The Journey Begins

I was standing in the hallway of another out-patient center. The mystery illness was finally being revealed. I was physically standing there in a public hallway in front of my son’s physician as the words continued to flow from her mouth. I didn’t hear anything after, “Your son has Crohn’s Disease.” She touched my forearm gave me a smile and said you can see him in recovery, make a follow-up appointment for this week and she walked away.

At the time of our children’s initial diagnosis parents need specific emotional, practical, economic and social support. There was none for me at that time. I specifically remember getting on the internet immediately and trying to research EVERYTHING I could to educate myself on what journey our lives were heading towards. The more I read the more afraid, hopeless and alone I became.

As parents we all want the best for our children. In order for us to provide the best for our children, we need a strong community support of partners for us. The EBK Newsletter will hopefully be part of that village support for you.

This first of it’s kind newsletter, is written BY parents of kids with IBD FOR parents of kids with IBD. The goal for this newsletter is to provide you the parent with a collection of information based on the experiences and expertise of parents on the same journey.

Welcome to the first issue of what I hope to be an invaluable tool for all families to help ease fears, create hope and knowing that YOU are not alone. In this first issue, we highlight Dr. Richard Colletti of ImproveCareNow as he reviews 30 years as a pediatric gastroenterologist and what he sees for the future of treatment for IBD children. In addition, twelve parent contributors have shared stories on a variety of common experiences. We all need a community of experts to help support us, a community that includes the expertise of parents as well as our child’s care providers. This newsletter was written by those who have, and who are walking the path you are on right now. We are all part of the same community, sharing the common experience of caring for our child with IBD.

Julia Ament-Cox, Editor in Chief

This bi-monthly newsletter can be sent directly to your email’s inbox.

Sign up at http://www.EmpoweredByKids.com
In Sickness and In Health

By: Jennifer Erickson

Marriage and parenting is hard enough! Sticking it out with love and patience day to day just isn’t easy. We all know about the high divorce rate in our country. Add in extra financial burdens, new medical language, and the very common lack of solid sleep that families of children with IBD, or any chronic illness face and sadly the divorce rate is much higher. I lead KwCCpdx, a support group in Portland, Oregon for families of pediatric patients with IBD and marital stress is a common topic. I write with hopes of more conversations and more understanding; less arguments and anger.

The most common complaint is often a version of “He is a control freak and totally over protective now that (insert child’s name here) has Crohn’s.” “She’s so scared he’ll have a flare if he gets upset, she lets him get away with everything!” It is not unusual to have one parent be more permissive or authoritarian than the other in any family. But, when a child gets sick sometimes roles reverse or go to extremes. Both behaviors are natural reactions, but getting on the same page as parents is important to the unity of the whole family.

The other common problem is a matter of balance and trust. It’s not a male or female thing, and I can’t even hit on the stress and exhaustion of single parents who, on the bright side, have no one with whom to argue. Yet, when one parent (generally the mothers based on my 17 years of waiting room observations) becomes the primary caregiver, managing all of the doctor appointments, they also bear the duty of filling in the other parent; maybe having to convince, or sell them, on why certain choices were made. Later, they may battle guilt if the treatment doesn’t prove beneficial. While the other parent, having been removed from the decision making, feels helpless, doubtful of the options, and piles blame on top of the guilt if there isn’t a positive result. Adding to the distance between a couple, there is often a large “information gap” when one parent spends more time digging for alternatives on the internet and kept up with new research, leaving the other to have to play catch up. Both parents want the best treatment for their child, but stress, guilt, worry and fear kick in when there aren’t clear answers or as a series of attempts fail to help. Everyone deals with frustration, grief, fear, and exhaustion differently and statistically, more often than not, the pressure is divisive to a couple. The sensitive child may come to feel it is all their fault perpetuating a stress cycle. Getting both parents out of work to attend to every check up is simply not realistic, but getting to as many appointments together, especially in the early stages, may be key to starting out as partners and learning together to fight IBD instead of each other.
Find Your Village

By: Sheri Pilley

Almost as important as finding your pediatric GI specialist.....is finding your new “village.”

