 12 (2011). I am sure like me, you have asked 'why?' Unfortunately, no answer came and I made sure I appeared strong and composed for my children. I was hoping and praying I would be brave enough for them as they were fighting their battle with this disease. I wish I could say those magic words that would make it all go away but as I now know life is a collection of moments and doesn't work that way.



It is often said our children learn from their parents. Crohn's disease has shown me as a parent we learn from our children. I have learned how resilient and confident our children are. They face the day with a smile and ensure this disease does not define them. As a matter of fact they work harder to achieve greatness and be grateful for the good days. We have pushed and encouraged them to do well and pushed them to strengthen their bodies so as not to accept Crohn's in defeat.

After our son was diagnosed we encouraged our son to try out for swimming. It was heartbreaking for the first few years as he worked hard to keep up with his peers. We kept encouraging him that he could do it. He is now a high school Varsity Swimmer. After our daughter was diagnosed we felt she needed to be confident about her body as well. We signed her up for Tae Kwon Do. She is now two belts away from black belt. Again all of this came with daily frustrations. There were times we all wanted to give up and thought it would be so much easier to wallow in self pity. Trust me we still have moments like that. But, it's true when they say, children are resilient.

Our children taught us how to overcome life's disappointments. They are truly our heroes. During this time, there were a number of people who encouraged us and helped us. Our community is truly that of paying it forward. Please know that now this emotionally stronger parent is ready to pay it forward. Please contact me to just talk about anything or just a few words of support or just...I know how that feels...Warm regards...

*Cyrus* (A father inspired by his son and daughter)





My son is 13 and has Crohn's Disease. The diagnosis when he was 2 years old was scary, and he and our family have experienced many health related difficulties over the years.

Along the way, through my involvement with different communities of those affected by this disease, I have connected with incredible people, parents of kids with the disease, and kids and adults of all ages. Friends I would have never met otherwise, stories I would have never been told, and countless moments of insight and inspiration I would have never been able to be a part of-this has been my journey.

The strength I see in the children I have met amazes me, mostly because they just want to be kids and will fight through the bad days and difficult times to go to school, participate in their activities-basketball game, dance recital, etc., and to hang out with their friends.

Of course we face many challenges and have endured periods of medical uncertainty. But I know for sure that my son's strength and perseverance has pushed me and our family to understand others and their struggles in a deeper way, to step outside of our own comfort zones to reach others, and push forward towards helping improve the lives of all those living with Crohn's or Colitis every day. One thing I would never trade is the people I have met, and the experiences I have had. I know you will find unexpected sources of inspiration and compassion as you travel down this road.

Stacy : Parent



## What does this mean?

When my daughter was diagnosed with Ulcerative Colitis in 2010 just days before her 10th birthday, the "Why?" of course came into my head but it was quickly overcome with, "What does this mean?"

What it means is, as a parent, your "new best friends" are your child's medical team. There is no easy road or answer with IBD, whether it is Crohn's or Ulcerative Colitis. And to get your child into that magical place, the world of remission, it takes work. The best way to accomplish this is through teamwork with an integrated medical team that you and your child are on your child needs to become the "quarterback" for their care, someday. That process starts the day of diagnosis. Your child's care must be done "with them" and not "to them" and that includes you. Thankfully at our care center, patient-family centered care is a hallmark and my daughter's state of wellness today is a testament to that approach being successful. As a parent, it means you must teach your child by modeling the behavior they need to learn with their medical team because sadly, they grow-up and it is a special life-skill they cannot live without.

As a parent, I had to teach my child how to communicate symptoms to her medical team in meaningful ways. With maturity she had to learn her limitations and to "stop" when she felt her body changing. When something was not right, then it was her job to communicate that something was not right. This does not happen overnight, but it will happen when everyone is tuned-in and talking. I have learned that this disease rears its ugly head over time and is not like flipping a switch of – fine one day, very sick the next. While it can seem so, we learned early on that there are many early, very subtle signs that point to trouble. Learn those for your child. Be watchful and vigilant, but not overbearing. Learn not to make the disease the "center of attention" in their life and yours. It is a strange dance that we must all learn and getting into that rhythm with it makes life smoother. This disease will take a prominent place in your world but it does not have to take over your world.

