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# I've Been Diagnosed: A Champion! Crohn's & Colitis Family Day

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# **I've Been Diagnosed: A Champion! Crohn's & Colitis Family Day**

An Honors Thesis submitted in partial fulfillment of the requirements for Honors in the  
School of Nursing.

By  
Samantha M. Goldberg

Under the mentorship of Deborah Allen

## **ABSTRACT**

This Honors thesis outlines the creation of “I’ve Been Diagnosed: A Champion! Crohn’s & Colitis Family Day”—an experience designed to provide Southeast Georgia children and families affected by inflammatory bowel disease (IBD) an opportunity to enhance community involvement and build a support network through therapeutic recreation, team-based activities, education, and a positive family-centered environment. Following the nursing process focusing on the community as the patient, this paper is organized by assessment, diagnosis, planning, intervention, and evaluation. A literature review was conducted and interviews with a medical professional and a patient were completed. Specific interventions were planned using the nursing process by identifying community needs. The planning process involved collaboration among formed partners within the university community, including Georgia Southern University Student Health Services and Campus Recreation and Intramurals, the Crohn’s and Colitis Foundation of American-Atlanta Chapter, and local gastroenterology physicians who assisted in participant recruitment. Student volunteers were recruited and trained to assist in facilitating the event, acting as a liaison to Georgia Southern. On the day of the event (April 12, 2014), five southeast Georgia families participated in our one-day camp-like experience, which included dancing, a carnival, team-building games, arts and crafts, the Southern Adventure’s Challenge Course and rock wall, disease education and a support group, and a closing ceremony. Through this program, families were able to build a stronger community and find support in each other, along with becoming closer as a family unit and better able to cope with the affects of IBD.

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Finally, I would like to thank all the families who attended the event, got silly, tried new things, shared themselves with the group, made new friends, and made this first-ever program such an amazing experience.

When I was fifteen years old I was diagnosed with Crohn's disease—a heart-wrenching moment for both my family and I. Not only was I forced to deal with painful, embarrassing, and inconvenient symptoms on a daily basis, but I now had to accept the reality that I would be living with a chronic illness for the rest of my life. My family, too, felt the stress and fear and worry over my condition. Together we started the journey of becoming educated on the illness, learning how to manage it, and attempting to maximize my quality of life. Over the years I have had many trials with my Crohn's, including months of hospitalization and thousands of dollars of medications; however, I undoubtedly consider my triumphs to be greater than my challenges.

It was my own personal connection to inflammatory bowel disease and my desire to “give back” that first led me to camp. In July 2012 I volunteered at Roundup River Ranch during Camp Oasis—a weeklong camp for children and teens aged seven to seventeen with Crohn's disease and ulcerative colitis. There I witnessed the campers building amazing friendships, sharing openly about their illness, and having fun in an environment that was positive, safe, and therapeutic. My experience that week drove me to go back to Roundup River Ranch the following summer, where I worked ten weeks as a staff camp counselor, serving children and teens with various chronic and life threatening illnesses. Week after week I watched campers transform through the powerful spirit of camp—developing social skills, gaining more self confidence, finding a new hobby, expanding their comfort zone, sharing with others, learning more about themselves, and ultimately, becoming stronger.

I came home after the summer of 2013 with a dream that I could somehow bring that positive and uplifting camp energy to my community, and share my joy of camp with

them. It became evident that my Honors Capstone Project was a perfect medium for such a venture, and thus began the process of creating Georgia Southern's Crohn's & Colitis Family Day. The following paper will outline my experience of organizing the event through the nursing process, which includes community assessment, diagnosis, planning, implementation, and evaluation.

### **Community Assessment**

The population that was chosen for this project was Southeast Georgia pediatric inflammatory bowel disease (IBD) patients, which includes diagnoses of Crohn's disease and ulcerative colitis. When discussing the cases of pediatric patients, it is necessary to not only consider the child but the caregivers as well, as it is the nurse's role to provide comprehensive care to the entire family. To gain insight into this community, subjective information was gathered by way of informant interviews. Due to patient privacy, objective data about the regional population was unable to be ascertained, although some reported information was found regarding pediatric inflammatory bowel disease and other trends were reported subjectively. The focus of this assessment was aimed at understanding more about how disease education is presented, how the chronic illness affects development, and how the child and family cope with the illness. Through this, an educational and recreational program was designed and implemented to fill the needs of the community.

### **Literature Review**

In the United States, between 1 and 1.6 million people suffer from IBD, and about 20% of those individuals are diagnosed before age 18 (Reigada et al., 2013). Research has shown that multiple genes are involved in disease development (Rampton &

Shanahan, 2008). Familial occurrence is a major risk factor for IBD, as research shows that the risk of IBD increases 10- to 15- fold for first-degree relatives (Grzybowska-Chlebowczyk et al., 2012). This occurrence is more prevalent in children than adults: up to 40% of pediatric IBD patients have a relative with the disease (Grzybowska-Chlebowczyk, et al., 2012). Physiologically, it is known that an inappropriate immune response leads to immune-mediated inflammation and tissue damage (Rampton & Shanahan, 2008). Research is continuing to explore the role of the microbes in the gut in disease development and the immune system's response to external triggers (Ellis & Cole, 2011). However, the disease remains classified as "idiopathic" (Gould & Dyer, 2011), and there is no known cure (Lewis, Dirksen, Heitkemper, Bucher, & Camera, 2011).

What distinguishes pediatric IBD from the adult disease is the impact on growth and development seen in children, which is highly dependent on nutrition (Ellis & Cole, 2011). Malnutrition is a very common outcome of pediatric IBD, affecting hematology, weight, growth, and puberty. This undernutrition is an outcome of altered energy and nutrient requirements, malabsorption and increased gastrointestinal losses, and especially suboptimal nutritional intake from food aversions or loss of appetite (Gerasimidis, McGrogan & Edwards, 2011). Inflammation of the intestinal wall impairs the ability to digest and absorb food, which causes a lack of protein and vitamins (Gould & Dyer, 2011). Low concentrations of plasma nutrients are common: protein undernutrition and anemia are the most clinically significant (Gerasimidis et al., 2011). The prevalence of anemia in children with IBD has been shown to be in the range of 41-88%, depending on the study (Gerasimidis et al., 2011). This anemia is primarily due to eroded blood vessels

on intestinal ulcers and bleeding hemorrhoids, which present as blood in the stool (Gould & Dyer, 2011). These nutritional deficiencies play a major role in the delayed growth and onset of puberty for many pediatric IBD patients, especially when disease onset occurs prior to puberty (Gerasimidis et al., 2011).

When dealing with a child or adolescent with IBD, it is especially important to consider the emotional and psychological impacts of the disease. The debilitating and often embarrassing symptoms can lead to difficulties with accepting his/her own body, adopting an appropriate social role, development of close social relationships, preparation for professional and romantic relationships, and independence from parents (Ellis & Cole, 2011). Delayed puberty and growth can cause social- and self-stigma, which are important issues for adolescents, whose normal psychosocial development is dependent on peer interaction (Ellis & Cole, 2011). Children and adolescents with IBD may experience anxiety over the uncertain course of their illness, inability to control their environment, and social anxiety from fear of peer-rejection (Pinquart & Shen, 2011). Studies have shown that children with diagnoses of 5 years or less had elevated anxiety levels compared to those who have had their illness longer, suggesting that children learn to adapt, cope with their illness, and return to a normal state of psychological well-being (Pinquart & Shen, 2011).

Children and adolescents often have difficulty coping with their disease because of a lack of emotional development and maturity, so special attention must be given to the caregivers and families of these patients (Lewis et al., 2011). It is important that everyone help with the coping process. For pediatric patients, parents often struggle from their own psychological quandaries with symptoms of anxiety, confusion, helplessness,

and depression, which is often seen when parents recognize their child is not perfect (Venning, Elliott, Whitford & Honnor, 2007). It is important that parents seek education and support to ease their distress, improve parenting behaviors, and be better prepared to handle their child's suffering and medical symptoms (Eccleston, Palermo, Fisher & Law, 2012).

### **Physician Interview**

A community leader interview was conducted with a local pediatric gastroenterologist, Dr. Christopher Rittmeyer, whose practice is in Savannah, GA; he is the only pediatric GI physician serving the southeast Georgia region. Dr. Rittmeyer reported that the majority of his patients diagnosed with inflammatory bowel disease are adolescents. It was noted, however, that those who are diagnosed at a younger age typically present with more aggressive cases of the disease. Dr. Rittmeyer stated that he has seen an overall increase in the incidence of pediatric IBD over the years, which could be attributed to possible environmental triggers or increasing awareness of the illness. No trends were seen in gender of patients or socioeconomic status, although he did recognize the impact socioeconomic status has on how well a family is able to take care of their child's illness. Those with poor economic situations or complicated social histories are more likely to be late for appointments or have difficulty with medication adherence.

When asked if there were any established programs designed to allow families affected by IBD to network with each other, Dr. Rittmeyer confirmed that he is unaware of any network that is currently being offered in this local area. In his own practice, Dr. Rittmeyer has often purposefully connected patients who have similar situations in order for them to benefit from personal connections. Unfortunately, this is the only networking



system in place at that time. Although there are occasionally informational/educational sessions given by various doctors in the area, Dr. Rittmeyer stated that support groups for children are difficult to find. He attributed this to the notion that it is hard to get children and adolescents inspired to become an active participant in their care in that way. For that age group, sitting around and sharing feelings may not be the best way to approach the situation, whereas a program designed to be fun and interactive might have more success in encouraging participation from children and adolescents. On the other hand, Dr. Rittmeyer noted that he has had several mothers who have been interested in putting together support groups, which could possibly be beneficial to help with exchanging educational information and coping support. Dr. Rittmeyer did note that because his patients are so geographically dispersed, it would be difficult for a consistent networking group to be established. Also, the nearest Crohn's and Colitis Foundation of America (CCFA) chapter is located in Atlanta, which is approximately five hours from the Savannah area. This is where the majority of educational sessions, fundraising opportunities, support groups, and camps are based. While his practice does not promote any camps designed specifically for children and teens with IBD, he stated he has had some patients attend them and most reported positive experiences.

