



# Robbie's Rainbow and IBD

By: Lavan Sivanathan

I had the privilege of attending a presentation featuring Dr. Thomas Walters, co-director of Sick Kids IBD program and Kate Murray, founder of Robbie's Rainbow, a children's charity for kids suffering through IBD (Inflammatory Bowel Disease). Kate described what started her interest in founding the charity, beginning with her son Robbie.

Robbie Murray, since the summer of 2007 at the age of 5, had had a pretty challenging life for a child his age. His mother, began to notice small changes within him, he began avoiding the foods he once loved, he ate less from his plate, he cried of stomach pains, he slept longer, and he showed little interest in his little league baseball team. Trips to the doctor showed normal blood results, and months went by with Robbie getting worse. By October he was running to the washroom up to 8 times a day, he could barely walk from the kitchen table to the couch. Mealtimes were nerve wracking for Kate who never knew what kind of response his body would have next.

It wasn't until later that Kate and Robbie got their answer, and he was diagnosed with Crohn's disease, a chronic disease that causes inflammation within the gastrointestinal tract, and is one of two conditions under the umbrella of Inflammatory Bowel disease (IBD). Symptoms that included fatigue, rapid weight loss, chronic diarrhea, abscesses, and within children cause a delay in growth and puberty. IBD is often confused with IBS (Irritable Bowel Syndrome) but they are not the same. Crohn's disease will be a part of someone's life until a cure is found. Crohn's causes canker like sores and inflammation in the digestive tract, that start from the gums in the mouth to the end of the digestive tract. The illness is not contagious, and not the result of a poor diet, rather a dysfunction of the immune system.

It took time to find medication for Robbie that actually worked, but once they did, his health transformed and he was clinically in remission. Early on in the journey they realized that not all medications that are used to treat IBD are best for them and that many families were financially burdened with the cost of treatment. Kate, Robbie, and a team of volunteers created Robbie's Rainbow, a children's charity that is dedicated to improving the health and quality of life for children living with Crohn's disease. They achieve their goal by providing vulnerable children with financial assistance for IBD treatments, creating education resources and programs on a variety of IBD top-



ics, specifically for children, teens and parents, as well as collaborate with patient groups to build education programs to improve and empower patients.

Some of the hurdles Kate and Robbie had to leap over was the issue with other parents and Robbie's own education. Conveying that although he has a disease, it is manageable and it is nothing to be afraid of was an important thing to explain to other parents. As was sharing the diagnosis at school, the necessity of explaining the disease to the principal and his teachers, and what Robbie would need to continue learning. Things like requesting having unrestricted access to the washroom, or having the ability to go to the

office to rest when, food or water in class if he needed it. Sick days would have to increase if he has to change his treatment, needs surgery, or if he catches another illness.

The most important thing was starting an ILP (Individualized Learning Plan) because Robbie's attendance would probably be inconsistent, it was important to have a formal accommodation put in place so he could stay as current as possible if he missed school. And starting that process began with a letter from his gastroenterologist, Dr. Thomas Walters, co-director of Sick Kids IBD program. Dr. Walters would go on to say as important advice for parents who think their child may have the symptoms of a chronic disease

"As the parent, you are the parent advocate, and that's your role. You should be an informed parents. The resource is the expert, and I don't think a parent should expect to need to be the expert. Be practical, these are my concerns, and it's your physician's job to deal with your concerns."

A medication that Robbie was on had the side effect of changing his appearance. He looked as if he had gained weight rapidly, and children tend to notice this quickly, often making hurtful jokes and comments. It was not only important to explain the disease to parents and teachers but also to the children. Robbie was asked if he was comfortable sharing crohn's with his class, and explaining just what it was. What Kate and Robbie discovered was that once the discussion took place, "this is what I have, I have to take this medication to make me feel better but it changes the way I look", there was a deeper level of understanding and compassion amongst his peers.

As Kate finished, I got to hear from Robbie as well. Robbie in 2017 is a very different person now. He is a teenager who seems fairly confident about life and has adapted to the disease that has troubled him so. The disease has affected his hobbies like skiing but he's learned not to push himself too far. Listening to him, he feels that the biggest misconceptions about IBD is people assuming that he can be fixed with just a change in diet and that he has to go the washroom 6 to 8 times a day even now, when it's more like 2 or 3. He doesn't share his disease with everyone as that may be overwhelming but to the people who want to know why he misses class occasionally, he eases them into it. With the presentation concluded, I had a greater understanding of how difficult IBD is for people, especially for children, who just want to do something as simple as run around and play with their friends but are so challenged by the disease, and how important charities like Robbie's Rainbow and the work Sick Kids does to help these kids get better.

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