

"It Takes Guts": Examining the Relationships Between Age at IBD Diagnosis and  
Socioemotional Factors

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### Abstract

Chronic illness can have physical, developmental, and psychological impacts on pediatric patients. Inflammatory Bowel Disease (IBD) is under researched in pediatric populations, especially in terms of psychosocial impacts of illness. Younger age at diagnosis has been associated with anxiety and depression, and IBD patients are more likely to demonstrate dysfunctional coping mechanisms. The relationships between social support and coping are largely unknown, as well as the impact of age at diagnosis and coping. In the current study, younger age at diagnosis was associated with greater use of humor and self-distraction as coping mechanisms. Lower reports of social support were related to more dysfunctional coping mechanisms, and time since diagnosis was related to lower reports of anxiety and depression. More research is needed in order to assess psychosocial functioning over time. Longitudinal research beginning at the time of diagnosis is needed in order to assess trajectories for adaptation to IBD over time.

*Keywords:* inflammatory bowel disease, chronic illness, impact of IBD

## Introduction

Inflammatory Bowel Disease (IBD) is a chronic autoimmune disease that includes Crohn’s Disease and Ulcerative Colitis and affects as many as 3 million Americans (“Crohn’s & Colitis”). While very similar, Ulcerative Colitis affects only the colon and rectum, while Crohn’s Disease can occur in any part of the GI tract (Woodward et al. 2016). Both Ulcerative Colitis and Crohn’s Disease causes inflammation and ulcerations, damaging the gastrointestinal tract, and making it difficult for the body to absorb nutrients from food. IBD patients can easily suffer from deficiencies of proteins, calories, and/or vitamins. Pediatric patients with IBD often suffer from growth delay and delayed puberty. Symptoms of IBD vary in each patient and can change daily. Symptoms include but are not limited to stomach pain and cramping, diarrhea, gastric reflux, fevers, mouth sores, fissures, abscesses, colonic strictures and/or fistulas, uveitis, skin rashes, joint pains, and pelvic floor dysfunction (2016). Children with IBD are at higher risk than healthy children for experiencing negative psychosocial symptoms, including anxiety, depression, and difficulties with behavioral and emotional functioning (Mackner, Sisson, & Crandall, 2004). Literature shows that pediatric populations outside of IBD also experience the emotional burden associated with chronic pain, and suggest early psychological intervention in order to promote active coping strategies (Warschburger et al., 2013).

Age at diagnosis has been identified as a predictor of IBD-related quality of life (IBD-QoL). Younger age at diagnosis is associated with reports of poorer IBD-QoL, in part because a diagnosis before the age of 30 interrupts life events, creating additional distress in younger patients with IBD (Katz et al. 2016). The sample examined in the study conducted by Katz et al. included patients diagnosed with Crohn’s Disease or Ulcerative Colitis that were over the age of 18, but similar findings have yet to be found as they relate to youth populations in the IBD

community. Further investigation into Health-Related Quality of Life is needed in order to assess pediatric populations. IBD-related distress was also examined by Woodward et al. in order to develop a scale for assessing disease and distress more generally (2016). Utilizing data from previous studies, researchers employed the DELPHI method to determine five main themes: emotional distress, healthcare-related distress, interpersonal/social distress, treatment-related distress, and symptom-related distress. The negative psychological impact of an IBD diagnosis highlights the need for more research into psychological impact, particularly anxiety and depression. van den Brink et al. (2018) examines the development of anxiety and depressive symptoms in a European sample of youth diagnosed with inflammatory bowel disease. Capturing the seriousness of depressive symptoms in IBD, the authors state, “a chronic disease, at this age, is a threat to a healthy psychosocial development. It has been observed that particularly adolescents with IBD are at risk for psychological problems such as anxiety and depression, and thereby decreased quality of life.” The authors note that anxiety and depression are more prevalent in pediatric IBD populations compared to other chronic illnesses, and that younger age at diagnosis is associated with anxiety and depression. It is recommended that psychological screening be implemented in young IBD patients. Participant’s ages in this study ranged from 10-25 years old, which helps to encompass the development of depressive symptoms from childhood to young adulthood.