To address the topic of patient education, Dr. Rittmeyer was asked how he typically goes about educating the patients and families about their illness. He explained that once there is suspicion of the child having IBD, he starts by giving some very basic background information on the illness, so that they are not overwhelmed immediately with too much detail. After testing confirms the diagnosis, he talks to the families for about 20 to 30 minutes. At this time he gives them the most important information, which

is most often how to proceed with treatment options. Then every time they come back into the office for an appointment he will divulge more information and answer any questions. Sometimes Dr. Rittmeyer will supplement his education by giving out literature or recommending books. By doing this, he feels families are able to absorb the information and increase their understanding of the illness. He stated that parents often want to educate themselves, but that often leads to misinformation, especially by using the Internet. For this reason, Dr. Rittmeyer stressed the importance of establishing a trusting relationship with parents.

Dr. Rittmeyer stated that the topic of diet frequently comes up when discussing the treatment and management of inflammatory bowel disease, but said that he does not recommend any specific or restrictive diets for his patients. It is his opinion that diet does not have an overall impact on the illness, although he did have some recommendations regarding nutrition. He advises all his patients to take a multivitamin; watch their fiber intake if they have ulcerative colitis; and increase their calories, if weight loss is an issue for Crohn's disease. Dr. Rittmeyer did express concern regarding placing children on restrictive diets in an attempt to manage their illness; he says this often impacts their growth. He stated that his patients are often 18 months behind their peers in growth, including height, weight, and puberty. By putting a child on such severe food restrictions, it can impact their emotional and psychological views of food too. Overall, Dr. Rittmeyer did not endorse using diet to manage IBD, unless there was a food allergy-related component that made restricting foods necessary.

When discussing pediatric populations with chronic illness and disability, it is important to assess how the children are affected developmentally, including areas such

as education, socialization, and maturity. When asked if he noticed any trends in his patients, Dr. Rittmeyer said it varies immensely between cases. While overall he stated that his patients seem fairly well adapted to having this chronic illness, it does affect some children more negatively than others. Delayed growth can affect self-esteem, since falling behind your peers is not easy for children or teens. While he has experienced some cases where a patient's educational outcomes were compromised, overall he has found that these children want to attend school and maintain academic status equal to their peers. A more difficult time presents itself during the transition into college, where Dr. Rittmeyer reported having several patients who forget to continue proper self-care (i.e. taking medications, getting enough rest, proper nutrition) or "partied too much", which affected their health and subsequently their education. Another problem he has witnessed was the inability to join the military due to having a preexisting medical condition, which can be disappointing for young adults who have that aspiration.

Children with chronic conditions have various coping skills. Dr. Rittmeyer stated that his patients seem to cope fairly well with the disease. Sometimes the symptoms of the disease can be embarrassing for children, and the disfiguring side effects of medications like prednisone (i.e. weight gain, striae, acne, mood changes) can greatly affect adolescents. However, Dr. Rittmeyer stresses to his patients that having this specific disease process will make them a better person in the long run and it shouldn't limit what they can accomplish. He likes to tell his patients about all of the famous and influential people who have IBD, like President Eisenhower and many professional athletes, in order to encourage them to stay positive about their future.

While he has found that the patients themselves cope fairly well with having the illness, it is often much more difficult for the parents to cope with it. Parents desire a “healthy, normal” child. They want to protect their children from all types of harmful situations, so it is difficult to resolve within themselves that this illness is out of their control. Many parents have a hard time accepting disfigurement in their child, such as the side effects of steroids, having surgery, or perianal involvement. The whole situation is frustrating for a parent, and the amount of information they’re given to process all at once is often overwhelming. Dr. Rittmeyer noted that for this reason he believes some sort of support network would be beneficial. This would allow parents to share in their lived experiences in order to improve coping skills.

### **Patient Interview**

In an attempt to better understand the caregiver’s concerns, a second interview was conducted with the mother of a patient with inflammatory bowel disease. The child of this parent is a six-year-old female, who was diagnosed with ulcerative colitis at age three. The patient’s family consists of mother and father, who are married, and four other children ages one to fifteen. The family would be considered middle class and they reside south of Atlanta. For the reader’s information, this patient’s medical provider is not Dr. Rittmeyer.

When asked about her experience with networking, support, and education programs, the mother stated that although their provider has said there are some online, she does not know of any support groups in their local area and she’s never found a way to formally network with other pediatric IBD parents. Regarding the education provided of the disease process, the mother stated that she was very unsatisfied with the

physician's approach. She stated that when her daughter was first diagnosed, the doctor gave them a coloring book about the digestive system and referred the mother to some educational websites. She expressed frustration because all the face-to-face education that was provided used medical terminology that she was unfamiliar with. According to the mother, most of her education about the disease came from reading online and asking other people who have IBD about their experience. Ultimately, the frustration with the physician's approach to patient education led to the family switching providers.

The mother expressed further frustration about her daughter's care. She stated feeling that the "doctors don't even know what's going on", that her daughter is a "guinea pig", and that the providers "just throw different drugs at her and hope something works". When it comes to how she cares for her daughter, she referred to it as "a guessing game". The only thing she feels like she can directly control is her daughter's diet; however she isn't confident that her efforts to manage the illness through food are making a real difference. Overall, the mother expressed significant distress over losing control of her daughter's health, the lack of comprehensible information, and the uncertainty over the disease process.

Like many others, the mother put a lot of emphasis on diet, although all the information she received did not come from her provider. The mother stated that the only education regarding diet that she received from her daughter's physician was to feed her daughter a low-residue diet, which according to the mother, was "all processed, canned food that was unhealthy", and to also try avoiding milk products. Because the mother was so unsatisfied with this education, she used the Internet and literature to self-educate on the topic and has subsequently placed her daughter on a very specific and restrictive diet.

Although she experimented a lot with foods and has seen some improvement, she says she often doubts what she's doing and if diet actually has any impact on the disease at all. She expressed frustration with the strict diet, saying "Other parents think I'm a wacko mom because I can't let her eat certain things and I want to read the ingredients list." Not only that, but the mother admitted that she spends a lot of money on special foods for her daughter. Overall, she feels frustrated that medical professionals have different opinions on the topic and she wishes that more research would be done about the role of diet and nutrition on the disease.

When questioned about the child's development, the mother did note some changes in her daughter that she attributed to having IBD. The mother noted that her daughter is especially shy and seems "clingier than normal", which could be attributed to having the disease. Mostly, though, she feels like her daughter is impacted socially because she stands out from her peers because she has to eat different things. The mother stressed how difficult it is for her daughter to attend birthday parties or social gatherings, because all the other children are eating cake and candy and she feels left out. Even at school, there is a lot of emphasis placed on food and snacks, which requires the daughter to have more much self-control than others at her young age. The mother expressed her desire for her daughter to just be normal, stating, "Nobody wants their child to be the different one."

For the young child, coping with a chronic illness has been a difficult process. The child herself has expressed unhappiness about having such a restricted diet, because she knows it makes her different from her peers. Further, the child is embarrassed that she still wears a diaper to bed in case she soils herself due to urgency, and she tries to

hide it from all her friends. The symptoms of the disease have also been trying, such as frequent stools and abdominal pain. When the child was hospitalized, the mother stated that any sort of invasive procedure (i.e. needle sticks) was very traumatizing for the child. Despite all this, the mother states that in a way she believes it's a blessing that her daughter was diagnosed so young because "it will be all she knows."

When asked how well she copes with her daughter's illness, the mother expressed fear that the disease is going to be a trial for her daughter throughout her life and it will affect her level of happiness. She stated: "The hard part as a parent is wanting your kid to be happy and feel like they fit in...My sadness comes from knowing she's sad. I just want her to be happy and healthy." The mother frequently alluded to the desire to "take away" her daughter's pain and suffering, and how she often feels so helpless because there's nothing she can do. It was clear that the mother is experiencing a great deal of emotional struggles due to her daughter's condition and that it is a very stressful situation for the entire family.

Finally, the mother was asked what would be a helpful intervention for her family and her daughter. She stated that it would be beneficial for her to meet other moms with young children going through similar experiences. She also noted how wonderful it would be for her daughter to meet other children her age who have IBD "so she doesn't feel so alone." As of now, the family knows other adults who have IBD, but no one who is a true peer of their daughter.

### **Assessment Conclusion**

Although regional data was unable to be found, it is clear that inflammatory bowel disease is a significant concern for the pediatric population. Through interviews

with both a physician and a parent of a patient with IBD, similar conclusions can be drawn. First, there is no established means of connectivity or support between these community members. A primary contributing factor to that is the fact that these patients are so geographically spread out and separated from the primary networking center of Atlanta, where the Georgia CCFA chapter is located. Second, it seems as if gaining enthusiasm for a “support group” for children or adolescents would be minimal because that age group can be adverse to a program centered around divulging emotions in that way. However, it is clear that parents of these patients would benefit from some type of support network. They seem to suffer from a lack of satisfactory information—partly due to the unclear nature of the disease and also from a lack of appropriate provider communication. While many parents may turn to the Internet for education, that information can often be an unreliable source. Parents struggle to cope with their lack of control surrounding their child’s health, while children and teens seem to suffer most from the social impacts of the illness.

A program designed to give both patients and caregivers the education and peer social interaction they crave could potentially benefit the whole family unit. Such a program would allow this community to come together for the first time and interact with each other, create networking bonds, and find social support for each other. By showing children and adolescents diagnosed with IBD that they are not alone in their illness, the hope is that their social anxiety will be alleviated and their self-confidence will be enhanced. Any such program should focus on creating a fun and interactive space for children to interact while providing parents with educational information and time to network with other families.



### **Community Diagnosis**

After data was gathered regarding this population, several pertinent nursing diagnoses were formed to outline the problems faced by the community. The first of which is “Ineffective community coping related to deficits in community social support services” (Ackley & Ladwig, 2011, p. 274). Because no established support networks currently exist in southeast Georgia for families who have a child suffering from inflammatory bowel disease, there is no medium for community interaction. Although community members have expressed a desire for some sort of community involvement to find support and decrease stressors, such as feelings of isolation and confusion, a lack of cohesion and apparent powerlessness has created a lack of social support systems. By creating a program that would allow for improved communication among community members, the goal is that a community support network will follow to allow for enhanced community coping, problem solving, and unification.