Every one of these "Gutsy Kids" is unique and so is how the disease dwells in their bodies. By understanding the early signals, the warning signs, the disease pattern for your child, the options available medically, and having a medical team tuned-in to your child and their needs, you are then in a position of strength to help your child be what they want and need to be – happy and well.

Wishing you all the best on this journey,

**Mary,**

**Parent of one Gutsy Kid with Ulcerative Colitis**

**Care Center - Texas Children's Hospital**

## Dear Family,

We wanted to share a little of our hearts with you, as we know you are going through such a tough time! You see we have been right there in your shoes, wondering if we would ever get to go home from the hospital or what our life was going to be like if we did get to go home. When Jacob was first diagnosed with U.C./ Crohn's undetermined we did not realize it could ever get this bad. We also did not know that we would end up living at the hospital for

2 months, having blood transfusions

and doctors trying everything medically they could think to do. Jacob was declared a medical failure and we had no choice, but to have surgery, which led to another.

When Jacob was well enough to finally leave the hospital we ended up leaving with a ileostomy bag, a hickman, home health and a very sickly boy for months and months to come. We made many E.R. visits those next several months for obstructions and complications, but we are here to tell you the good news about Jacob now. It was about 6-10 months later that we were sent to a wonderful surgeon. Because Jacob had slowly gained his health back, the Dr. would now entertain the thought of the reconnection of his intestines (the J-Pouch surgery).

We had been hoping and praying this would be the case since it was not an idea that was entertained just months before, because of the major complications Jacob had after his first colectomy surgery. Our surgeon, Our gift!, performed the two step surgery and it changed our son's and our life forever. I'm not saying it happened with no complications,

but it happened! As Jacob has healed and had his ups and downs of dealing with all that goes along with this disease, we are here to tell you he is alive, healthy, energetic and a joy to have.

We always held strong to our faith through this process. We also clung to the verse Jeremiah 29:11 "For I know the plans I have for you, declares the Lord, "plans to prosper you and not to harm you, plans to give you hope and a future.

We knew that through our tough journey God had a plan for Jacob, just like He has a plan for all of our precious children.

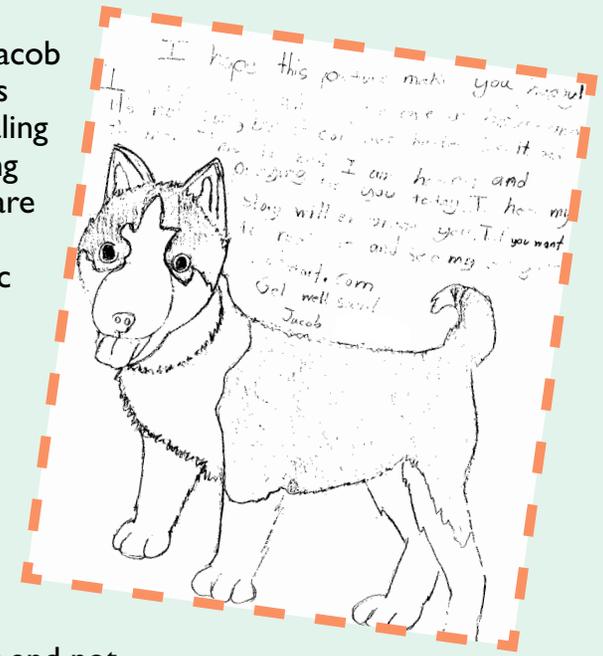
*We are believing with you!*

~ **Lindsay & Stephanie**

Being diagnosed with IBD can be scary. Everybody is always worried. Others who have IBD know how you feel. I have walked in your shoes. If you ever get hospitalized, the nurses always take awesome care of you, and some make you laugh. A piece of advice is to never stop believing, NEVER give up and to surround yourself with people who care.

**Best Wishes**

**Kathryn, 12 Crohn's Disease**



Hi!