In addition to age at diagnosis, methods of coping are also related to IBD. Coping style is defined by Viganò et al. as “someone’s preferred way of dealing with stressful situations” (2015), and the link between Crohn’s Disease and psychiatric disorders (especially depressive and anxious disorders) are highlighted as well. Crohn’s patients suffering from depressive symptoms are more likely to demonstrate dysfunctional coping strategies, such as self-blame,

denial, and behavioral disengagement. The researchers recommend an interdisciplinary approach between gastroenterologist and psychiatrist for IBD patients, as a way of implementing more positive coping mechanisms soon after diagnosis. Such an approach could be crucial in improving psychological wellbeing. It is important to consider that severity of illness varies patient to patient, and the age at diagnosis can be a major factor in assessing coping mechanisms and social support later in life. Generally, a strong source of social support helps improve quality of life in IBD patients, but the addition of symptom catastrophizing as well as experiences in which the patient feels helpless makes it more difficult to improve QoL with social support (Katz et al. 2016).

In a study conducted online, Purc-Stephenson, Bowlby, and Qaqish (2015) utilized open-ended questions in a sample with ages ranging from 18 to 62. The participants in this study are approximately the target population for the current study, although age at diagnosis was not specified. The goal of the study was to gather information about positive and negative life changes since diagnosis of IBD. Using a 5-point Likert-type scale where 1 = not at all and 5 = a great deal, participants were asked to respond to the questions “To what extent do you feel that IBD has (positively/negatively) affected your life?” Further, participants were asked to respond to the open-ended question, “Could you please describe the (positive/negative) effect(s) IBD has had on your life?” Common categories for positive effects were coded as “interpersonal relations,” “new life paths,” “personal growth,” “valuing life,” and “spiritual growth.” Commonly reported negative effects after diagnosis included “freedom restrictions,” “psychological side effects,” and “social isolation.”

The purpose of this study is to examine the relationships between age at IBD diagnosis, anxiety, depression, social support, and coping. Anxiety and depression will be measured in the

current study using short forms of the PROMIS questionnaire. Age at diagnosis seems to be a key aspect in the development of anxiety and depressive symptoms in this study, and the current study seeks to explore more about how the specific age at diagnosis can impact patients later in life. Coping strategies will be assessed in the current study with the Brief COPE Questionnaire, with the hope of filling in some of the gaps in the literature surrounding how age at diagnosis impacts coping strategies specifically. It is hypothesized that younger age at IBD diagnosis will be significantly related to dysfunctional coping, and higher rates of anxiety and depression. It is also hypothesized that higher reports of social support will significantly relate to positive coping mechanisms as well as lower reports of anxiety and depression. Exploratory analysis will additionally examine any relationships between time since diagnosis, coping, anxiety, and depression.

### **Methods**

The target population consisted of adult participants (18+) that were diagnosed with a form of inflammatory bowel disease (IBD). Qualtrics surveys were distributed to potential participants via online support groups, listservs, and postings in appropriate medical/mental health clinics. The recruitment process began with a social media posts by various organizations associated with inflammatory bowel disease. Information about the study was also sent to Stephanie Brenner, LCSW, of Chronic Illness Psychotherapy. Ms. Brenner distributed the same information as the social media posts to other clinical psychologists that specialize in treating patients with IBD, reaching private practices in the Chicago area and Portage, Michigan. Information about the study reached as far as The University of Adelaide in South Australia, where the same social media post was shared to appropriate patient populations by the Director and Head of IBD Services at Royal Adelaide Hospital.

When potential participants clicked the link to the survey, they were led to a brief overview of the study, which contained inclusion criteria as well as any possible risks in participating. They were prompted to accept their voluntary participation, and proceeded to complete the survey.