A second nursing diagnosis appropriate for this population is “Readiness for enhanced family coping as evidenced by family members seeking out experiences to optimize wellness, improve health promotion, and make contact with others experiencing a similar situation” (Ackley & Ladwig, 2011, p. 291). Because all the families attending the program have a child with a chronic illness, they are inherently facing a health-related crisis; however, the families, and especially the primary caregivers, have likely already become proficient at managing the adaptive tasks related to the child’s illness. Still, those families who sign up to participate in this program will be exhibiting a desire to enhance the child’s health and growth. The goal of the program is to facilitate family involvement, integration, and communication through both educational and skill-building

opportunities. Interventions that involve mutual goal setting, problem solving, teamwork, and support will allow families to become closer as a unit and allow families and opportunity to interact with others facing similar challenges and experiences. This has shown to reduce caregiver's stress and lead to better outcomes for children (Ackley & Ladwig, 2011, p. 292).

There are several nursing diagnoses that relate specifically to the emotional wellbeing of the diagnosed child: "Risk for loneliness", "Readiness for enhanced self-concept", and "Risk for compromised resilience"(Ackley & Ladwig, 2011). Due to the alienating nature of having a serious illness in childhood while amongst generally healthy peers, it is common for these children to feel social isolation. Also, these children face physical disease-related problems such as frequent diarrhea, surgeries, and disfiguring medication side effects that can cause embarrassment and decreased sense of self-efficacy. By providing social interaction with others facing the same illness and similar complications—their true peers—the goal is that these children will discover meaningful relationships, have positive interactions, and increase their sense of self-esteem during the program. Furthermore, it is difficult for the child to stay positive when they are faced with multiple health concerns and other adverse situations. By giving the child and family community resources and support to call on in the face of crisis, and by enhancing the child's overall self-efficacy, the outcome will hopefully be an increased sense of resilience as well.

Finally, the last nursing diagnosis for this population is "Readiness for enhanced knowledge of disease-related information related to lack of exposure to reliable resources" (Ackley & Ladwig, 2011, p. 521). Although there is a wealth of information

available about inflammatory bowel disease in both print and online media, not all of it is credible. While the primary care physician or specialist is typically a useful source of education to the child and family, a lack of quality time with patients often leaves patients and caregivers desiring more. Also, conflicting information among healthcare professionals can cause confusion and frustration for these families. Parents of children with Crohn's disease or ulcerative colitis often struggle to understand the illness and are left with many questions, especially in the topics of treatments, nutrition, and prognosis. The goal is to use the program to provide education from various different professionals that will give caregivers the opportunity to have their questions answered and ultimately increase their knowledge of their child's illness.

### **Planning**

#### **Making Connections**

Once I decided on the type of interventions I wanted to complete, it was clear that I needed to form connections with community leaders who had the necessary resources to create an event of this magnitude. First I reached out to my gastroenterology physician, Dr. Joseph Hathaway, who suggested I contact Mary Ball—the Director of Education and Support for the Atlanta Chapter of the Crohn's and Colitis Foundation of America (CCFA). On September 30, 2013 I emailed Mary the following:

“Mary,

My name is Samantha Goldberg and I'm a nursing student at Georgia Southern University. I am a part of our University Honors Program, and as my final project I have decided to create a weekend family camp for local kids with Crohn's and colitis here on my campus. I spent my whole summer working at

Roundup River Ranch in Colorado, which is part of the SeriousFun network, and the year before that I volunteered there for CCFA week. I have fallen in love with the magic of camp and seen the wonderful things it can do for the kids. Also, I just attended GSU's first Crohn's and Colitis support group, which showed strong interest in helping me make this camp happen. Dr. Joseph Hathaway is my doctor and he advised I contact you at the CCFA. Currently I am working with Dr. Hathaway and a local pediatric doctor to try and set up a system for recruiting campers and their families, but I was wondering if the Georgia chapter of CCFA would be interesting in helping me with this endeavor? It would be helpful to have some official backing and assistance with marketing and recruiting! I would love to talk with you some more and explore some options.

Thank you so much,

Samantha”

She expressed interest in being a part of the program and we agreed to meet on October 9, 2013. During our meeting I was able to give Mary more details on what I envisioned for the program and how we could make it a reality. Mary confirmed that the CCFA would support this endeavor and that she would play an active role in the program planning and implementation.

It was also fortunate that I had been attending Georgia Southern's new Crohn's and colitis support group since September 2013, which was lead by Dr. Brandonn Harris of the Sport and Exercise Psychology program in the Department of Health and Kinesiology. Dr. Harris was supportive of my idea from the start and was incredibly helpful in navigating the systems within the university. I came to him with all my

thoughts and ideas and he would always point me in the appropriate direction. Dr. Harris suggested I reach out to Paul Ferguson, Director of Georgia Southern University's Student Health Services, who had been instrumental in starting the support group. On October 21, 2013 I emailed Paul:

“Hi Paul,

This is Samantha Goldberg and I'm a nursing student at GSU who also is a part of the new CCFA support group. Brandon Harris suggested I contact you about a project I'm working on.

For my Honors Capstone project I am going to hold a one-day "camp" at GSU for kids with IBD and their families. The School of Nursing is going to help me put this on, along with the CCFA from Atlanta. I've been talking with the Recreation Activity Center (RAC) about holding the event there and communicating with doctors for support as well. I was wondering if Student Health would possibly want to be a partner for this event and help give some support.

I'd love to talk more with you about it if you like the idea!

Thanks so much!

Samantha”

I met with Paul and Laura Thompson, a student assistant at Student Health Services, on November 1<sup>st</sup>, where Paul confirmed that Health Services would provide financial support along with assistance in planning and implementing the event. Paul requested that I provide an event description that could be used to market our program to our departments. I sent him the following:

“My name is Samantha Goldberg and I am a Nursing Student at Georgia Southern University. As a part of my Honors Thesis Project I have decided to do what I love most: Camp. I spent an entire summer working at Roundup River Ranch in Colorado—a camp for kids with chronic and life threatening illnesses. There I was lucky enough to witness the pure joy, life-changing friendships, and incredible growth that come from the camp experience. For these kids, camp is a time when they can feel normal, safe, and most importantly—have fun! It is my goal to bring that experience here to Georgia Southern.

I am working with multiple organizations, including the Crohn's and Colitis Foundation of America, the Georgia Southern Nursing Program, and GSU Health Services, to create a supportive environment where kids can have fun in an atmosphere promoting teamwork, leadership, and friendship. The event will involve recreational activities, the RAC Challenge Course, arts and crafts, team challenges, and also some education about pediatric inflammatory bowel disease and how to support a child with a chronic illness. Not only that, but it will also provide parents with the opportunity to form connections with other parents who are experiencing the same struggles with their child's illness. This is a need that is not yet filled in our community. Even the local pediatric gastroenterology physicians I am working with feel that this event will make a big difference to these families.

Having Crohn's disease myself, I know the physical and emotional struggle IBD brings, and having social support among your peers is crucial to thriving in childhood and adolescence. By bringing this population together,

families and kids can form relationships of understanding and empathy, which will hopefully continue to provide a network of support after this event. Not only that, but this program shows that Georgia Southern is committed to caring for their students, even if they have a physical challenge, and will quite possibly be a great recruitment opportunity for the adolescents in attendance.

It is my goal to make this event cost-free to the families by utilizing university services and accepting donations from participating organizations.

I deeply appreciate your time and support to make this special experience possible for these children and their families."

Paul was able to use this material to reach out to others who could, and did, help make the event possible. Marketing experts in Health Services created a t-shirt design and additional promotional materials. Paul also contacted Eagle Dining Services for event catering, as well as local hotels, which would provide discounted rooms for families wanting to stay overnight before or after the event.

### **Event Details**

The first step was to set a date for the actual event so reservations could start being made. For some time, we toyed with the idea of making it a two-day event, but ultimately found that making on-campus housing arrangements would not be possible, so we chose instead to simply hold the program on a Saturday. To allow for ample planning time, all parties agreed that it would be best to hold the program in the late spring semester of 2014.

I decided that the Georgia Southern RAC would be the best location for the event, because it included a variety of spaces and it had other elements I had hoped we could

utilize, such as the Challenge Course and rock wall. Dr. Harris put me in touch with America Minc, Director of Recreational Facilities & Fitness for Campus Recreation & Intramurals at GSU. I emailed her, requesting use of the RAC for the program, and she agreed to meet me on October 23, 2013 to go over specifics. After coordinating between personal schedules and availability at the RAC, the date of the event was set for April 12, 2014 and reservations were made to use the RAC facilities.

America Minc directed me to contact Matthew McBride, Southern Adventures Director at GSU, to discuss using the Challenge Course and rock-climbing wall. I completed a reservation request to use the course in early December, and in January, Matthew and I met to discuss more specifics about the program. During our meeting we decided that our group would use the High Challenge Course, including the zip line and other high elements. He explained to me that participants must be 10 years or older to participate, but there was no age limit to use the indoor rock wall. He also informed me that there were no restroom facilities out at the course location, so I would have to look into getting a port-a-potty.

Meanwhile, I was continuously working on creating the details of the event, which included working with and through various important people. Paul and I met with leaders of Eagle Dining on January 20<sup>th</sup> to discuss the meal plan, which would have to be tailored to our participants' digestive needs. Eagle Dining's Nutritional Coordinator, Brittany Parham, also got involved and agreed to attend the event to give some education on nutrition and diet regarding inflammatory bowel disease. We also decided that the final meal of the day should be a special occasion, so we reserved the Performing Arts



Center ballroom for a banquet dinner. To add to the experience, Paul reached out to Georgia Southern's Spotlight Show Choir and invited them to perform at the banquet.

Dr. Harris put me in contact with Kelley Catenacci, a graduate student, who volunteered to facilitate the arts and crafts portion of the program. I communicated with her multiple times during the planning stages of the event to coordinate activities and supplies.

Mary and I also reached out to several physicians to attend the event to provide some education. We first reached out to Dr. Rittmeyer and Dr. Hathaway, but due to personal circumstances they were unable to attend. Finally, we got in touch with Dr. Eli Penn, an adult gastroenterologist in Statesboro, who agreed to do an informational session. Dr. Harris agreed to facilitate the support group session for the children and adolescent participants, so I worked with him to plan that part of the program.

It was also crucial that I collected the necessary waivers for the participants and volunteers from Campus Recreation and Intramurals, Southern Adventures, and an overall Media Release.

Leading up to the event, I had meetings with Paul Ferguson, Mary Ball, and Brandon Harris quite often to ensure that every necessary step was being taken and that we would be prepared on the event day. Supplies were collected from personal collections, volunteer donations, and purchased through Health Services.

### **Recruiting the Participants**

To recruit participants, it was crucial that we worked through local pediatric gastroenterology physicians. Fortunately, Mary Ball had contacts with several doctors whose practice locations were in Savannah, GA. In late October, we spoke with Dr.