I just wanted to let you know you are going to be ok. I was scared in the beginning too. I was only 9 years old when I was diagnosed and to be honest, I didn't know what Crohn's Disease or IBD even were. When you are ready, tell your friends because they will help you, just like they do with anything else. Your family and friends will be there for you and you will find out you are not alone. My journey with this disease has made me stronger and has made me an advocate for others with IBD. We will fight until we find a cure!

~ Tyler



*Hi, My name is Cameron.*

I'm a 10th grade kid who just happens to have Crohn's disease. This all began six years ago-about the time I was in 4th grade. I had always been a pretty healthy kid and very active. I played sports, swam, surfed, golfed and traveled a lot with my family.

Then one day out of no where I got sick, like very sick. At first the Dr. said it was a virus and would run its course. At this point I had lost a total of 24 pounds. I was now very sick. I could no longer play sports. It was such a task just to get up out of bed.

My Dr. was at a loss and sent me to a Pediatric Gastroenterologist (a special Dr that knows about the digestive system). I went through a whole lot of tests, including blood work, a colonoscopy and endoscopy and I had to drink this really disgusting white stuff for X-rays. We finally got a diagnosis: CROHN'S DISEASE!

I was so depressed! I was so tired of being sick. I hated getting IV's and having to have weekly blood draws. I knew before, but really knew now that my life would never be the same again. I had lost my freedom and the rights to just be a kid.

I used to take pills every day. This continued for a few years until I was finally taking 16 pills a day. I still didn't want to eat much but things kind of got better. Then in October 2012 things changed again. I was sick, "failure to thrive." I was not growing, losing weight again and no appetite. I had to have another colonoscopy/endoscopy. My results were not much different than 6 years before. My Dr. took me off of oral meds and I began infusions-Remicaid.

On March 17, 2013 I rushed to the hospital. It was my very first time. My life as I had grown to accept it was going to change in a very big way-AGAIN! It went in a direction I could have I never had imagined. I had a perforation of my intestines. Surgical result: removal of 1/3 of my colon, 15cm of small intestines and a temporary Ileostomy. I'm happy to say that in June I had surgery again-this time to remove the ileostomy and reattach my intestines. I am back together and feeling great.

I continue to have a pretty normal childhood. I so wish I didn't have Crohn's but I do. I deal with it the best I can with the support of my family, friends and my Dr's. I know there are people out there that have it worse than me.

You may be reading this around a difficult time, diagnosis. I want you to know that you are not alone. When our son was diagnosed with Crohn's Disease, he had just turned 9. We were so overwhelmed by the diagnosis and didn't really know much about the disease. We literally went into information overload trying to learn as much as we could. Our goal was to understand the disease and get him the best care that we could so he could feel well and just be a kid. Over the years, we have learned so much, met so many others affected by IBD and will continue to fight to find a cure. Today, my family and I continue on our journey but with much more confidence and a lot less fear than we initially had. We still attend educational events in our area when they are available, we fundraise as a family to raise money for research and we each speak openly about the disease, as advocates, to try to increase awareness. The strength and courage I have seen in these kids with IBD continues to amaze me, they are truly an inspiration. You have so many others by your side! We are all in this together and will be stronger together.

Tania - Parent

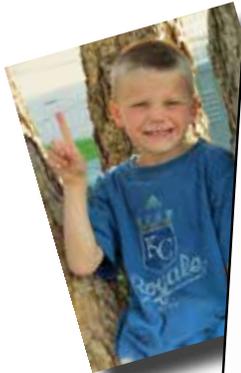
J.M. was born, a puffy redheaded Muppet baby, in 1999. By her 2 mo. check up it was determined that she had Turner's Syndrome. (46x chromosome, I will let you look it up). Before she entered Kindergarten, J.M. had ear tubes put in; tonsils and adenoids taken out; a tethered spinal cord released; her bladder and kidney tubes reconstructed, and was on daily growth hormone injections. She was regularly followed by an Endocrinologist, a Urologist, Allergist, and a Cardiologist as well as her "team captain" Pediatrician.