As most parents, when our son was diagnosed with Crohn’s, we struggled with understanding the magnitude of living with a disease for which there is no cure. Like others we spent months researching on google and quickly became traumatized by what lied ahead. We faced the unknown as we prepped our son for scary procedures, and second-guessed every decision we had to make without the luxury of time to make those important medical decisions. Like most parents, we didn’t know much about Crohn’s disease and we certainly didn’t know anyone else who had a child living with it. We were alone, learning a new language that was virtually foreign the month before. We quickly learned that to get through it all we had to find our “troops,” our new network of friends, our village of support who could help us better understand this new language and be there for us when we needed people who could relate.

We set out early on to find others in our shoes and establish some relationships that could help us navigate. Through good old-fashioned networking, reaching out to that friend of a friend of a friend who knew someone with a child who had Crohn’s, We eventually found five other families in our area and have created bonds that now run pretty deep. These fellow villagers of ours have helped us with everything from healthy eating grocery store tours to demonstrating the least painful subcutaneous injections we now have to administer to our son at home. Our village has helped us through flares, symptoms and prep for surgeries, and showed us how to save big bucks on medications that nobody had ever bothered to mention. They have helped us write 504 plans for school and given us suggestions for the best child psychologist in town. And over a glass of wine we have shared a good laugh as we swap details of bowel movements, advice on the best public restrooms, and recipes for the best gluten-free, dairy-free, sugar-free cakes and cookies that can be passed off as “normal” to our kids. They are an email or text away when we need to know we are not alone; but most importantly, our children get together and then realize that they are not alone.

Leaning on our long-time friends and family throughout this journey is a given. These important people in our lives will be there for us during rough times and celebrate with us when our children are in remission. But unlike the families in our village living day-to-day with this disease, they truly cannot fully understand our new language. So for the sake of your sanity and for the emotional well-being of your child living with Crohn’s or colitis, sign up for the support group, show up to a Crohn’s walk, send your child to CCFA’s Camp Oasis, call the friend of the friend who has a child with IBD, just do something to connect with others and you’ll be glad you did.
Interview with Dr. Richard Colletti of ImproveCareNow

Dr. Richard Colletti is the director of ImproveCareNow, a network of gastroenterology care centers and professionals who specialize in the treatment of pediatric Crohn’s Disease and Ulcerative Colitis.

ImproveCareNow’s network of participating centers now totals more than 68 in the United States and the United Kingdom and care for 19,000 children with Inflammatory Bowel Disease.

EBK: Why did you choose medicine as a career?

DR. COLLETTI: Oh, that was back a long time ago. You know I think I was 10 or 12 years old when I decided I wanted to be a doctor. I thought of myself as a pediatrician more than anything else and I don’t know how and why it happened. It just fit.

EBK: How did you bridge going from pediatrics into pediatric gastroenterology (GI)? Do you have a family connection or was it a natural course?

DR. COLLETTI: You know it was more circumstantial I think than anything. I was at a point in my career after doing general pediatrics for about seven years that I decided that I wanted to go into a sub-speciality. And where I was working at that time had no pediatric gastroenterologist. It was an area that I thought would interest me so in some ways it was circumstantial. From being a general pediatrician for seven years, I had encountered many children who had gastrointestinal symptoms.

EBK: Have you always practiced in Vermont?

DR. COLLETTI: When I finished my residency I went to the University of Vermont and I joined the faculty in the primary care division where I was a general pediatrician. I was one of the founding members of the pediatric practice at the University of Vermont. I helped establish and build up the practice and then after a while I felt I was ready to do something else.

So I went on sabbatical and got some training in pediatric GI. This was at the time before board certification was required in pediatric GI. I did one year of training and then went back to Vermont and began practicing pediatric GI. At the same time, I was calling a lot of my mentors to get advice on how to manage difficult cases. Now I’ve been doing pediatric GI for 30 years.
EBK: Over those 30 years, how have you seen the treatment of IBD change?