Christopher Rittmeyer, who agreed to help us by giving promotional materials to all his patients with inflammatory bowel disease. Meanwhile, I was working on creating marketing materials for distribution. Because this was a first-time event with no former reputation, I decided it would be best to write a letter to the families explaining who I was and why I was doing this (See Appendix A).

I also set out to create a flyer to promote the event. My mentor, Deborah Allen, directed me to Jennifer Anderson, Assistant to the Dean of the College of Health and Human Sciences, who agreed to help create the marketing materials. After sending her a draft of the flyer content and pictures from Mary Ball's previous camps, Jennifer helped me create an event logo and flyer (See Appendix B). After getting approval from the Nursing Department and Student Health Services, Mary Ball printed the materials in January 2014 and sent them to Dr. Rittmeyer's office so he could distribute them to his patients.

Finally, Mary and I created the content for the website, so that families could go online to get more information and to register for the program. We used the CCFA's existing website to have a link for "GSU Crohn's and Colitis Family Day". On the webpage, an event description, including the date, time, and location; an event Q&A (See Appendix C); and a link to the online registration—one for families and the other for volunteers—was provided. When families registered, we obtained the following information: the parent/guardian name, email, phone number, address, and ethnicity; how many participants would be attending, their ages, and t-shirt sizes; how they heard about the event; if they wanted to be contacted about hotel accommodations; if they had any

special dietary requests; and if there were any pertinent medical or behavioral concerns we should know about their child.

On March 24<sup>th</sup> I sent the following email to all the registered participants to remind them of the event and request some additional information:

“Hello!

It's Samantha Goldberg here from Georgia Southern! First off, I just want to say how beyond excited I am that you and your family have chosen to spend a day with us in April. It is going to be a BLAST!

Right now we're doing a ton of planning and preparing for the big day, but before it arrives I would really appreciate a few things from you:

1. Please take a minute to fill out this survey:

<https://www.surveymonkey.com/s/campfamilyday> ...The information you give will be used to better understand how IBD affects children and their families. All answers will be kept anonymous and confidential. Thank you!

2. Who's excited for the Challenge Course?! Georgia Southern has an awesome outdoor, up-in-the-trees adventure course that involves climbing, flying, teambuilding, jumping, swinging, and all that crazy stuff! Sadly, this portion is only for those participants who are 10 years old and up; however, there is an indoor climbing wall and we will have other activities available for any younger folks. To give us an idea of how many participants to plan for, please respond with how many people in your group are old enough and interested in doing the Challenge Course.

3. Regarding hotel accommodations: Georgia Southern will be reserving a group of rooms in a nearby hotel that will provide a good discount for our event. NOTE: Families will still be responsible for the payment, but Georgia Southern will ensure that it is a nice hotel at a low cost. If your family is interested, please respond with the number of rooms you would like so the reservations can be made as soon as possible. Please let me know if you have any questions!

As the big day gets closer I may be sending out more emails and updates, so be on the look out! Once again, thank you all so much for signing up to participate in this event. We are looking forward to meeting you and your family very soon! If you have any questions or concerns, please don't hesitate to ask!

Best wishes,

Samantha Goldberg”

Then on April 9<sup>th</sup> I sent the families another email with some last minutes information for the event day:

“Hello families!

This is Samantha Goldberg from Georgia Southern's Crohn's & Colitis Family Day. I can't believe it but this Saturday is the day we've all been waiting for, and I am beyond excited to meet everyone! I just wanted to hit you with a few reminders before the weekend arrives...

The event starts at 9:00 am at the Georgia Southern University Recreational Activity Center located at 2687 Bunny Akins Blvd-Statesboro-GA-30458. Parking is free on weekends, so don't worry about not having a permit.

Once you park, make your way to the lobby of the building where you will be greeted by the volunteers!

Don't forget to wear comfortable, closed-toed shoes! I would suggest bringing a backpack or bag for carrying personal items and possibly some gifts you'll receive during the event!

Be ready to play games, learn some stuff, get a little loud and silly, and make new friends! It's going to be a blast!

Please let me know if you have any questions or concerns. If you need to get ahold of me for any reason (i.e. having trouble with directions!), feel free to call my cell at 907-350-5802.

Best wishes,

Samantha”

### **Program Planning**

In addition to the administrative work, throughout the process I was continually planning the program for the event. Considering the problems and nursing diagnoses that were formed based on the community assessment, I wanted to create an event that allowed for therapeutic recreation, education, and the development of supportive relationships. Using ideas from my own personal experiences at camps designed for children with chronic illness and their families, I developed a list of activities that would be inclusive to age and gender, provide skill-building opportunities, allow for participant interaction, and of course—be fun! This list included activities to get to know each other, dancing, singing, arts and crafts, group games, rock climbing, the outdoor Challenge Course, and also time for physician-led education for the adults and a support group for

the children. Mary Ball and Dr. Brandonn Harris assisted me in planning the event schedule. After many revisions, the event schedule was finally completed in early April (See Appendix D for Event Day Schedule).

### Selecting and Training Volunteers



Starting in early February, I began to seek volunteers for the event day through my peers in the nursing program and also Georgia Southern students I had met while volunteering at Camp Twin Lakes. I deliberately asked students who demonstrated a desire to serve others, were outgoing, and would serve as positive ambassadors for Georgia Southern. I also requested help from nursing faculty to attend the program as “medical volunteers” in case of an emergency. When they completed the required online registration they officially committed to volunteer their time from 8:00 AM to 7:00 PM on Saturday, April 12<sup>th</sup> for the event and from 5:30 to 8:30 PM on Friday, April 11<sup>th</sup> for volunteer training. As volunteers registered, I assigned them (with their input) to either be “program staff”, who’s job would be to run activities, or “family volunteers”, who would

be assigned a specific family and stay with them throughout the day (See Appendix E for Staff List). Through connections in the Honors Program, I enlisted the help of several photography and film students (Mallory Taylor and Daryl Sullivan) who volunteered their time to attend the event, take pictures and video, and ultimately make promotional videos using that media.

Meanwhile, Mary Ball and I worked together to plan the volunteer training, which was meant to prepare the volunteers to interact with the population, teach them the activities they would be leading at the event, inform them of the event schedule, and complete any last-minute projects (See Appendix F for Volunteer Training Agenda). I also put together a PowerPoint presentation for the volunteer training that outlined the purpose of the event, the role of the volunteer, volunteer etiquette and program policies, and an overview of inflammatory bowel disease (See Appendix G for Volunteer Training Presentation).

### **Implementation**

It may be useful for the reader to refer to the schedule (Appendix D) when reading this section.

#### **Set-Up**

On the day of the event all the staff arrived at the RAC at 8:00 AM to prepare for the families to arrive. Eight families had registered to attend the event, for a total of 30 participants. Prior to their arrival, volunteers helped distribute supplies to the appropriate



areas and begin set up. I coordinated with the RAC employees and Eagle Dining to ensure that all program areas were set up, including the stereo system, food and drink stations, and emergency medical supplies. Everyone was incredibly enthusiastic. They were helpful in all requests for input and it was clear that all the volunteers were excited and eager for the families to arrive.

### Arrival

Families started to arrive around 9:00 AM, where they were greeted outside by an excited group of cheering volunteers. The volunteer assigned to that specific family would escort them inside the



RAC lobby where they were welcomed by Mary and I. There they filled out the necessary participant waivers, made their nametag, and received their goody bags (event t-shirts, Health Services promotional items, an event schedule, and educational pamphlets from the CCFA).

From there they were escorted into the gym, where the majority of the event would take place. There they could eat breakfast and mingle with each other. The breakfast consisted of fresh fruit, bagels, danishes, coffee, bottled juices and bottled water. Volunteers were instructed to get to know their family, introduce family members to other staff members and participants, and get everyone excited for the day's activities.



Unfortunately, out of the families that registered, only four families had arrived by the start time of 9:30 AM. Attempts were made to contact the other families via telephone, where we found out that three families were not going to be able to make it. We were unable to reach the last family, who was able to come later at lunchtime. The decision was made to start the event with the four families that were present, despite missing half the participants. Although this initially felt disappointing, having fewer people allowed the volunteers an opportunity to focus on those who were present and make the day a special experience for them.

### **Introduction**

The program began with me introducing myself, acknowledging all the collaborations that made the event possible, and thanking those who had helped throughout the planning of the event. I explained why I wanted to share the camp atmosphere and experience with them and my background: I believed this could be an opportunity for personal growth, strengthening of the family, development of new friendships, and a lot of fun.

I also explained the few guidelines for the day, which included:

1. Children must always stay with a parent when leaving the gym.
2. All family members should remember to stay with their volunteer/tell them where you're going.
3. Remember to stay hydrated by filling up water bottles at the water jugs/fountains.



4. If anyone needs to sit down and rest during any activity, please do not hesitate to step out and take a break.
5. If for any reason medical support is needed, these are our nurses [introduce nurses]—any volunteer can contact them for you.
6. Finally, restrooms will be located at every activity area, and feel free to step out at any point to use them.

After going over the guidelines, we briefly went through the day's schedule of events so that everyone had an idea of what activities were ahead. Then the volunteers introduced themselves by performing two humorous skits.

At this point in the day, the participants had limited opportunities to talk to one another or get to know anyone other than their own family. Therefore, it was crucial that the program start off with some activities designed to help them get comfortable in the group setting and learn more about each other. First, we played two “ice breaker” games called “All My Neighbors Who...” and “Rock Paper Scissors Evolution”, which got participants moving around, mingling, and interacting with others in a nonthreatening



way (See Appendix H).

After about fifteen minutes of that, the volunteers helped me to lead the cheer “Can You Iggle?” chosen because it was an easy, interactive and fun song. Following that, I lead a

couple of dances, including “500 Miles” (with choreography I learned at summer camp) and “Roar” (with choreography I created).

The next activity was making “goal bracelets”. Families were instructed to connect with their volunteer, who had a string and a bead for every person in the family. The volunteer explained the purpose of the bracelets and led the family through their discussion. This was a way to make the program intentional—to allow participants to create a deliberate goal, so they could be mindful of achieving it throughout the day, and later use it to reflect on their camp experience—using a tactile method. The string was to represent the family’s goal, which had to be decided upon collectively. Examples could be to cheer each other on in every activity or to learn one new thing about everyone in the family. On the string went the bead that represented the individual goal, which the participant could share with their family so that everyone could help them achieve it over the course of the day. Examples of individual goals are to make a new friend or to try something new like go down the zip line. Once everyone in the family had come up with their goals, they were to tie on the bracelets to have as a constant reminder of what they wanted to get out of the experience. By having the volunteers participate in the activity and be aware of the participants’ intentions, the volunteer was then able to encourage and assist the family/individual to achieve those goals, if possible.