### **Questionnaire Completion**

Following the voluntary participation section, participants were asked to complete a series of questionnaires, which would take about 15-20 minutes to complete. These questions include the following measures. For the first hypothesis, age at diagnosis was the independent variable, and all remaining measures were dependent variables. Social support was the independent variable for the second hypothesis, with all remaining measures as dependent variables.

**Demographic Information.** The following demographic information was collected: age, race, ethnicity, and gender.

**IBD Diagnosis.** Participants were asked a series of questions in order to verify IBD diagnosis. If a participant selected that they have not been diagnosed with a form of IBD by a medical professional, they were led to the end of the survey. If participants self-confirmed their diagnosis, they were asked for a specific diagnosis (Crohn’s, Ulcerative Colitis, Indeterminate Colitis, or Other). Participants were asked for the age when they first noticed symptoms of IBD and their age at diagnosis. To control for social support, participants were asked if they have met other individuals with IBD as well as whether they have attended the Crohn’s & Colitis Foundation’s Camp Oasis, and in what capacity.

**Health-Related Quality of Life (HQoL).** Participants completed the Short IBD Questionnaire (SIBDQ), a short form of the original 32-item IBD Questionnaire (IBDQ). This



10-item scale measures quality of life as measured in four domains—bowel symptoms, emotional health, systemic systems, and social function (Irvine, Zhou, & Thompson, 1996).

**Illness Perception.** Participants completed The Brief Illness Perception Questionnaire, a 9-item scale that measures illness perceptions which can have a significant impact on patient behaviors. Changing illness perceptions can lead to improved patient outcomes (Broadbent, Petrie, Main, & Weinman, 2006).

**Social Support.** Participants completed The MOS Social Support Survey, a 18-item scale that measures social support in four domains—emotional/informational support, tangible support, affectionate support, and positive social interaction (Sherbourne & Stewart, 1991).

**Coping.** A shortened version of the original COPE questionnaire, the Brief COPE measures a variety of coping strategies including denial, use of emotional support, acceptance, and self-blame (Carver, 1997).

**Anxiety.** Participants completed the PROMIS Short Form v1.0—Anxiety 8a in order to assess symptoms of anxiety over the past week (Bernstein et al. 2018).

**Depression.** Participants completed the PROMIS Short Form v1.0—Depression 8a. in order to assess symptoms of depression over the past week (Bernstein et al. 2018)..

**Data Analysis.** Descriptive statistics were run to describe demographics of participants. For the first hypothesis, correlations were run between age at diagnosis, coping, anxiety, and depression. For the second hypothesis, correlations were run to assess relationships between social support, coping, anxiety, and depression. Exploratory correlations were run to assess any relationships between time since IBD diagnosis, coping, anxiety, and depression.

## Results

Fifty-nine participants completed the survey, with ages ranging from 18-60 years old ( $M = 32.34$ ,  $SD = 12.496$ ). 93.1% of participants were female, 93.2% were white, with 96.4% of the sample being non-Hispanic. 34 participants had a diagnosis of Crohn’s Disease, 23 with Ulcerative Colitis, and one with a diagnosis of ischemic colitis. 58.9% of the sample were diagnosed with IBD when they were 18+ years old, and 96.6% had met others with IBD before. On average, participants were diagnosed with IBD in their early 20s ( $M = 20.43$ ,  $SD = 11.713$ ).

### *Age at IBD Diagnosis/Time Since Diagnosis*

Age at IBD diagnosis was significantly negatively correlated to both self-distraction and humor as coping mechanisms, meaning that younger age at diagnosis is associated with the use of self-distraction and humor. Time since diagnosis was also negatively correlated to self-blame as a coping mechanism (see Table 1), meaning that more time since diagnosis was related to less self-blame.