DR. COLLETTI: It has changed enormously ... one of the first changes was the use of the immunomodulators. It helped us to use drugs that were prednisone sparing. So, we finally had drugs that we could use that would allow us to avoid the use of prednisone. And of course the introduction of the new class of drugs, the anti-tumor necrosis factor drugs like Infliximab and Adalimumab, or Remicade and Humira are the brand names, have really revolutionized the care of kids with Crohn’s Disease and Ulcerative Colitis.

EBK: Did you have a role model at any point there in your career that you looked up to and what influence did they have on you?

DR. COLLETTI: Well, you know I think I looked up to my physician when I was a child a lot. In medical school, there were some really outstanding teachers who taught me how to think critically and the importance of being a disciplined and systematic caregiver. During my residency I had some really outstanding mentors including one who was particularly interested in how to communicate with parents. It wasn’t part of any kind of course or training, I used to meet with them on the weekend from time to time and we could talk about it. He opened my eyes about how challenging it is to communicate with families and how important it was for me as the physician and physicians in general to be able to do that and to be sensitive to their needs and perspectives.

During my fellowship, I had some excellent teachers as well. One of my mentors actually had Crohn’s disease. He’s now retired. He served as an excellent role model and someone who not only had great knowledge about disease but he also understood how to interact with patients. He also understood the importance of caring for patients and being responsive to their needs. I mean not caring for but caring about patients.

EBK: Is there one patient during your career that really touched and shaped you in some way?

DR. COLLETTI: You know I think I have one patient that comes to mind was so desperately ill. That had an impact on me. This kid was just so horribly neglected. What did I learn from that? I have to give some more thought about why that case still sticks out in my mind. I guess in some ways it’s relevant in that I understood that there was a part of taking care of that incredibly emaciated and depressed 18-month old.
There was just a part of gradually restoring them to health. I mean... First of all it was being able to make the diagnoses that it was child abuse and to carry out all of the legal and social aspects that are needed and then to do the medical part of getting the patient back to health and into a nurturing environment. In a way, I guess the importance of that case was understanding that taking care of providing medical care of people of those much beyond just simply writing prescriptions that it's really psychosocial experience as well as a biological one.

**EBK:** Could you imagine what ImproveCareNow has grown into?

**DR. COLLETTI:** Never. You know five years ago, we couldn’t even imagine what’s happening today. We keep evolving—and doing things better and better and I think we almost can’t imagine when we start out doing them. I like to say that we’re going so fast that we can’t even keep up with ourselves.

**EBK:** In a world without boundaries, what would you like ICN to look like in three years?

**DR. COLLETTI:** Well, in a world without boundaries, what I would like to see is that someone has found a way to both cure Inflammatory Bowel disease and to prevent it. Then, that ImproveCareNow had all the financial resources it needed to deliver to the cure to every patient with IBD and to deliver the prevention to everyone who needed it in the most efficient way. Typically there is a seventeen-year delay between the discovery, major breakthrough and its actual widespread implementation. And what ImproveCareNow can do is enable the application of new knowledge so much faster.

**EBK:** Looking back at your experience dealing with patients and families, what question or questions do you wish every IBD parent asked?

**DR. COLLETTI:** In general, if there’s not one question but there may be a series of questions whenever you go a doctor’s appointment. Just off the top of my head I would say things like how am I doing? And how do you know how well I’m doing? Are there things that I can be doing or you could be doing to improve my care? When a medication is prescribed, what are the chances that these medicines can help me, and what are the odds that the medicines can hurt me? What do you see my future being? How is this going to impact my life? How is going to impact my ability to function and engage my daily activities to feel well, to feel energetic and enjoy life? Or there things I can do to minimize my risks and increase my chances of success.
**EBK:** What is the biggest gap in the pediatric IBD treatment and where do you see treatment in three to five years.