### **Camp Carnival**

The second activity of the day was called “Camp Carnival”. As family members and volunteers were active in the bracelet activity, program staff set up the carnival atmosphere. Several stations were set up around the gym and





der around and play. Considering the population was inflammatory bowel disease patients and families, I decided to give the carnival a bit of “potty humor”—meaning the majority of the games at the stations had some sort of relation to toilets, toilet paper, or plungers. There was also face painting, a photo booth with funny costumes to dress up in, a basketball seat, a football throwing game, a Nerf® gun range, a

plunger ring toss, corn hole, and playing cards. This gave families an opportunity to interact with volunteers who were running the stations and the other participants. The premise was to allow children of similar ages and gender to group together to play the same games and for parents to have time to connect with each other.

### Group Game Time

After about 45 minutes of free-flowing playtime at the carnival, we transitioned into the next activity. A few volunteers and I led the whole group in a cheer (“Three Little Bears”) while the program staff cleaned up their carnival station and prepared for the games to follow. These group games were more structured, making them more conducive to



building the skills of teamwork, communication, and following instructions. After being randomly split into three groups, participants rotated through three stations where they played two games each. The six games they played were “Statue Tag,” “Blob Tag,” “Captain’s Coming,” “Chi Master,” “Group Juggle,” and “Hoop Transfer” (See Appendix I).

### **Lunch**

The lengths of the games were timed so that each group would get an even amount of time at each station and we would end the activity at exactly 12:00 PM for lunch. Eagle Dining had already cleared away breakfast and set up the lunch buffet, which consisted of hamburgers, hotdogs, a veggie tray, potato chips, cookies, lemonade, and bottled water. After participants obtained their food and sat down, the Eagle Dining nutritionist Brittany Parham was introduced. She and Mary Ball led a short informational session about IBD and nutrition. They allowed time for participants to ask questions and have discussions. The remainder of the lunch time was filled with chatting between families and volunteers, and several of the children finished eating before their parents and started playing together in the gym.



After cleaning up, I led the group in two cheers (“Joe Button” and “60s Party”) and then two dances (“Stand Out” and “Eenie Meanie”—with choreography I had learned previously at a camp). Meanwhile, program staff helped set up for the next activity.





During this portion, the fifth family arrived unexpectedly. While I continued to lead the group in the singing and dancing, Mary Ball introduced herself and the family's volunteer, oriented the family to the event, and offered them lunch. After the dancing was over, I introduced myself and the rest of the group to the new family, hoping they would feel welcomed and eager to participate in the rest of the day's activities.

### **Arts and Crafts**

Kelley Catenacci had volunteered to facilitate the arts and crafts portion of the event and had planned out several activities for the participants during this time. To go along with the "I've Been Diagnosed: A Champion!" theme, she developed a craft to create trophies out of Styrofoam cups, pipe cleaners, star stickers, and golden paint; and championship medals out of ribbon, cardboard, paint, and glitter glue. While the younger

kids worked on those crafts, many others made bracelets or necklaces out of strings and beads. Face painting was available for anyone who didn't get a chance to visit that station during the carnival activity earlier in the day. Most of the boys, including their dads, opted out of the arts and crafts activities and played basketball with each other.

This one-hour block was a perfect time for parents to have more intimate conversations, simply because it was more unstructured and informal. Several mothers grouped together at the craft table and began talking while the men bonded over sports; the volunteers intermingled among both. Other volunteers worked with the children doing different crafts and activities, helping in any way necessary, and provided entertainment. Because this time was not as structured, it allowed the participants to relax and get to know each other.

### **Adventure Time**

The next block of time was designed to allow participants to attempt a variety of activities and to be able to move among the activities as they desired. The available activities were: using the indoor rock-climbing wall, playing “Walleyball” (volleyball inside a racquetball court, allowing the ball to bounce off the walls), hanging out in the gym to play various games or continue with arts and crafts, or participate in the Challenge Course.

Because the Challenge Course is run through Southern Adventures and is a more structured activity, the original plan was to have participants sign up for one of two time blocks to go outside and experience the zip line and other Challenge



Course elements while the other remaining participants enjoyed the indoor activities.

However, it was noted on the sign-up sheet that every family wanted to participate in the Challenge Course. Since there were less people than expected and Southern Adventures had agreed to accommodate our numbers, the decision was made to have everyone go experience the Challenge Course together.

As a group, all the family members and volunteers (with the exception of program staff, who stayed behind to clean up the gym) walked outside through the woods—led by Matthew McBride—to the course, where we were greeted by the Southern Adventures staff. The staff then outlined the safety rules and explained the Challenge Course elements that the participants were able to experience. They explained the principle of “challenge by choice,” which means that while we wanted to challenge everyone to try and step outside their comfort zone to experience something new, no participant was required to do anything that they were not comfortable with. After a thorough demonstration of equipment and techniques required to participate in the course elements from the staff, the family members lined up for their turn. When they were not actively



doing an element, participants were encouraged to cheer each other on and support their family members. Volunteers were constantly cheering on the participants, encouraging them to push themselves, and congratulating them on their accomplishments. Several volunteers



were also tasked with watching over and entertaining the children who were too young to participate in the course.

Most participants went down the zip line, which required first climbing a roughly forty-foot pole to a tiny platform. Fewer participants tried the pamper pole, which appeared more daunting. It required climbing a pole that was about thirty feet, standing up on top of it without anything to hold on to, and then leaping off to grab a nearby hanging trapeze.

It is during activities like this—where one is challenged—that what I call “magic moments”, or moments of growth and triumph, most often occur. During our Crohn's & Colitis Family Day, we were able to witness a very special moment happen on the



Challenge Course. There was a young boy who had been incredibly shy the entire day and resistant to participating in most activities, but who had seemed genuinely excited for the chance to try the Challenge Course. When we got out there, he was one of the first participants to climb up the pole to the zip line. But when he made it to the top, he panicked and refused to ride

down the zip line, and instead climbed back down the pole. Embarrassed and scared, he rushed off to the side where he vomited in the woods. His family and a medical volunteer rushed to his side to comfort him and ensure his wellbeing. At that moment, he appeared defeated. After recovering, he sat to the side and cheered on his family members and

others as they did the course elements. At the end of the activity, when we were about to go inside, he spoke up and asked if he could try the pamper pole. That boy climbed right to the top of the pole, stood up, and jumped off like a real champion, with his family cheering him on the whole way. Afterwards he admitted to overcoming his fears, and he could not stop smiling for the rest of the day. His parents, too, could not wipe the grin off their faces; they were so proud of their son. It is moments like that that make a difference in someone's life, and make all the hard work and planning so worth it.

After everyone got a chance to participate in the Challenge Course elements that they wanted to try, all participants went inside for the remainder of the time block. Instead of utilizing the available gym space, the indoor rock-climbing wall and the racquetball court were used. The



participants took turns climbing the different rock walls, again being supported by their family members and friends. Others chose to play a casual game of Walleyball, which was facilitated by several staff volunteers.

By 4:30 PM, I began rounding up all the participants and volunteers to meet in the RAC lobby. We made sure that everyone had all their belongings and then set out to drive to the Performing Arts Center (PAC) for the rest of the program. Participants were

given maps with driving directions, but also relied on following volunteers to the destination.

### **Education & Support Session**

Once everyone safely arrived at the PAC, we explained that for this portion, parents would be receiving information from a physician while the children would attend another session lead by Brandonn Harris and Mary Ball. The parents and children were directed to their respective meeting places in the PAC; once settled, volunteer staff were allowed to take a break for the next hour. The decision was made to have this block as a break-time for staff because it could be overwhelming for the children to have so many adult volunteers in the room with them and make it less likely for them to share openly about their feelings.

Dr. Eli Penn led the educational session for the parents. He had prepared a PowerPoint presentation to go along with the identified topics. After giving a brief explanation of inflammatory bowel disease pathology, he talked to the parents about different treatments. Parents were able to tell Dr. Penn what medications their children were taking so that he could focus his presentation on those. Dr. Penn also talked about disease prognosis and how to best transition the child from pediatric to adult care. During the session parents were encouraged to ask questions and discuss thoughts/concerns openly. This was helpful to them because they were able to ask things that their child's primary care physician had not previously answered. They were also offered different perspectives regarding treatment options.

While the parents were receiving education, the children and teenagers participated in an activity in which every member responded to questions about how IBD

had impacted his/her life, whether they had the diagnosis themselves or if it was one of their loved ones. The atmosphere was intentionally more upbeat than a typical support group; the kids stayed engaged and were not put off by the idea of discussing their feelings. Using beach balls with pre-written questions, one at a time the participants shared their experiences while providing feedback or comments of support to one another. The discussion revolved around how living with IBD (or with someone who has IBD) can positively or negatively impact different aspects of their life, including how it affects daily routines and the emotional impacts of the disease. This gave the children an opportunity to process and openly discuss how this illness is often difficult, frustrating, and scary, but also how it has brought families closer together and made them unique. All the participants shared with the group and seemed to enjoy the experience.

### **Dinner & Closing**

After their respective sessions, the parents and children came back together and met the volunteers in the PAC ballroom, where a banquet-style meal had been prepared. The dinner consisted of pasta salad, grilled chicken breast, roast beef, mashed potatoes, green beans, fresh fruit, French silk pie, tea, and water. After all the participants received their food and sat down, the Spotlight Show Choir was introduced. They performed for about fifteen minutes, singing songs that were uplifting and familiar to most participants. The participants seemed to enjoy the entertainment and frequently sang or clapped along during the performance.

I had planned the closing session to consist of several cheers and dances, but it was clear that the participants were tired and ready to get on the road; many would have a long drive home. The decision was made to do one final dance called "World's Greatest"

(with choreography I had learned at camp) because it would leave the participants with a good parting message that they are great, they are important, and they are strong.

