Crohn's disease

Health & Medicine, Disease

Being diagnosed with an inflammatory bowel disease, such as Crohn’s disease, requires lifelong care and management of symptoms. Crohn’s disease, sometimes called regional enteritis or granulomatous colitis, is an idiopathic, serious, chronic, inflammatory bowel disease, involving genetic and immunological influences on the gastrointestinal tracts ability to distinguish foreign from self- antigens. Inflammation extends all the way through the intestinal wall from mucosa to serosa and is characterized by the thickening or toughing of the wall, narrowing of the intestinal lumen, and a cobblestone appearance (caused by fissures or linear ulcers that separate islands of mucosa) (Crohn’s disease, 2013). Although Crohn’s disease can develop anywhere in the digestive tract, from the mouth to the anus, it most commonly is established in the last part of the small intestine (terminal ileum) and first part of the large intestine (colon).

Crohn’s disease commonly initiates in a person’s late teens and twenties, with 90% of patients experiencing symptoms by the age of 40 (Crohn’s disease, 2013). Symptoms and signs of Crohn’s disease can vary from patient to patient. Some of these complications include, persistent diarrhea, rectal bleeding, urgent need to move bowels, abdominal cramp and pain, sensation of incomplete evacuation, and constipation, which could lead to bowel obstruction. Anemia may also develop due to low iron or vitamin B-12. Patients suffering from Crohn’s also tend to experience loss of appetite and may lose weight as a result. A feeling of low energy and fatigue is also common. Furthermore, since the immune system is prevalent in the disease patients tends to have symptoms outside the digestive tract. Such as joint pain, eye problems, skin rashes, as well as the possibility of liver disease

((Crohn’s disease 2013). The average duration of symptoms before diagnosis and initiation of therapy used to be 2–2 ½ years, but this postponement has been shortened with better imaging techniques such as ultrasonography and computed tomography (CT) (Crohn’s disease 2013).

The intestinal nature of the disease may be difficult to assess. A patient may have a completely normal physical examination of the right lower quadrant. For months, the only objective evidence of disease may be unexplained low-grade fever, iron deficiency, anemia, hypoalbuminemia, guaiac-positive stools, elevated C-reactive protein, or an elevated erythrocyte sedimentation rate (Crohn’s disease 2013). The disease is established by a combination of medical and family history, physical exam, lab test, contrast studies, computerized tomography scan, x-rays and an intestinal endoscopy. Furthermore, there are an estimated 780, 000 current cases of Americans diagnosed with Crohn’s disease in the United States (Crohn’s & Colitis. 2018).

Margarete was one in the 780, 000 cases that was diagnosed with this disease. Margarete was an average size, blond haired 30-year-old, stay at home mother of beautiful twin boys, and a loving husband named Parker, that taught high school biology at a military academy. Margarete, Parker (42), and Colt and Clint (4) enjoyed many outdoor activities, including camping, swimming, sports, and hiking. Prior to Margarete discovering that she had Crohn’s Disease, she began to notice bouts of stomach pain after eating which was addressed using NSAIDS such as Ibuprofen. The pain was accompanied with increasing fatigued and sporadic episodes of nausea. The

morning after Margarete's 33rd birthday (October 19) dinner, that she spent out with her husband, she awoke with debilitating pain to such an extent that she couldn't stand upright. Margarete had thought that she had appendicitis and or an ectopic pregnancy. Margarete called her husband at work. When he arrived home (10 minutes later), he ran up to the bedroom to find Margarete in severe pain. He immediately called the ambulance and made arrangements to have Margarete's sister, Janet, watch the children.

After arriving to the hospital, Margarete and her husband were greeted by the on-call physician who ordered numerus tests. These tests included bloodwork to check for anemia, which was positive, abdominal x-rays (obstruction series), and an abdominal CT scan that revealed ulcerations as well as severe obstruction of parts of the small and large intestine. Emergency surgery (ileo-Colic Anastomosis) was performed by a general surgeon. After cutting Margarete open and observing her intestines as well as the surrounding organs, the surgeon removed Margarete's inflamed appendix, and about 3 feet of intestine (large and small). Margarete received a large incision (6-7 inches) on the right lower quadrant of the abdomen. The incision was then stapled after the surgery. When Margarete awoke after her first surgery, Dr L, a gastrointestinal physician, was there at her bed side to tell her that she had Crohn's disease. She was concerned after being confronted with having a disease she knew nothing about. Dr L. calmed her fears by explain what Cohn's disease was in a professional manor. Margarete remained in the hospital for about two weeks and remained in the care of Dr. L. Margarete's husband remained by her side for the first few days but eventually had to return to work and to facilitate care for the children.