Despite all of this she was a vibrant, brilliant, apparently healthy girl...until she was 12. At the end of her 6th grade year, she was missing a lot of school with complaints of pain and fatigue. A regularly scheduled asthma check up ended with a, "by the way, I've had a lot of stomach pain and some diarrhea..." A second look at her weight chart showed a drastic loss of 7lbs. She had just started estrogen therapy, a common protocol for Turner's girls, and had been seeing blood in the toilet. She thought she had possibly started her period, but hadn't told anyone yet. Soon, blood work found she was severely anemic and Vitamin D deficient, a colonoscopy found the center of her pain, then we waited to find out if her official diagnoses would be Crohn's or Ulcerative Colitis.

By her 13th birthday, she had gone from 113lbs (just on the chubby side for her short stature) to 72lbs. A girls size 16, back to an 8/10! She missed 47 days of her last trimester of 6th grade. I helplessly watched Tinkerbell's light going dim. Several bad flares led to trips to the ER, hospital stays, IV's, steroids, and recommendations for Remicade. For J.M., with compromised heart and kidney's, it was not the best option. We made a major lifestyle change and decided to home school her for 7th grade. She and I went on the Specific Carbohydrate Diet (Elaine Gottshall - Breaking the Vicious Cycle) in hopes of avoiding the heavier drugs. This diet and the addition of VSL-3 Probiotics, along with her prescribed Azathioprine, Asacol, and Allopurinol made a huge difference. She thrived doing online school, eating the starch free diet, and we began doing individual food challenge tests to see what she really must avoid. We were slowly able to add back in some ground corn, rice occasionally, and her favorite sweet potatoes back into her diet. She leveled out with these adaptations and we believe the carbohydrates help her metabolize her meds and make them work better.

By her 14th birthday she was in her second school play, had walked a 5K, only missed 2 days of 8th grade due to Colitis symptoms, and graduated from middle school with the highest honors. Now, a Freshman in high school, she packs her modified Paleo lunch to school every day and has a 504 medical plan that gives her clearance to leave class and access to the nearest restrooms to each classroom at her discretion. She is sensitive to stress and will have a flare if she gets overwhelmed with life, or if she eats something wrong for her. My daughter is feisty and tough, compassionate and imaginative, and willing to help anyone who is dealing with IBD.

Jennifer: Parent



Hi my name is Jack. I am 6 and a half and I have Crohn's. I live a very normal life, I trust in God and you can too.

In August 2008 our son was admitted to the hospital for a colonoscopy. He was 4 years old. He had been struggling with symptoms for many months, yet when the doctor told us our son had Crohn's Disease, I found myself literally unable to stand up.

I am certain all I heard was the word Disease. He was 4! He was too young! The doctors were mistaken. As it turns out, they were not mistaken.

That was 5 years ago. Over the last 5 years, we have experienced a lot: new medical terms, IV's, pills, doctor visits, blood draws, educating schools, looking for bathrooms in all sorts of places, learning to keep a change of clothes in the car, and soaking up any and all information we could find about Crohn's Disease.

But that's only part of the story! The rest of our story is, over the last 5 years we have also experienced vacations to Sea World, new school years, soccer games, flag football, basketball tournaments, learning to ride a bike, chess club, birthday parties, and a week at summer camp!

While Crohn's Disease continues to be part of our son's life; his life (and ours) is so much more than this disease.

**Jamie**  
Parent

## Dear Parents, H—O—P—E

I am sorry that your child has been diagnosed with a chronic Inflammatory Bowel Disease. Although this may come as a shock to you, please do not think you are alone as there are thousands of kids in the UK with this illness.

There is no doubt that your child is on a long road to recovery, but with love, understanding and support, most children and families learn to adjust to the illness and cope. Medical procedures and the constant round of doctor appointments could become stressful for you and your family, but good preparations before these can reduce fear and distress. The IBD team of doctors, researchers, nurses and dieticians at ImproveCareNow Centres are all really lovely and kind people and you can rest assured that you are in very good hands!