In terms of depressive symptoms, time since diagnosis was negatively correlated to both anxiety and depression (see Table 2), such that more time since diagnosis led to lower reports of anxiety and depression. Measures of social support were not found to be significantly related to age at diagnosis and/or time since diagnosis (see Table 3).

### *Social Support*

Total social support was found to have a significant negative correlation to both anxiety and depression (see Table 4). Higher social support is significantly correlated to lower reports of anxiety and depression. Higher scores for social support were significantly correlated to higher active coping, emotional support, instrumental support, and positive reframing, while lower

scores for social support scores were significantly correlated to higher substance use, behavioral disengagement, and self-blame (see Table 5).

### **Discussion**

Age at diagnosis is a vital factor to take into consideration in the research of IBD populations. Because many patients are diagnosed under the age of 18, it is essential to examine how a diagnosis impacts individuals' coping, anxiety, and depression, as well as the importance of social support in managing psychosocial impact of disease.

Younger age at diagnosis is associated with greater use of humor and self-distraction as coping mechanisms. This could be because children diagnosed with IBD may use humor as a way to explain their illness to peers, and distract themselves as a way to take their focus off of their pain. Both of these findings were supported by existing literature. Humor as a coping mechanism is often used by pediatric patients to lessen feelings of anxiety, anger, and pain (Dowling, 2002). Since humor was shown to be a coping mechanism for participants diagnosed at younger ages, it is conceivable that this coping mechanism stayed with them as they continued to cope with their IBD. Dowling also identifies self-distraction as a common coping mechanism utilized by school-age children, due to its effectiveness in coping with disease-related stressors (2002).

Longer time since IBD diagnosis is associated with lower reports of anxiety and depression, possibly because more time has passed to allow for patients to accept their illness. This may also be because greater time since diagnosis could be associated with higher rates of remission., or simply more time to adapt and form active coping strategies. This finding was supported by existing literature that found a relationship between shorter disease duration and

increased disease activity (van der Brink et al., 2018). More research is needed in order to assess the relationships between disease duration and specific coping mechanisms.

Age at diagnosis and time since diagnosis are not significantly related to measures of social support. Higher social support is associated with lower reports of anxiety and depression, as well as higher reports of active coping, emotional support, instrumental support, and positive reframing. Patients reporting lower social support scores were associated with higher substance use, behavioral disengagement, and self-blame. Social support is crucial in terms of how patients with IBD learn to cope with their illness, as lower reports of social support were shown to correspond to dysfunctional coping mechanisms, and higher reports of social support were related to positive coping mechanisms.

Limitations of this study include the lack of male participants. Future studies could seek out specific organizations for men with IBD, so as to have a more representative sample of the IBD community. The nature of this study relied on the completion of surveys, but interviewing participants could provide for more in-depth answers as well as the opportunity for follow-up questions. The sample size was relatively small, and all data was self-reported, which can always lead to error. While a cross-sectional study is still useful in this under researched area, longitudinal research would provide more information about the long-term lifetime effects of IBD, as well as provide insight into the periods of flares and remissions in an IBD patient's life. Future research could assess psychosocial functioning over time, starting closer to diagnosis (especially in pediatric populations) rather than retrospective surveys. Existing literature supports the importance of longitudinal research of pediatric IBD, as a way of investigating trajectories for adaptation to the disease over time (Mackner 2004).

While social support was not found to be related to age at diagnosis, it was found to have significant relationships to various methods of coping. Establishing mechanisms of social support may help promote positive coping in IBD patients. Social support was also strongly related to lower reports of anxiety and depression. More research is needed to assess how social support impacts IBD-related quality of life and illness perception. Future research should examine the role of coping and social support on children’s adjustment to living with IBD at the time of diagnosis. Collaborative care between pediatricians, gastroenterologists, and psychotherapists is needed to support newly-diagnosed children with IBD. Early psychological intervention is crucial in order to promote positive coping mechanisms, establish social support, and lower pediatric patients’ risk for anxiety and depression.