**DR. COLLETTI:** I worry that these great new drugs we have like Infliximab and Adalimumab are not being used optimally. They may not be started at the right time. They may not be administered at the right dose or the right frequency. It may be necessary to use second drug along with it in order to ensure it’s going to continue to be effective. So I’m just concerned that the drugs, not just those drugs but all drugs that we have, that they’re not being used in most appropriate fashion and has a result children are not staying well as long as they can. Sometimes drugs described as failures are really failures to use the drugs optimally. So one of the goals of ImproveCareNow is to help clinicians use drugs optimally. Optimally, not only from the point of view of what does the patient need to be healthy but help from a cost effective way. So the problem is when drugs stop working, because sometimes a drug like Remicade will work and then it will stop working, then you begin to have fewer and fewer options. That’s why I think it’s so critically important that we really be disciplined about the use of these drugs and use them properly. And not think that well if this doesn’t work then we will use something else because eventually there is nothing else. So I think the most important to do today is to be sure that we use the treatments available to us in the most effective way.

**EBK:** Thank you Dr. Colletti for taking the time to share your insights.
Our New Friend – Buzzy

By: Liz Dapp

As a parent who administers multiple weekly injections to their child, using the term “game changer” to describe Buzzy seems like an understatement. For the last two years, my son has received weekly injections of methotrexate and biweekly injections of Humira as treatment for his Ulcerative Colitis. This therapy started when my son was six years old. In hopes of developing an understanding of his experience, we tried to research descriptions of what Humira injections felt like. No description paints a pretty picture. One blogger described it as “ten most agonizing seconds of my entire life.” Lovely.

Trying to convince a six year old to take shots in general is difficult. Trying to convince a six year old to take a shot that is very painful is a whole different hurdle. Our process consisted of 30 to 40 minutes of negotiation along with bribes and other unsuccessful attempts at minimizing the injection pain. We tried our best to allow our son to have some control over the situation by waiting for him to tell us when he was ready. In the end, we were just getting frustrated. That is until we found Buzzy (www.Buzzy4Shots.com). Buzzy works on the Gate Control Theory of Pain. It is designed to confuse the nerves with both temperature and vibration. The theory is that this distracts from the injection pain and interrupts the neural pain pathways.

The first time we used Buzzy, we wanted to make sure we did everything correctly. We let the Humira get to room temperature. We placed the ice wings on Buzzy, turned him on, and strapped him at the injection site. After 60 seconds, we moved him up and gave my son the distraction card that came as a bonus with our order. As we administered the Humira, there was NO indication that my son was feeling ANYTHING! After a second or two, he kind of made a face and said that it felt “weird” but it was nothing like the burning that he had experienced before. Since that initial use, we have found that we need to make sure everything is done properly to have a positive result.

Overall, Buzzy has greatly improved the time spent administering injections, everyone’s level of frustration, and the overall pain of the injection. These kids go through so many procedures and experience so much pain with their diseases. It is wonderful to have a small tool to help in a big way.
Enteral Feeding As A First Line Of Therapy In Inducing Remission in IBD

By: Anahita Daruwalla

Being informed creates a feeling of security and it is important to keep up with new therapies which help induce remission in children with IBD. Great Ormond Street Hospital’s (London England) standard first line therapy in inducing remission in children with IBD is total enteral feed/nutrition. While both therapies improve symptoms; nutritional therapy allows the gut to rest which leads to 74% mucosal healing as opposed to corticosteroids which induce up to 10% of mucosal healing. Azathioprine will always be started as a maintenance medication in the background to maintain remission once feeds are stopped after 8 weeks. This type of therapy is very popular in the U.K. and has been shown to be a safe and successful option; however there are some circumstances where total enteral nutrition will not be the appropriate treatment. In this case, the Consultant can opt to include medications and use the enteral feeds as a supplement rather than as a sole source of food.

A multi-disciplinary team including the dietician, ward nurses and local hospitals co-ordinate the training for carers and regime for the feeds. Most children are able to drink the feeds but if needed a nasogastric tube can be inserted. Nutritional feeds contain protein, carbohydrate, fat, water, minerals and vitamins – it gives all the elements needed to maintain a good level of nutrition whilst the normal diet is stopped.

If the child cannot tolerate drinking the feed due to the taste or volume a nasogastric tube can be inserted. In the UK medical professionals or trained parents insert and remove NG tubes. The tube can cause discomfort and injury or trauma to the nasal mucosa on insertion. Acute complications are rare. Tubes can become displaced easily particularly during activities at the nursery or school. It is for this reason that the position of the tube needs to be checked by the carer before each feed. This can be done quite easily by aspirating the tube to check the pH value.