Margaret’s mother and cousin helped to take care of the children while she was in the hospital.

After two weeks of recovery in the hospital, Margarete was finally discharged. Margarete had lost 30 pounds while in the hospital. Rebecca, Colt, and Clint were very excited to see Margarete but were startled by her appearance due to her significant weight loss. Margarete was still in pain but was able to maneuver herself around the house. Margarete was prescribed asacol which is a nonsteroidal anti-inflammatory drug that prevents flare-ups of ulcerative colitis and Percocet for pain. Margarete remained on Percocet for the next 6 weeks and would take 4 asacol pills before each meal and before bedtime totaling 16 pills per day. It was an emotional struggle for Margarete, trying to be a stay at home mother and wife, while recovering from her invasive surgery. However, Margarete never really recovered. Four months later, Dr. L ordered a Small bowel contrast series, which revealed cobblestone appearances within the terminal ilium of the small intestine. A CT scan also revealed that Margarete had some mesenteric inflammation and narrowing of the lumen in the ileum.

The CT study further revealed that Margarete had an enlarged fallopian tube (size of a walnut) due to the buildup of fluid, from the previous surgery. Dr. L came to the conclusion that Margarete needed further surgery to alleviate the continued chronic, aching pain. After reviewing the results of the tests, Dr. L referred Margarete to an intestinal surgeon, Dr. S. Within that month, Dr. S performed exploratory surgery of the intestinal tract and removed another foot of small and large intestine as well as Margarete’s fallopian

tube. She received a 9-inch incision starting an inch above her umbilical region. Margarete also received a colostomy bag for 6 weeks to help the surgical ends of the colon to heal. After the 6-week period, Margarete had surgery, performed by Dr. L, to reverse the temporary colostomy (reconnection of the bowel). Margarete received 5 quarter inch incisions from the robotic arms that were used to reconnect the intestines. Margarete remained on asacol for another two years until a bad flare up occurred. Dr. L discontinued the asocol prescription and was prescribed Prednisone, which was an anti-inflammatory steroid, for three months. Margarete was then placed on Pentasa which was a nonsteroidal anti-inflammatory drug that was used as a daily maintenance therapy.

After receiving care from Dr. S, Margarete was sent back to Dr. L who, after evaluating all of the data and findings from Dr. S, prescribed an aggressive process that included the use of a drug called Purinethol and a new drug infusion by the name of Remicade. Remicade is a chimeric monoclonal antibody used to treat Crohn’s disease and other diseases such as rheumatoid arthritis, psoriatic arthritis, ulcerative colitis, ankylosing spondylitis (Cunha P. 2017). Margarete began her Remicade treatment with three starter infusions over the first six weeks. The first at the start of her treatment, then another 2 weeks later followed by one more 4 week’s after that. She is now on a regiment of Remicade infusions every 8 weeks. The treatment lasts approximately 3 hours and includes 9 vials of Remicade infusion and 2 bags of sodium chloride to help with dehydration and joint pain. The application of Remicade proved to be very beneficial and the more drastic symptoms of Crohn’s were forced into remission. Margarete no longer

continues to take Purinethol due to the chances of developing lymphoma. The ramifications and effects upon the family were both emotional and financially stressful. Emotionally speaking, drastic arrangements had to be made on behalf of Margarete and her husband in order to see that the children were as unaffected as possible during the first couple of months.

Soon the family returned to some degree of normalcy. The financial burden, however, was devastating. The cost of health insurance became a real threat to the financial stability of the family. However, the staff at Dr. L’s practice stepped in and introduced Margarete to an alternate financial group which would help to defray the initial cost of the Remicade. The initial estimated cost of Remicade per an 8-week period was roughly $9, 000 dollars, resulting in a dreadfully high health insurance monthly rate. The staff at Dr L introduced Margarete to RemiStart which is a patient rebate and extended access program that was able to addresse an out of pocket expense greater than $50 dollars per infusion, to include the initial insurance deductible. RemiStart allowed the family to reduce the monthly cost of insurance by paying a higher deductible thus reducing the financial stress on the family budget.

To this day Margarete struggles with minor self-esteem issues surrounding the numerous scarring on her abdomen. However, due to the use of Remicade treatment, she has been able to reduce the number of types of medication to include, two Imodium, each morning, a multi vitamin daily, and her vitamin D3 (2000IU), and B12 (1000mcg), along with an annual colonoscopy. She is now leading a relatively normal life with little or no

limitations. Her Crohn’s is now in remission and has been for over 10 years. Through the combined efforts of friends and relatives, the family was able to maintain a continuous loving and nurturing environment with no lasting effects due to Crohn’s.