After doing the dance together as a group in a big circle, I allowed participants or volunteers an opportunity to share with everyone something special that happened during the day, something they were grateful for, or something they were proud of. One mother shared how grateful she was to have had the opportunity to attend the event, because it was the first time it made her daughter feel special because of her disease and not different in a negative way. A volunteer spoke up and acknowledged the boy who had overcome his fear of heights and climbed up the pumper role, saying how proud they were of him. A sister of a child with IBD thanked everyone for putting on the event, saying what a great experience it was for her family to attend together. There were others who gave thanks, as well, and it was clear that everyone had a positive experience.

Once everyone had a chance to speak, I thanked those who had helped make the event possible, including Mary Ball, Brandon Harris, Paul Ferguson, Eagle Dining, the RAC and Southern Adventures staff, the physicians, Dr. Rittmeyer for helping recruit and Dr. Penn for the education session, my mentor, Deborah Allen, the medical volunteers, and all the student volunteers. I also thanked the families for spending their Saturday with us and taking a chance on this first-time event. After a group picture was taken, it was time for the families to depart. Before they left, many individual family members came up to me and other volunteers to give thanks and hugs goodbye.

After all the family members left, the volunteers helped clean up the venue, took a group picture, and said their goodbyes.



### Evaluation

Following the program, a post-evaluation was sent out to families via email (See Appendix J). The general consensus was positive. Participants felt like the information provided was helpful and the program catered well to their needs, but would have appreciated more IBD-friendly food options. Although there was a wish for more families to have been involved, the participants felt as if their child did benefit socially from the experience. One parent said, “[My daughter] really felt special, understood, and prized. The activities encouraged developing friendships.” There was an overwhelming positive response to the staff and volunteers who were a part of the program and to the activities that were planned. The one main suggestion that appeared was a desire to have more unplanned periods where parents could talk and get to know each other better.

In regards to the established community nursing diagnoses, a subjective evaluation can be made. Through this program, community members were able to meet each other and interact. Many families exchanged contact information. Thus, the program



did succeed in improving communication among the community members, which will hopefully lead to the creation of a support network for families in this region.

The event succeeded in allowing positive family interactions among participants. Many instances were noted where family members offered support and encouragement, worked together as a team, and enjoyed playing with one another. They were also able to meet and interact with other families who could relate to their disease-related struggle. All of these outcomes will likely lead to better coping as a family unit.



During the program, all the children diagnosed with IBD were able to meet another child going through a similar situation. These interactions seemed to make the children more comfortable opening up about their illness and made it easier to make friends. One parent even noted, “[This program] made my daughter not feel so alone in her illness.”

Finally, the goal to provide disease education was successful because we had a gastroenterologist come and provide this information to parents. They were further given an opportunity to ask personal questions, which ultimately gave the parents a better understanding of their child's illness.

### **Recommendations for the Future**

First and foremost, the recruiting process needs to be improved. It took quite some time to get all the necessary materials created, approved, and distributed, leaving families with little notice to incorporate the event into their calendar. I would suggest starting to get materials out to potential families at least four to five months in advance. Using the local pediatric physician practices is still a great way to reach families; however, it would also be good to advertise through local school nurses and local adult gastroenterologists who may have teenage patients.

Thanks to the volunteer film students who took wonderful photos and videos of the event, actual Crohn's & Colitis Family Day photos can be used on promotional materials for future events. These individuals also created two music videos using event footage that shows participants in action and having fun. There is now evidence to support the event's success; therefore, this media can be used to entice future participants with testimonials from this year's participants.

Also, I believe that in the future it would be extremely beneficial to somehow convey to participants that by filling out the online registration, they are committed to attend the event. The planning is very sensitive to the number of participants and once individual families register, it should be expressed to them the importance of joining other participants at the event. They should be contacted via telephone by the event



director, who can introduce themselves and the program, answer any questions, and obtain any necessary information. After the event director contacts the family, a packet of forms (including waivers, pre-evaluations, and any other necessary registration information) should be sent to the participants either electronically or by mail.

Participants should understand that registration is not complete until these forms are completed and returned; this allows the event planners an assurance of the necessary items they need in order to successfully plan and implement the program. Throughout the time leading up to the program, event planners should stay in frequent contact with families to ensure their participation, through both electronic and telephone methods. Obtaining a final confirmation of the number of attendees one week prior to the event will help ensure that plans are made accordingly (i.e. the proper amount of food, number of counselors, time blocks for activities, hotel reservations, etc.).

### **Lessons Learned**

While I believe we had a fantastic group of volunteer counselors, I believe that they could have been better prepared as far as how they were expected to interact with the participants. It should have been stressed that whether assigned “program staff” or “family volunteer”, everyone was expected to be interacting with the families. It was a challenge this year because several families did not show up as expected so there was an excess of volunteers; however, there were times when kids were playing by themselves in the gym during free times and volunteers were clustered together, talking in groups. It would have been wise to stress the “family first” idea, so that volunteers understood that they should constantly be looking for opportunities to interact with all members of the family, even if they aren’t assigned to one.

Another aspect that could have been improved was the meal times. While I had originally intended for meals to be an opportunity for families to mingle and have unstructured interactions, several factors interfered with that plan. First, families were sitting far away from each other in their own groups. In the future, intentional assignments could be made for each meal (i.e. breakfast: parents at one table, kids at another; lunch: girls at one table, boys at another; dinner: free choice) so that participants were able to meet other participants and have intimate conversations as desired. It would also be helpful for volunteers to intermingle among the participants, ready with age-appropriate conversation starters. The second problem with meal times was that parents were very focused on supervising and feeding their own children. This is where the volunteer should offer to help serve the children, cut their food, and entertain them throughout the meal so that the parents can relax and converse with others. Because only one volunteer was assigned to a family, program staff should take this opportunity help out when there is more than one child in a family.

Another important consideration for an event like this would be the menu choices. There was only one participant with a dietary concern (no wheat or sugar) for this event, and she was left with limited options, especially when it came to desserts. Because this population can be particularly sensitive to certain foods and one of the goals of this program is to make participants feel welcomed and comfortable despite having their disease, it is very important that the event planners choose menus that can be eaten by all participants. If someone has a dietary concern that excludes them from eating what is on the menu, a special plate should be provided for that participant.

The only other major issue we had during the event was the fact that it was a long day without many times designated for rest. This is a problem mostly because those with IBD can fatigue easily and younger children require rest periods throughout the day. As the program went on, it was clear that many participants were getting worn out and it was a challenge for the parents to care for their tired and emotional children. In the future I would suggest making this a two-day event, and if possible, utilizing convenient on-campus housing for families. If that were possible, there could be an afternoon rest period on the schedule where families could return to their rooms for an hour or two, which would allow participants to refresh before the evening activities. By making the event an overnight experience, the programming would not be compromised. In fact, the programming could be expanded, like possibly utilizing the swimming pool, for example.

### **My Reflections**

Doing this project was truly an amazing experience for me. Although I had spent several summers working at camps designed for children with serious illnesses, I could have never imagined how much goes in to actually starting one. It took nine months of dedicated planning and so much support from other community leaders to make the first Crohn's & Colitis Family Day at Georgia Southern possible. Without the generous support of the university—especially Health Services—and the CCFA, there is no way I could have created such a



successful program. While it was hard work, I feel confident that all the effort and resources put into this program were worthwhile.

It was wonderful to witness the growth of the families and individual participants throughout the day. While many came into the experience shy, quiet, and kept to themselves, by the end of the day all the children and teenagers were playing together, and the parents had exchanged contact information with the hopes of staying in touch. In every activity I saw participants smiling, having fun, and being engaged with their loved ones and new friends. We gave many kids and adults the opportunity to try things they had never done before, which is an excitement in and of itself.

Through this program, these families were able to be open about their experiences with Crohn's disease or ulcerative colitis, relate to one another, find means of support in each other, and build new relationships and happy memories as a family and as a community. According to Georgia Southern Health Services and the Atlanta Chapter of



the CCFA, the Crohn's & Colitis Family Day event is going to be continued as an annual program, which is a huge success! It is my hope that as this program continues, the community of families affected by IBD in southeast Georgia will grow in number and support. In the end, I truly believe that everyone who was a part of the Crohn's & Colitis Family Day experience has honorably been diagnosed: a Champion!

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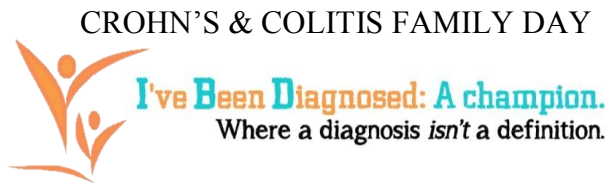
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## Crohn's & Colitis Family Day

*Are you the parent of a child diagnosed with inflammatory bowel disease, Crohn's or colitis?  
If so, you may be concerned that your child will experience:*

- Physical pain
- Embarrassment or feeling "different" from peers
- Lifestyle limitations
- Fear or uncertainty about the future

My name is Samantha Goldberg. I'm a nursing student at Georgia Southern University and I have been living with Crohn's and colitis for six years.

When newly diagnosed with a chronic illness or dealing with the day-to-day challenges of IBD, it can be hard to find the silver lining. Although living with my IBD has been a struggle, it has given me some wonderful opportunities—the most powerful of which is the Crohn's & Colitis Foundation's Camp Oasis. I was fortunate enough to spend my summer working at Roundup River Ranch, a camp in Colorado for children with chronic illnesses, where I've been continually inspired by the strength and light ignited within our campers.

Camp Oasis is a place where "I can't" turns into "I can", where kids who often struggle at home can feel normal, have fun, and find bonds of friendship unlike ever before. Ask any former camper and they will tell you with a triumphant smile: "Camp has made me stronger."

Facilitating this transformation is something I am truly passionate about. After returning home last summer I knew it was my calling to bring this powerful camp experience here to the local community. When I proposed the idea, Georgia Southern was overwhelmingly supportive and now my dream is becoming a reality! This is your invitation to join us at the first-ever:

***"I've Been Diagnosed: A Champion! - Crohn's & Colitis Family Day"***.

Luckily for you, this camp experience is not limited to the kids...adults can have fun too! There is something so wonderful about parents, children, and siblings all playing together, supporting each other, and growing together in a worry-free environment. My goal is to offer you and your family an opportunity to bond with each other, other families, and feel supported by your community. We have some wonderful organizations sponsoring the event, which will be cost-free to families!:

- The Crohn's and Colitis Foundation of America-Georgia Chapter
- The Georgia Southern Nursing Program
- Georgia Southern University Student Health Services

The big day will involve recreational activities, a challenge course, arts and crafts, team challenges, and also educational sessions for parents and kids about best practices for living with IBD. Please see our flyer for more specifics and visit our registration website at <http://www.cdfa.org/chapters/Georgia/events/crohns-and-colitis-family-day.html>

I am looking forward to meeting you and inspiring the champion in your children.