There is no doubt that this type of therapy, either on its own or in conjunction with medications, improves the inflammation in the lining of the gut. England has been successfully using this therapy as a first line treatment for Crohn’s disease for over 25 years and perhaps it is time for more Consultants and Centres to initiate this therapy as a first option. It has certainly helped in the case of my daughter’s remission!
A Shot in the Dark

By: David Alain Wohl, MD

Entering the dark room, the beam of the intruder’s head lamp easily found its target, laying only partially covered on the bed, face-up. Lucky. It would have been harder to get a clean shot if he had found him curled, or even worse, on his belly. Fox-walking closer, he heard the deep rhythmic breaths of the sleeper grow louder as he approached—a satisfying confirmation that the sedative slipped in the drink a couple of hours ago had taken hold. If all went well, there would be no sound, no resistance. He would get it over with and be gone, undetected. He focused his light on the belly and away from the sleeping eyes. Crouching down, deftly and swiftly he did what he had come to do. A deep inhale and it was over. Until next week.

The opening of a best-selling thriller? No, this is a scene played out weekly in my 10 year old son’s bedroom as we inject him with methotrexate—a drug that helps to control his Crohn’s Disease but which he can not even stand to look at without immediately and violently starting to vomit.

Anticipatory nausea and vomiting is well described in persons receiving cancer chemotherapy. It typically occurs just before a dose of the offending drug and is a classic case of Pavlovian conditioning: a medication starts to cause nausea and with repeated cycles this experience becomes paired with not only the drug but also things associated with it. The nurse who comes in to administer the medication, the smell of alcohol swab used to clean the skin, the sound of the syringe wrapper opening all can trigger a wave of unbearable nausea. A friend’s young son with Rheumatoid Arthritis began up-chucking whenever he simply saw the bag of frozen peas his parents had been using to numb the spot where they injected the methotrexate. Once established anticipatory nausea is it is hard to break (ever try to get the cat to stop meowing whenever you use a can opener?). The best approach is to not allow the association between the experience of taking the medication and the nausea to get started - that is, to prevent nausea before it starts.

In our case, we tried but failed. The weekly injections of the drug seemed to be remarkably well tolerated. On a “shot night” we put some topical lidocaine on our boy’s belly, pre-dosed with a nausea medication, waited a half hour and then gave the shot. He never complained about nausea but, now we suspect it was there. One night after a few months on the methotrexate, we saw exactly why they call it projectile vomiting. Simply the tube of topical anesthetic was enough to make him green. The smell of the alcohol swab was too much to bear. It only got worse after that and it quickly spelled the end of conscious administration of methotrexate for us. That is when we secretly hatched Plan B.

Methotrexate, like many medications, is a poison. The drug inactivates an enzyme used to make folate, an essential ingredient in the creation of new DNA. Without folate, a cell cannot divide. A similar principle is employed by antibiotics to kill bacteria. The side effects of methotrexate are therefore predictable with human cells that regenerate most rapidly, like the cells lining the gut, falling prey to its effects. Why it produces nausea in some people, 10-20% by some estimates, is not understood. It does seem that the oral form of the medication is more commonly associated with nausea and a consistent finding is that children are more susceptible than adults. Administration of folate as a supplement has been found to reduce some of the side effects of methotrexate without diminishing the drug’s effectiveness but, its protections against side effects are not complete.
A Shot in the Dark (cont.)

After he was diagnosed with Crohn's Disease, my wife and I along with our pediatric gastroenterologist decided to treat our son with a combination enteral nutrition and our selected poison, methotrexate. There are limited data regarding methotrexate in pediatric Crohn's Disease but there is a vast experience of use of the drug to treat Juvenile Rheumatoid Arthritis; our choice was also influenced by our leeriness of the possible cancer risks associated with azathioprine and 6-mecaptopurine, particularly in boys. We are also the type of IBD parents who strive to avoid biologics like infliximab, in order to save them for when our son may need them later on. So, we were committed to keeping the methotrexate going - to fight rather than switch.

