Transition & The Children’s IBD Center

By Clare Ceballos, NP

Transition is part of all of our lives. As the school year ends, children transition to summer and celebrate the excitement of completing another grade or even graduating from elementary, middle or high school. We eagerly anticipate some transitions and are more cautious to embrace others. For young adults, there are many transitions to celebrate and embrace. Finishing high school, starting college, graduating college, finding employment and possibly leaving home are all major milestones. For young adults with chronic illnesses, such as IBD, these transitions can hold special challenges. One of the major tasks for pediatric providers is to ensure that young adult patients are well prepared to take on the responsibility of their disease and to help them to transition their care to adult providers.

Transition of care is a process, not a single event. As children mature into teens, it is important for them to take over more responsibility for their medications, reporting symptoms and self-advocacy. As they mature further, they should start to make their own appointments, arrange their schedules, pick up their prescriptions and track insurance information. These skills take practice and can be taken on one by one. We want to work with you to help initiate this process and keep nurturing it to make the eventual transition to an adult

(Continued on page 2)
Transitioning from Pediatric Care

By Danya Rosen, MD

Dr. Rosen is a third year Pediatric Gastroenterology fellow at Mount Sinai. She is conducting a research project on transition of care which she describes here.

The number of children diagnosed with Inflammatory Bowel Disease (IBD) each year is increasing. This means that a growing number of patients will eventually need to transition from pediatric to adult care. The transition period is a critical time when adolescents begin to take responsibility for their health care and make decisions for themselves. Medication and visit non-compliance during this time may be associated with worse health outcomes, such as more emergency room visits or hospitalizations for IBD flares. Research from other areas has shown that a structured transition program can improve medication compliance and disease control, but so far there have been no large-scale studies looking at outcomes of a structured transition program for patients with IBD.

At the Mount Sinai IBD Center, we are currently conducting a study on transition of care. If you are an IBD patient over the age of 18, you may be asked to participate in our study. We will ask you to complete a survey at the time of your visit that asks about how ready you are to transition, and if you have already started talking about transition with your pediatric gastroenterologist. We aim to survey 120 young adult patients with Crohn’s disease and ulcerative colitis ages 18 to 25. Our goal is to find out if there are certain factors that lead to a more successful transition, and also if there are any barriers to care. As a joint pediatric and adult IBD center is scheduled to open at Mount Sinai in October 2014, we hope to use the information from this study to establish a structured transition program that meets the needs of our IBD patients on an individual basis.

Transition at the Center (continued from page 1)

provider a comfortable, successful process.

At the Children’s IBD Center, we are also in the process of transition. Towards the end of this year we will combine with the adult IBD Center at Mount Sinai. The Helmsley Inflammatory Bowel Disease Center will be in a new location in the hospital and both children and adults will be seen. Families will of course continue to be seen by their regular provider. Having a combined Center will facilitate the transition towards independence for teens and young adults, one of the many benefits to the new Center. We will continue to offer a multi-disciplinary team approach, with the opportunity for families to work with nutrition, social work, nursing and child life. We will continue to work together to provide you with excellent care to ensure the best possible outcomes for all families of children with IBD.

Celebrating Life (continued from page 1)

my family. I would imagine that if you are reading this article, you too have been affected by IBD, either being a patient yourself, or having a loved one with these illnesses. The IBD Center has always approached treatment of IBD not just in medical tests and prescriptions, but for all aspects of the lives of those affected. For that, I am forever grateful.

Fast-forward many years and I was blessed to meet the love of my life and she said ‘yes’ when I asked one of the scariest questions a young man will ever ask. When the planning started, we both knew that the IBD Center had to be a part of this joyous occasion. What is so amazing about the Center, and the care and support they give you, is that these efforts allow us to grow and create a life. If not for all the hard work by Dr. Benkov and his amazing team, I would not have been able to accomplish what I have. Giving back to the Center as part of our wedding was the very least I could do to begin thanking everyone there for all that they do.

When you decided to raise funds for the Center, you let people know that you have Crohn’s disease – was that difficult? At the wedding, there were placards placed throughout the ballroom. The placards did not specifically indicate why we were making the donation to the IBD Center, but it was clear who the IBD Center was, and what types of medical conditions were treated. Although there was no specific announcement that we were donating because of my personal experience and diagnosis, most people in our lives are very aware of the fact that I have Crohn’s disease. I am blessed to be surrounded by family and friends that appreciate the gravity of the illness and support whatever is necessary to ensure my continued health.

Do you have a message for kids or teens who are dealing with IBD? Anything you would like them to know? Crohn’s and Colitis are two challenging diseases and that is something everyone who is diagnosed with these illnesses, or has a loved one that is, will agree with whole heartedly. In the same breath, though, we should all remember that our minds are stronger than the disease will ever be. With the advances in medicines today, the promise of newer and better medicines on the way, and the amazing team at the IBD Center, together, we are showing Crohn’s and Colitis who really runs the show.