## References

- Bernstein, C. N., Zhang, L., Lix, L. M., Graff, L. A., Walker, J. R., Fisk, J. D., . . . Marrie, R. A. (2018). The Validity and Reliability of Screening Measures for Depression and Anxiety Disorders in Inflammatory Bowel Disease. *Inflammatory Bowel Diseases, 24*(9), 1867-1875. doi:10.1093/ibd/izy068
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). Brief Illness Perception Questionnaire. *PsycTESTS Dataset*. doi:10.1037/t10379-000
- Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine, 4*, 92-100.
- Cook, K. F., Jensen, S. E., Schalet, B. D., Beaumont, J. L., Amtmann, D., Czajkowski, S., . . . Cella, D. (2016). PROMIS measures of pain, fatigue, negative affect, physical function, and social function demonstrated clinical validity across a range of chronic conditions. *Journal of Clinical Epidemiology, 73*, 89-102. doi:10.1016/j.jclinepi.2015.08.038
- Crohn's & Colitis. (n.d.). Retrieved from <https://www.crohnscolitisfoundation.org/what-is-crohns-disease/overview>
- Dowling, J. (2002). Humor: A coping strategy for pediatric patients. *Pediatric Nursing, 28*(2), 123-31.
- Katz, L., Tripp, D., Ropeleski, M., Depew, W., Curtis Nickel, J., Vanner, S., & Beyak, M. (2016). Mechanisms of Quality of Life and Social Support in Inflammatory Bowel Disease. *Journal of Clinical Psychology in Medical Settings, 23*(1), 88-98. <https://doi.org/10.1007/s10880-015-9431-x>

- Irvine, E.J., Zhou, Q., & Thompson, AK (1996) The short inflammatory bowel disease questionnaire: a quality of life instrument for community physicians managing inflammatory bowel disease. CCRPT investigators. Canadian Crohn’s Relapse Prevention Trial. *American Journal of Gastroenterology*, 91(8), 1571-1578
- Mackner, L., Sisson, D., & Crandall, W. (2004). Review: Psychosocial issues in pediatric inflammatory bowel disease. *Journal of Pediatric Psychology*, 29(4), 243-57.
- Purc-Stephenson, R., Bowlby, D., & Qaqish, S. (2015). “A gift wrapped in barbed wire” Positive and negative life changes after being diagnosed with inflammatory bowel disease. *Quality of Life Research*, 24(5), 1197–1205. <https://doi.org/10.1007/s11136-014-0843-0>
- Sherbourne, C. D., & Stewart, A. L. (1991). The MOS social support survey. *Social Science & Medicine*, 32(6), 705-714. [http://dx.doi.org/10.1016/0277-9536\(91\)90150-B](http://dx.doi.org/10.1016/0277-9536(91)90150-B)
- van den Brink, G., Stapersma, L., Vlug, L. E., Rizopolous, D., Bodelier, A. G., van Wering, H., ... Escher, J. C. (2018). Clinical disease activity is associated with anxiety and depressive symptoms in adolescents and young adults with inflammatory bowel disease. *Alimentary Pharmacology & Therapeutics*, 48(3), 358–369. <https://doi.org/10.1111/apt.14832>
- Viganò, C., Calzolari, R., Marinaccio, P. M., Bezzio, C., Furfaro, F., Ba, G., & Maconi, G. (2015). Unrevealed Depression Involves Dysfunctional Coping Strategies in Crohn’s Disease Patients in Clinical Remission. *Gastroenterology Research & Practice*, 1–7. <https://doi.org/10.1155/2016/7803262>
- Warschburger, P., Hänig, J., Friedt, M., Posovszky, C., Schier, M., & Calvano, C. (2013). Health-related quality of life in children with abdominal pain due to functional or organic gastrointestinal disorders. *Journal of Pediatric Psychology*, 39(1), 45-54.