We considered that many an unpleasant thing had been done to our boy in the quest to diagnose and monitor his Crohn's Disease – and, thankfully, most of these were done when he was anesthetized. If we could knock him out for the placement of a video capsule, we figured, why not sedate him for a quick methotrexate shot. It all started to gel. For this to work we would have to be sneaky. And, we are.

Our routine starts with soda. This highly desired but restricted nectar of the youth, is offered as a special treat, starting a cascade that ends with a small red dot on the belly after a successful injection 0.6 cc of bright yellow methotrexate. Into the orange Fanta a small but miraculous tablet of Ativan dissolves. A sedative and an anti-nausea medication, it is perfect for the task at hand. Soon after the bubbly liquid is downed, and with a knowing look from my wife, we watch as over the next half hour our son's eye get a bit of glaze. He becomes a bit clumsy as he makes his way to brush his teeth and we have to make sure he refrains from his usual double tuck, half twist dive into bed.

Within an hour he is deeply asleep. We place some warmed lidocaine (too cold and he stirs) an inch or two from his belly button and cover it with a square of Saran Wrap. After 30 minutes one of us creeps in, head lamp on, syringe in hand, and Operation Shot in the Dark begins. Occasionally, we have to abort: not deeply enough in dreamland, or the dreaded laying-on-the-belly, and we have to wait or reposition, but most times it goes off without a hitch.

I was sheepish about our deceit. This was a trick and was counter to the honestly we used with and expected from our children. At a clinic appointment I was unsure whether our gastroenterologist would view this duplicity as immoral or evidence of some fanatical reluctance to embrace, so-called, more advanced therapy. Instead, when I described what we do he looked at me as if I were the 10 year old and reminded me that we, as the parents, informed as we are, are doing what we feel is best for our child. We are protecting our son and helping him to stay well. We should feel no guilt for that. It was nice to have an accomplice.
Help Your Child Swallow Pills

By: Tania Moon

Your child was just diagnosed with Crohn’s Disease or Ulcerative Colitis and now the medications and vitamins begin, another step along the IBD journey. There are so many new things to learn. How do you help this special, little person who is the highlight of your life swallow large pills every day....and perhaps many of them? It has to become easy because it will be a daily routine to help keep them well. You also want it to be easy so it’s not something they avoid, fight with you about or just flat out refuse to do, but how?

One of the best pieces of advice I received when my child was diagnosed was not to comment about the size of the pill. It seems like common sense until you open the pill bottle. Our children follow our lead. If you present it like it’s not a big deal, it won’t be as big of one. If you are shocked at how HUGE the pills are and announce it in front of your child, you may have just started a very difficult uphill battle. As parents we get so wrapped up in our child’s illness that we forget the impact our words and actions have on their perception. If and when they fight taking their medicine, remind them they swallow large pieces of food every time they eat! If that isn’t working, practice swallowing ice chips. Even if they struggle at first with ice chips, they melt and will go down easily! Some medications can be sprinkled or crushed into foods too. Just be sure to ask your doctor or pharmacist about options like that before you do them. Have patience and be there with them, they may just be scared. You may want to try having your child take them at different times of the day and see if that makes a difference for them. With encouragement from you, you’ll see the confidence you can help your child build with taking their daily medications and vitamins.

Interview with a rising High School Senior

By: Jamie Hicks

Q: Aidan, tell us what’s going on with your disease right now?

A: It has been a rough year. The medications weren’t helping and I developed a fistula in a very inconvenient area of my body. My parents took me to see specialists at the University of Chicago hospital and I am glad we went. My weight got too low and I had malabsorption so the doctor made me have this NG tube and feedings. I used to this I could never take an NG tube but I feel better with the nutrition. The most important thing was getting my life back and being drum major, getting to hang out with my friends and not in my hospital room!

Q: Your mom mentioned that you recently had pictures taken and you made the decision to NOT Photoshop your NG tube out of the photo. Can you tell us about that decision?

A: If I had chosen to have them use Photoshop, every time I would look at that picture all I could think to myself would be, “Oh yeah, this is the one where they edited my NG tube out.” I’d rather look at the picture and have it show who I really am right now.