The first piece of advice I would give to kids or teens dealing with IBD is that it will get better. I am sure you hear that from a lot of people in your lives like your doctor, parent, religious leader and so on. I am also sure that when you hear it from these people the first thought is either ‘no it won’t’ or ‘you don’t know that.’ I had the same feelings and there is nothing wrong with such a reaction. I can tell you though, from a kid with pretty severe disease and many surgeries, that although they haven’t gone through what you are going through, they are right. It does (Continued on page 3)
get better and it does get easier.

The second piece of advice I would give kids or teens dealing with IBD is that it is OK to ask for help and support from friends and family. There is a bit of a helpless feeling, from what I have gathered, in people who love and surround you during these tough times. Let them in and you will see that it improves things for everyone, you included.

When IBD interferes with normal life, is there anything you do or turn to help you cope?

There will, sadly, be times when IBD interferes with your 'normal' life. Always remember that there will be another sleep-over, baseball game, trip to the amusement park, etc. In the moment it is sad to miss that event, but remember there is always another one just around the corner.

Where do you hope to go from here?

Although I have accomplished quite a bit in spite of this illness (went away to college, got a law degree and legal job, and recently got married) there are always more goals to achieve both personally and professionally. Almost to the day, 16 years after diagnosis, and innumerable different treatments and surgeries, I have been in clinical remission since May of 2011. Surprisingly, nearly all of the benchmarks listed above, and many more not listed here, were accomplished during times of flares and/or transitions in care and surgeries. Why I note this in a question to "where do I go from here" is simple: If that is where I went during times battling this disease, there is no limit on where I will go from here.

The Importance of Regular Check-ups

By Clare Ceballos, NP

Managing a chronic illness, such as IBD, is a challenge. After the initial diagnosis and treatment adjustments, regular follow-up remains an important aspect of care. Interestingly, a student who spent a month with us had this reflection on the time she spent observing at the IBD Center: "After spending a month in the Pediatric Gastroenterology department, I have learned many things. I was able to see firsthand why regular checkups are important. Although emailing a doctor is a great way to keep him or her updated on a patient's progress, it doesn't give a complete view of how a patient is feeling. By coming in for a regular checkup, doctors are able to physically see the progress a patient is making and better decide whether to keep medication doses the same, or alter them based on progress. A regular checkup not only gives a doctor an image of how a patient physically looks, but it allows for a conversation of symptoms that is more descriptive than an email could be. It also gives a doctor the ability to measure growth and hear about daily activity - all indications of progress. These regular checkups are key to help prevent patients from having a flare up."

Once you have a treatment regimen that works for you and you're feeling well, why do you need to come for a follow-up and how often should you make an appointment? IBD has cycles of activity or flares and periods of quiescence or remission. Our goal is to work in partnership with families to have children and teens in sustained remission. This is best achieved by having regular monitoring of the disease. It enables subtle symptoms to be detected and treatment regimens to be adjusted to maintain remission. Many of the medications used to treat IBD require regular blood work monitoring to ensure that the dose is optimal and safety is maintained. Generally children and teens with IBD, especially those who are still growing and maturing, should be seen every six months when they are in remission and more often if the disease is active.

So once you have made your appointment for a checkup, how do you ensure that you get the most out of your visit? Keep a list of the questions you have and bring it with you to your appointment. Try to come to an appointment on Thursday afternoon when you can meet with other families and members of the IBD Center team. Discuss with your child how they can actively participate in their care and the office visit. Finally, encourage them to take a little more responsibility at each visit, so they can build skills needed for transition and independence.

Racing to November with Team IBDkids

Ready to lace up your sneakers and run to help kids with IBD? Team IBDkids is taking shape and the runners are training hard for the November 2nd big race. We have one of Mount Sinai's surgeons running. We have an immunology research scientist. We have parents and cousins of kids with IBD. We have friends of their families. We have runners with IBD themselves. We also have a few entries left for people who want to take on a marathon and help support the Center's research and programs. Follow Team IBDkids on Facebook as the training season ramps up and the marathon approaches (www.facebook.com/TeamIBDKids). If you are a runner or know someone who would like to run, then contact Tom Fitzsimmons at 212-241-6727 or Thomas.fitzsimmons@mssm.edu
The Children’s IBD Center at Mount Sinai offers the following services for families:

- Regular sessions where you can learn more about the disease and interact with other families and Center staff
- IBDChat and Teen Alliance, interactive groups for kids with IBD and their siblings
- Gut Feelings, a parent to parent mentor program
- IBD Thursdays, where you can see our Social Worker, Child Life Worker, Nurse Practitioner and Dietician in the Manhattan Office
- A website of resources for families at www.IBDKids.org

Can you think of creative ways to support the Children’s IBD Center newsletter? Each edition of the newsletter reaches over 1800 families and costs $2,150. Our corporate sponsorship for the newsletter ended & we welcome private sponsorship. You may sponsor one edition, part of an edition or a series of editions. Celebrating a special occasion? Sponsor our newsletter in honor of your special day or person.

Resources for Families:
www.IBDKids.org
www.CCFA.org
www.medlineplus.gov

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