Sincerely,

*Samantha Goldberg*







**I've Been Diagnosed: A champion.**  
Where a diagnosis *isn't* a definition.



# Crohn's & Colitis Family Day

**Saturday April 12<sup>th</sup>, 2014**

Georgia Southern University Recreational Activities Center  
9am-7pm



Modeled after CCFA's Camp Oasis, Georgia Southern University is proud to host its 1st Family Day for children & teens under 18 diagnosed with IBD.



Join us for a day of fun in an atmosphere that promotes teamwork, leadership, & friendship. Enjoy a supportive environment for both families & kids where everyone is normal and no one is left out.



Activities include:

Team Challenges  
Arts & Crafts

Challenge Course  
Time to network  
& meet new friends

Recreational Games  
IBD Education



**Enroll online now to secure your family's spot!**

Limited space available

[ccfa.org/chapters/georgia/events/crohns-and-colitis-family-day.html](http://ccfa.org/chapters/georgia/events/crohns-and-colitis-family-day.html)

Event is free to families.

Breakfast spread, lunch, dinner, snacks and water included.

Proudly Sponsored by:



SCHOOL OF NURSING



A Patient Centered Medical Home Accredited Health Center



With Dr. Rittmeyer, Dr. Murphy, other medical professionals, trained student volunteers, & GSU faculty  
Questions? Contact: Samantha Goldberg, GSU Nursing student & Program Director, (907)-350-5802, [sg02797@georgiasouthern.edu](mailto:sg02797@georgiasouthern.edu)





### GSU Crohn's & Colitis Family Day Q&A

#### *Who can come?*

You, your child, and anyone in your family who plays a special role in your child's life and wants to be a part of this fun day is welcome! (Brothers, sisters, grandma, grandpa, cousins, etc!) All are welcome, young and old, however, we have some active games planned and we will be spending several hours outside, so it might be best to leave the little ones at home!

#### *What should I bring?*

Be sure that everyone is wearing clothes that are comfortable, easy to move around in, and won't be ruined if they get a little messy! Closed-toed shoes are a MUST! You're welcome to bring a backpack/bag for carrying your family's personal items, extra layers of clothing, cameras, medications, etc. We'd advise that you bring sun protection—hats, sunglasses, and especially FUNSCREEN! We will provide a breakfast spread, lunch, dinner, and plenty of snacks and water along the way!

#### *What if I live several hours away and that sounds like a long drive early in the morning?*

If your family needs accommodations the night prior to the event or that evening, please let us know when you register. We can facilitate lodging at a local hotel for significantly discounted rates!

#### *Who will be with my family all day?*

Every family will have a trained volunteer counselor with them all throughout the day at every activity. That counselor will act as your liaison to the Georgia Southern facilities and our event, and they will make sure you are safe and having fun the whole day! Every activity area will have more trained staff to facilitate the activity and assist your family in any way. The Challenge Course will be run by certified GSU Southern Adventures staff. We will have medical personnel readily available in case of any emergencies.

#### *What kind of activities will we be doing?*

Be ready for anything! We will have indoor recreational games, teambuilding activities, arts and crafts, and maybe even some singing and dancing too! Additionally, you'll have the opportunity to experience our Southern Adventures Challenge Course, which includes multiple high and low course elements where you and your family can challenge yourselves, improve communication and teambuilding, and experience the thrill of being in the treetops! For a brief look watch this video: <http://recreation.georgiasouthern.edu/southern-adventures/challenge-course>. The day will also include Crohn's & Colitis Parent and Child Educational Programs and time to meet and mingle with other families.

#### *But...but...my child has Crohn's or colitis. Is this going to be too much for them?*

We understand that Crohn's and colitis can impact your child in a lot of ways. Let us help reassure you that our event will be a fun and safe experience for them. 1.

Bathrooms will be available around every activity area! 2. Water and Gatorade will be provided constantly to prevent dehydration! 3. Getting too worn out? No big deal. At any time if your child needs to step out of an activity, one of our counselors will hang back and entertain them. 4. Nursing staff, gastroenterology experts, and emergency medical personnel will always be readily available. 5. Special diet requests? Just let us know when you register! 6. Ostomy bag? Your child has no need to be embarrassed around this group. Just let us know when you register and we will be sure our staff is aware and can accommodate your child in every way possible. Note: As your child's guardian you hold primary responsibility for your child's actions and safety, but for this event we are a team and we are here to provide a safe and fun experience for you, your child, and family, so if there's anything else you need from us, please let us know!

**I've Been Diagnosed: A Champion!**  
**Crohn's & Colitis Family Day**  
**April 12, 2014**

**8:00-9:00** Set up

- Booth in RAC Lobby—Family volunteers
  - Banner up, Bags/packets ready, Name tag station
- MAC Gym—Program staff
  - Tables set up to eat, Get carnival supplies ready & know where you're going
  - Stereo system set up (AUX), water jugs, trash cans, first aid kit

**9:00-9:30** Arrival

- Check-in: (RAC Lobby) \*start outside with signs!
  - Get bags, sign forms & pre-eval, meet with volunteer, make nametag
- Mingle: (MAC)
  - Breakfast, get to know family!
  - Sign up for Challenge Course [2-3:15/3:15-4:30] \*Find Sam!

**9:30-10:00** Introduction

- Welcome
  - Introduce staff (skits)
  - Go over rules & schedule
- Icebreakers
  - All My Neighbors Who...
  - Rock Paper Scissors Evolution
  - Cheers: "Can You Iggle?"
  - Dance: 500 Miles & Roar
- Goal bracelets \*Program staff set up carnival station
  - Break into family groups—family goal + individual goal
  - Come into circle and share

**10:00-11:00** Camp Carnival! (MAC Gym)

- Face paint Kelley & Kelsey
- Photo booth Mallory, Daryl, Alexis
- Basketball toilet seat free throw Whitney
- Angry Birds football/toilet paper Sam
- Nerf gun shooting Justin
- Toilet paper bocci Mary
- Plunger-hat ring toss Katie
- Black Jack Brandonn
- Spoons/toilet paper "rolls" Wes
- Corn hole

\*After: Program staff takes down stations, set up tables for lunch

\*Transition: Cheers! ("Three Little Bears")

**11:00-12:00** Group Game Time! (break into 3 groups and rotate through stations)

- Station 1 Katie
  - Statue Tag & Blob Tab
- Station 2 Whitney & Wes
  - Captain's Coming & Chi Master
- Station 3 Justin & Kelsey
  - Group juggle & Hoola hoop transfer/Levitation w/ hoola hoop

**12:00-1:00** Lunch (MAC Gym)

- Nutritionist Talk—Brittany & Mary
- Cheers: "Joe Button" & "60s Party"
- Dances: Stand Out & Eenie Meanie

\*Program staff helps set up for A&C

**1:00-2:00** Arts & Crafts (MAC)

**2:00-4:30** Adventure Time!

- Challenge Course Mary (Group 2 meet at 3:00 in MAC w/ Sam)
- Rock Wall (3:00-4:30) Brandonn
- MAC for games Whitney & Wes
  - Knee Tag, Captain's Coming, Where's my Chicken, Squirt, Ninja, Group Juggle, Hand Slaps, 2 Truths & 1 Lie, Green Glass Door (stuff we didn't do in groups)
- Walleyball Justin & Katie
- Arts & Crafts cont. Kelley & Kelsey

**4:30-5:00** Meet in MAC...Drive to PAC

\*Program staff stay behind to clean if necessary!

**5:00-6:00** Education/BREAK TIME FOR STAFF!

- Parents (Rm 2911) Dr. Penn
- Kids (Rm 2904) Mary & Brandonn

**6:00-7:00** Dinner (Ballroom)

- Show Choir performance (6:10-6:25)
- Post-evaluation
- GROUP PHOTO
- Closing
  - Cheers: "Fred the Moose" & "Form banana/orange/avocado/potato/corn/mullet"
  - Dances: World's Greatest & Roar
  - Sharing our Magic Moments

- Thanks

## **Crohn's & Colitis Family Day Staff List**

### Directors:

- Sam Goldberg
- Mary Ball
- Dr. Brandonn Harris

### Program staff:

- Whitney Jones
- Justin Gerido
- Kelsey Graham
- Wes Imundo
- Katie Ellwood
- Kelley Catenacci (Arts & Crafts Guru)

### Family volunteers:

- Tina Green – Carver Family
- Kelli Chandler – Davis Family
- Alex Murphy – McDonald Family
- Kathleen O'Neill – Stanton Family
- Meredith Eby – Lewis Family
- Lauren Williams – Villanueva Family
- Brian Pritchard – Acosta Family

### Photo & video peeps:

- Mallory Taylor
- Daryl Sullivan
- Alexis List

### Medical:

- Dr. Linda Upchurch (12-7)
- Dr. Debbie Allen
- Pam Ferguson

<b>Important! Phone #s</b>	
Sam Goldberg	907-350-5802
Mary Ball	646-623-4869
Brandonn Harris	785-477-8280
<i>Photo/video:</i>	
Mallory Taylor	912-223-0435
Daryl Sullivan	717-448-9249
<i>Medical:</i>	
Linda Upchurch	912-531-2325
Pam Ferguson	484-678-0524
Debbie Allen	912-536-3592



**Volunteer Training Agenda**  
 Friday, April 11 from 5:30pm-8:30pm  
 RAC Seminar Room

- Make name tag!
  - Sign waivers (CRI Standard Release & High Ropes & Consent to Photo)
  - Cheers:
    - Can You Iggle?
    - 3 Bears
    - Form Banana
  - Intro: say name, where you're from, what you do, what you want to do, and one interesting thing about yourself
  - Ice breakers
    - All My Neighbors Who
    - Rock Paper Scissors Evolution
  - Powerpoint! (Eat)
    - Why are we here?
    - Your role
    - Counselor/volunteer etiquette
    - Disease overview
  - Dances:
    - 500 Miles
    - Stand Out
    - Roar
    - World's Greatest
    - Eenie Meanie
  - Go over event schedule
  - Go over assignments
    - Meet your family \*Mary
    - Program Staff \*Sam
      - Sign up for carnival/leading games
  - Make Banner, arrival signs, signs for carnival, & help put together family packets!
    - Packets: Waivers (Standard release/minor, High Ropes, Consent to photo, CCFA) Schedule, Map, Pre-eval, Shirts, Water bottle (w/ strip of tape for name), giveaways—all in bag
  - Cheers:
    - Joe Button
    - 60s Party
    - Moose
  - Practice skits... WEE! Skit & Doctor's Office
- \*Reminders:
- Wear closed-toed shoes!
  - Bring a backpack & water bottle
  - Do bring your phones—not for personal use



## Crohn's & Colitis Family Day!

4.11.14

Volunteer Training!