Q: What advice do you have for families, parents, and kids of all ages who will be starting school in a couple of weeks and might be nervous about going back to school with a disease like Crohn’s.

A: Set up a 504 plan. Be prepared. As my dad likes to say, “Always have two paths forward.”
Travelling with IBD

By: Annette Kulzer

It is time for your family vacation. Oh Wait! Your child has an IBD. Now you are halted by wondering: “What do we need to do differently? What extra items do we need? How can we make this work?” Don’t worry, these are all valid concerns! Any trip requires planning, but to plan one with a child who has an IBD can be worrisome.

Whether we are traveling by plane or car we always pack a few necessities for our son:

- Extra Clothes? Check!
- Excessive amounts of medication? Check!
- Wipes and a plastic bag? Check!
- Portable toilet? Wait, What?

Now you may be thinking that’s just crazy, but I cannot remember how many times we were stuck in traffic or in an unfamiliar area and that last item came in handy!

Traveling is not a time to change your eating habits. Trying to stay consistent with eating and snacking and being sure to get plenty of rest are key elements especially when traveling. Did I mention sun screen? Most medications warn us about being in direct sunlight.

If you are planning on flying, check with your airline. Most are very accommodating. Some offer seats in the front or an aisle, early boarding or even help getting to the restroom when you should be seated, along with a place to store your carry on close by. Make sure you have your meds and any important information on you at all times.

While traveling with IBD can be challenging, a little pre-planning will help. Simple steps taken before will certainly pay off if the need should arise.

Happy Travels!
Quality Improvement and Why It Is Important to Parents

By: Cinda Lemont

If you hang around parents involved with ImproveCareNow for very long, you’re sure to hear us talk about quality improvement (QI). There’s a good reason for that – QI has been, in large part, the reason for ICN’s phenomenal success in improving outcomes for our kids with IBD. But, it can be overwhelming to dive into the QI arena with all its acronyms and statistical charts without any background in the subject. I’m going to try to help you survive (and thrive!) in the QI world through a series of brief articles about QI and how it’s being applied in pediatric IBD.

A fundamental aspect of QI is that it is a process of continuous improvement. It is not a like a project where there’s an end date. Once you take the plunge into QI, you’re in it for good.

Perhaps the most commonly used technique to support continuous improvement is the Plan-Do-Study-Act (PDSA) cycle. This technique is used heavily at the ICN centers and now the ICN parents are taking on their own PDSAs. Here’s how it works:

**Plan**  Agree on a goal. Choose a change that you think will move you toward that goal. Decide what constitutes success and how outcomes will be measured. Set the start and end dates of the cycle. Start small!

**Do**  Put your plan in action. Check frequently to make sure the plan is being followed and measurements are being collected as you go. Consistent and accurate metrics are key!

**Study**  Compile and analyze your results. Did the change have the expected result? Were there unintended consequences? Watch out for preconceived ideas about what should have worked but actually didn’t!

**Act**  Decide what to do with the knowledge you’ve gained. Often, that means starting a new PDSA cycle with the same goal but a new change to move you closer to the goal. Sometimes you find that you can do a better job at defining your goal. It’s progress even when you find out what doesn’t work!

Then you start over again with the next PDSA cycle. Use small changes to progress into more effective changes with more impactful results, reaching toward a goal that may have seemed unachievable at first.

**It works.** That’s been proven at ICN and in thousands of organizations around the world with virtually every kind of goal.
How to Live Well in Spite of a Chronic Illness

By: Beverly Blosser

Emily has Crohn’s disease and primary sclerosing cholangitis (liver disease). She was diagnosed almost four years ago at age nine after weeks of uncontrollable bloody diarrhea and severe abdominal pain. The journey to a diagnosis seemed long but the emotional journey she has been on continues and changes as her disease has progressed and eventually stabilized. After trying several medications, eight hospitalizations and ultimately an ileostomy, Emily’s disease has finally become much more manageable and she is now more energetic and involved in school sports and other activities. In fact, this past year she was goalie for field hockey and she made eighth grade cheerleading.