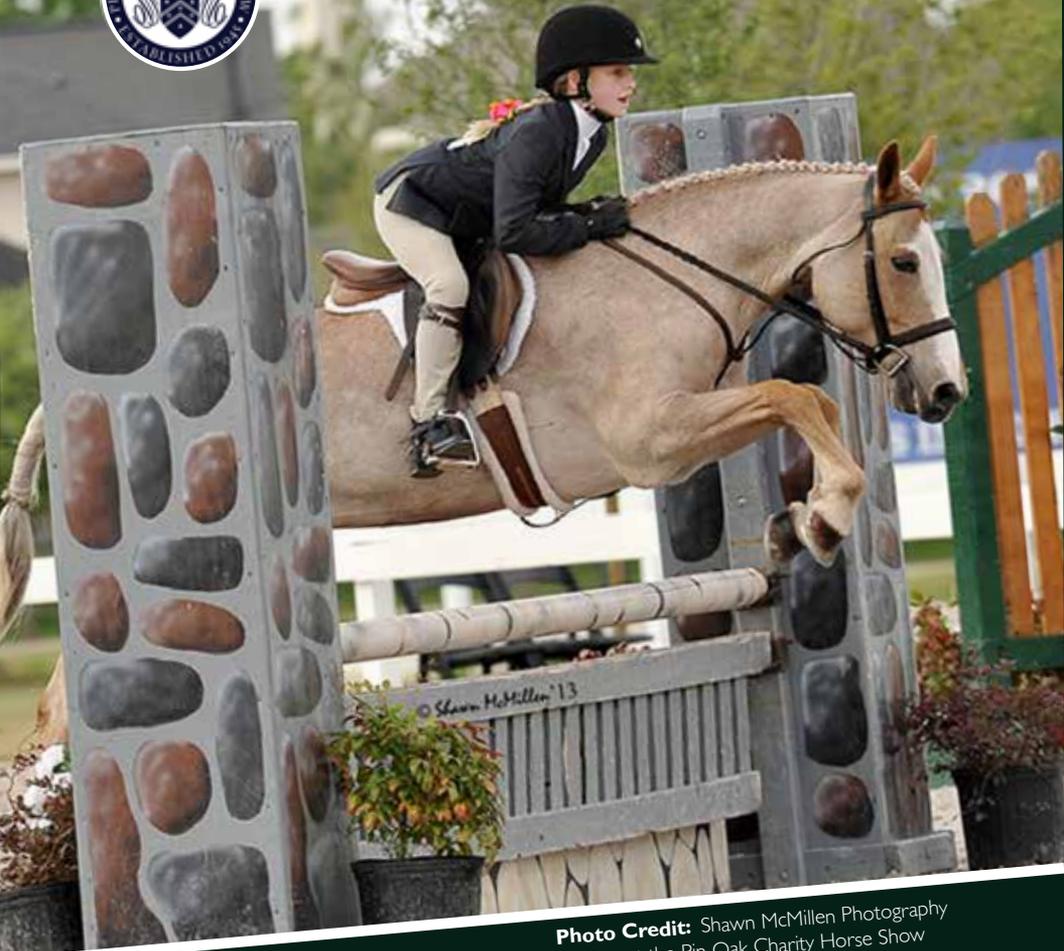
Talking about your experiences to someone who has already been in your shoes does help and many centres have set up a Parent Support Group for children with IBD. They are a group battling the same problem and understand exactly what you and your family are going through. We can all teach, and learn, from one another's personal experience, and share best practices and support strategies.

There may be tougher times to come before things get better, and there will always be a degree of uncertainty but be optimistic and remember H-O-P-E Hang Onto Positive Expectations!

Wishing your child a speedy remission,

**With best wishes,**

**Ana** Parent (GOSH: U.K.)



**Photo Credit:** Shawn McMillen Photography  
& Taken at the Pin Oak Charity Horse Show  
benefiting Texas Children's Hospital

# THIS IS WHAT REMISSION LOOKS LIKE

Layout: [www.KarrCreative.com](http://www.KarrCreative.com)