### How it all began...

- Honors Capstone project → Nursing Program → Crohn's & Colitis Foundation of America (CCFA) → Health Services
- + help from a ton of other people (CRI, Eagle Dining, Dr. Rittmeyer, Dr. Harris...)
- ...oh my gosh it's actually happening!
- So **THANK YOU!!!**



**Crohn's & Colitis Family Day**  
Saturday April 12th, 2014  
Georgia Southern University Recreational Activities Center  
State Park

Modeled after CCFA's Camp Oasis, Georgia Southern University is proud to host its 1st Family Day for children & teens under 18 diagnosed with IBD. Join us for a day of fun in an atmosphere that promotes teamwork, leadership & friendship. Enjoy a supportive environment for both families & kids where everyone is normal and no one is left out.

Activities include:  
Team Challenges, Challenge Course, Recreational Games, Arts & Crafts, Time to network, IBD Education & meet new friends.

Enroll online now to secure your family's spot!  
Lasted space available  
[cchug.org/chapters/georgia-southern-university-crohn-s-colitis-family-day.html](http://cchug.org/chapters/georgia-southern-university-crohn-s-colitis-family-day.html)

Event is free to families!  
Breakfast, snack, lunch, dinner, snacks and water included.  
Proudly Sponsored by:  
GEORGIA SOUTHERN UNIVERSITY, CROHN'S & COLITIS FOUNDATION OF AMERICA, and others.

**I've Been Diagnosed: A Champion!**

### Why are we doing this again...?

- Modeled after CCFA's Camp Oasis!
- This is a wonderful opportunity for kids with IBD to meet their true peers and to know that they are not alone with this frustrating, embarrassing, and often alienating illness.
- We want to maintain a **safe environment**, promote **friendships**, build **supportive relationships**, provide **skill-building** opportunities, and obviously...**HAVE FUN!**

### Kid-centered= Family-centered

- For this event we wanted to let families in on the action...
- Caregivers and families of children with chronic illnesses are also affected by the disease
- This event gives them an opportunity to:
  - *Network with other families*
  - *Share knowledge*
  - *Normalize the experience*

### Your role...

- If you are assigned to a family...
  - Stay with them all day!
  - Get to know them
  - Keep them involved
  - Be their advocate

### Your role cont...

- If you are "program staff"...
  - You will be running various activities
  - Keep everyone engaged!
  - Be flexible!
  - Also, help set up/take down activities

### Everyone's role!

- **#1 You are an ambassador to Georgia Southern!**
  - Tour guide, entertainer, facilitator, friend!
- Talk with families, kids, and encourage them to mingle with each other
- This is a **RECRUITING OPPORTUNITY!**
- Be enthusiastic about **EVERYTHING. SMILES FOR DAYS.**

Go EAGLES!



## A few reminders...

- Supervision: the rule of 3s! & Always keep your family/children in line-of-sight
- Appropriate physical contact
- Dress appropriately. I mean, c'mon.
- Put your phones away, please!
- Be a good role model! No profanity, etc.

## Okay, maybe a few more...

- Confidentiality...What happens at camp stays at camp. No pictures, no posting!
- Post-camp conduct
  - No sharing Facebook or cell phone #s
  - Exchanging email with the parents is okay!

## Everyone Poops!

...but these kids poop a lot.

- IBD includes both **Crohn's disease & ulcerative colitis**, which are chronic inflammatory conditions. The cause is unknown and there is no cure.
- **Symptoms:** fatigue, muscle aches, abdominal pain, frequent/urgent diarrhea, weight loss, growth delays

**IBD  
overview!**

## IBD overview cont...

- **Medications used:** anti-inflammatories, corticosteroids, immunosuppressants, antibiotics, biologics
- **Undesirable side effects:** acne, weight gain, puffy face, growth suppression, increased body hair, inability to fight infection
- **Diet:** some people can eat everything, some have more restricted diets
- **Surgery:** resection of part of the intestine may be a necessary treatment, which will lead to an ostomy

*So...What are we going to be concerned about?*

## Be mindful of...

- Always know where the nearest bathroom is!
- Watch for dehydration! Constantly remind about drinking water!
- Watch for exhaustion and allow for rest
- Including everyone! No one should feel different because of the way they look or how many times they have to run to the bathroom!

## ARE YOU READY FOR THIS?

NA NA NA!

- Questions? Comments? Concerns?
- But more importantly...

**are you ready to DANCE?**

Icebreaker Descriptions

- **All My Neighbors Who...**
  - Everyone gets in a big circle with one person in the middle.
  - Everyone in the circle takes off their nametag and places it on the floor to mark their spot.
  - The person in the middle introduces themselves and says "I'd like to meet all my neighbors who... \_\_\_\_\_" (ex: ...like ice cream, ...are wearing blue, ...have IBD)
  - Anyone who that statement applies to has to run around the circle and find a new spot. (You cannot move to the spot directly next to you!)
  - The last person in the middle without a spot has to introduce themselves and it's their turn!
  
- **Rock Paper Scissors Evolution**
  - Everyone starts out as eggs, which means you have to make an egg shape by getting low to the ground and waddling around.
  - You find someone and play a game of "rock-paper-scissors" with them.
  - The winner of that game becomes a chicken, which means they have to walk around flapping their chicken wings and making chicken noises. Meanwhile, the loser stays an egg and has to find another egg to play with.
  - The winner now has to walk around and find another chicken to play "rock-paper-scissors" with. The winner of that game turns into a dinosaur, which means they have to make dinosaur noises and have little, tiny T-Rex claws and stomp around. Once again, the loser remains a chicken.
  - The winner now has to find another dinosaur to play with, and the winner of that game turns into a superhero, who flies around with one fist in the air like Superman. The loser is still a dinosaur.
  - Eggs can only play eggs, chickens play chickens, dinosaurs play dinosaurs, and once you become a superhero you are a winner!
  - The game continues until everyone is a superhero; however, there will always be people who get stuck as the only person in their rank, but that's okay.

Group Game Descriptions

## Station 1

- **Statue Tag**
  - Choose three people to be “it”. Everyone else wants to avoid getting tagged. If you’re walking around, you are able to be tagged. You are “safe” if you stop moving, strike a pose, and keep your EYES CLOSED. As soon as you open your eyes you HAVE to move! If you are tagged, you are now “it” and the other person becomes a walker/statue. \* Make sure you designate boundaries.
- **Blob Tag**
  - Choose one person to be “it”. Designate boundaries where people can run around. When whoever is “it” tags someone, they have to link arms. Now they may both tag people. Whenever you get tagged, you have to join the chain. The last person to evade getting tagged is the winner.

## Station 2

- **Captain’s Coming!**
  - This is Simon Says for pirates! If someone messes up or is leftover, they’re out. Start by going over all the positions with the whole group. “When I call out \_\_\_\_, you do \_\_\_\_.”
    - “Captain’s Coming!” → Everyone stands at attention. “You cannot move until I say “At ease.””
    - “To the ship!” → Run to the right
    - “To the shore!” → Run to the left
    - “Mermaid” → each player puts their hand on their hip and yells out “howdy sailor”
    - “Man overboard” → (Requires 2 people) One person gets on their knee and the other puts their foot on that knee and both people scan the room like they’re looking for a man overboard
    - “3 Men Rowing” → (3 people) get in a line and pretend to row
    - “4 Men Eating” → (4 people) get in a circle and pretend to chow down
    - “5 Men Walk the Plank” → (5 people) get in a line with their hands on shoulders
- **Chi Master**
  - Explain that you are the chi master, and that you have the power to feel everyone’s energy and know their inner thoughts. Go over the following poses. You will face opposite the group, count to three, and you will turn around, striking a pose as everyone else strikes a pose. (Act like a ninja!) Anyone who is doing the same pose as you is out. The last person to avoid copying you is the new chi master.
    - Moose: hands make antlers, pouty lip
    - Snake: one arm bent at elbow with fingers clenched & hiss
    - Bear: arms up, mouth wide & growl
    - Flamingo: stand on one leg, chicken wing arms

## Station 3

- **Group Juggle**
  - Everyone gets in a circle. Make sure everyone knows everyone's name. Start by giving a ball to one person and instruct everyone to throw the ball around the circle until everyone has touched it once. \*Remember who you threw it to! Make them throw the ball in the same order again, while saying the name of the person they're throwing to. To make it more difficult, add in a second ball to follow the first. Keep making each round harder by adding in more objects, having them throw in reverse order, or have one ball being passed clockwise around the circle while one ball is being thrown in the original order.
- **Hoop Transfer**
  - Have everyone get in a circle and hold hands. Place the hoola hoop between two people. Instruct the group to move the hoola hoop all the way around the circle without breaking hands.

## Crohn's & Colitis Family Day Post Evaluation!

**Family name:**

On a scale of 1 to 10 (1 being the least and 10 being the most), how well did this program provide information on your child's illness?

1      2      3      4      5      6      7      8      9      10

Comments:

On a scale of 1 to 10 (1 being the least and 10 being the most), how well did this program cater to the needs of your child (i.e. food choices, safety, bathroom access)?

1      2      3      4      5      6      7      8      9      10

Comments:

On a scale of 1 to 10 (1 being the least and 10 being the most), how well did this program allow you to network with other families and find social support?

1      2      3      4      5      6      7      8      9      10

Comments:

On a scale of 1 to 10 (1 being the least and 10 being the most), how well did the staff do at making you feel welcomed and involved?

1      2      3      4      5      6      7      8      9      10

Comments:

Do you believe that this program was a good experience for your child socially? Please explain.

Do you believe that this program will help your child cope better with having Crohn's or colitis? Please explain.

Was this program beneficial for you, as a parent, and as a family? Please explain.

Would your family want to come back again next year?    Yes      No

Please tell us anything else we could improve, or anything we did great!