Emily never experienced much pain prior to the onset of Crohn’s disease. She had the typical childhood with minimal childhood illnesses and injuries. Her disease changed all of that. Pain and fatigue became her constant companion during the first year of her disease. This created a lot of emotional issues for Emily. Her pain was so intense that she would scream at the top of her lungs every time the cramps would occur. I recall the days where she would be in the bathroom crying and screaming out, “What did I do to deserve this? Why is God mad at me?” She would also scream at me and tell me that I could not understand her and that no one could because they were not going through what she was going through.

As a mother, I felt helpless. And of course she was right that I did not know what she was going through even though I prayed and wished so hard that I could endure the pain for her so she didn’t have to go through it. But how could I make her understand that God didn’t do this to her and also have her believe that this disease was not her fault? How could I help support her on her road to becoming physically healthy again and at the same time preserve help her maintain her emotional and mental health?

I look back on that first year and I can see clearly how we got through the worst days her disease. We took it one day at a time, we focused on the positive of each day and we breathed. Emily and I learned to breathe through a lot of her painful episodes. I spent so much time with her in the bathroom on the floor holding her hand, stroking her hair, listening to her cry and scream and telling her to breathe. I would begin to take long deep breaths with her to help calm her. As she calmed down, we would begin to talk and have conversations about the “why”. I would constantly reassure her that this was not her fault. Our conversations evolved from the “why this happened?” to talking about the good things that were occurring in our day and the things we had to look forward to in the future.

We also had some wonderful support from a child psychologist that taught us how to live well in spite of living with a chronic illness. Though this therapy that I attended with my daughter, I was able to develop new insight into the young women my daughter was becoming. Which I have to say her inner strength and her positive attitude not only amazed me but helped me maintain my positive attitude.

From the beginning of Emily’s disease, I have always realized that there are many things she has to endure alone even though I am right there beside her encouraging, supporting and loving her. I feel that it is important for her to be able to express what she is feeling even though it is sometimes so very painful for me to hear. She needs to have an outlet to express herself, whether it is with me, a therapist or a close and dear friend. And she needs to room to be herself and be a typical teenage girl.

Her journey and our family’s journey are far from over. Every time I start feeling the anxiety creep in about the uncertainty of Emily’s future health, I tell myself as I continue to tell my daughter, to take it one day at a time and to breathe.
Community Corner

By: Beth Nash, MD

Have you ever felt completely alone while trying to help your child receive the best IBD care? Have you ever wondered how other parents have dealt with specific issues like arranging special accommodations at school or packing supplies for a family vacation?

We’ve started an online pediatric IBD community on Smart Patients, a site that was founded with the belief that “patients are the most underutilized resource in healthcare”. The IBD community on Smart Patients is a forum where you can ask questions of other parents, share ideas and discuss topics of mutual interest. Parents have already started conversations about dealing with healthy siblings, the role of yoga and exercise in IBD, ways to get your child to complete their colonoscopy prep, dealing with the costs of infliximab (Remicade) infusions, transitioning to adult care and much more.

One interesting ongoing conversation concerns the role of diet in IBD. Parents are talking about specific diets they have tried, the role of enteral nutrition (using tube feedings in place of food) and use of probiotics (supplements that contain “good” bacteria). Participants are comparing notes, sharing advice they have received and posting relevant journal articles. Not only are parents talking about the diets they have tried but they are also talking about why certain diets may work better than others (did you know it may be related the bacteria in the gut?). We’ve also set up an instant poll within the discussion where you can indicate which diet your child is on (if any) and see how your answer compares with other parents.

To sign up for the community, go to https://www.smartpatients.com/ibd. If you’d like, you can receive email updates whenever a new IBD topic is started or someone responds to an existing topic.

Once you are logged in, you can find the diet survey at https://www.smartpatients.com/forums/1-conversations/topics/5284-the-role-of-diet-in-ibd or within the topic “The role of diet in IBD”. If you take the survey, you will see your results compared with those of others who have already completed the survey. You can also add a comment to the discussion.

While you are there you can also check out the clinical trials database we’ve set up so you can see some of the research studies about pediatric IBD that are still accepting new patients at https://www.smartpatients.com/ibd/trials/.

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