Woodward, S., Dibley, L., Coombes, S., Bellamy, A., Clark, C., Czuber-Dochan, W., ... Norton,

C. (2016). Identifying disease-specific distress in patients with inflammatory bowel

disease. *British Journal of Nursing*, 25(12), 649–660. Retrieved from

[https://ezproxy.depaul.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&](https://ezproxy.depaul.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=hch&AN=116419287&site=ehost-live&scope=site)

[db=hch&AN=116419287&site=ehost-live&scope=site](https://ezproxy.depaul.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=hch&AN=116419287&site=ehost-live&scope=site)



Tables

Table 1. Correlations Between Age at Diagnosis, Time Since Diagnosis, and Coping

	Age at Diagnosis	Time Since Diagnosis
Self-distraction	-.288*	-.063
Active Coping	-.065	.067
Denial	-.090	-.190
Substance Use	.096	-.206
Use of Emotional Support	-.058	-.032
Use of Instrumental Support	.063	-.129
Behavioral Disengagement	-.116	-.135
Venting	.118	-.258
Positive Reframing	-.170	.093
Planning	.088	-.035
Humor	-.320*	-.109
Acceptance	-.156	.216
Religion	.227	.055
Self-Blame	.088	-.310*

\*p < 0.05, \*\*p < 0.01

Table 2. Correlations Between Age at Diagnosis, Time Since Diagnosis, Anxiety, and Depression

	1	2	3
1. Age at Diagnosis	--	--	--
2. Time Since Diagnosis	-.299*	--	--
3. Anxiety	-.119	-.324*	1
4. Depression	.036	-.340*	.798**

\*p < 0.05, \*\*p < 0.01

Table 3. Correlations Between Age at Diagnosis, Time Since Diagnosis, and Social Support

	1	2	3	4	5	6	7
1. Age at Diagnosis	--						
2. Time Since Diagnosis	-.299*	--					
3. Total Social Support	-.160	.143	--				
4. Emotional/Informational Support	-.177	.179	.927**	--			
5. Tangible Support	.118	-.096	.654**	.445**	--		
6. Affectionate Support	-.244	.130	.861**	.727**	.442**	--	
7. Positive Social Interaction	-.212	.108	.882**	.750**	.418**	.823**	--
8. Additional Support	-.208	.113	.845**	.743**	.402**	.738**	.877**

\*p < 0.05, \*\*p < 0.01

Table 4. Significant Correlations Between Total Social Support, Anxiety, Depression

	1	2
1. Total Social Support	--	
2. Anxiety	-.428**	--
3. Depression	-.627**	.798**

\*p < 0.05, \*\*p < 0.01

Table 5. Significant Correlations Between Total Social Support and Coping

	Total Social Support
Active Coping	.309*
Substance Use	-.451**
Use of Emotional Support	.441**
Use of Instrumental Support	.384**
Behavioral Disengagement	-.421**
Positive Reframing	.289*
Self-Blame	-.438**

\*p < 0.05, \*\*p < 0.01

**My Guts**

The story of how I lost my guts, but found my courage.

**By Julia S. Golden**

### **Preface**

Over the years, whenever I was granted the opportunity to write about an important aspect of my life, I chose to write about my own experiences with Crohn’s Disease. What follows are five essays, each with an author’s note that offers retrospective analysis of the time the piece was written. These works mirror the nature of my research. Since I was diagnosed with Crohn’s Disease at age nine, any writing I have on my diagnosis is retrospective in nature, but it is still worth examining the developmental trajectory through my writing style. All essays were left unedited for grammar and flow in order to preserve the voice that wrote each of them. Some essays are more optimistic, others are darker, and all of them reflect my almost 14-year relationship with Crohn’s Disease.

**September 2013**

Author’s Note:

*September 2013 marked the beginning of my third year of high school, a year notoriously stressful for most American students as they dip their toes into the college search process. For me, this already overwhelming year was further convoluted by Crohn’s complications. The preceding summer, severe side effects from Humira injections required me to switch my treatment plan. When I began my junior year of high school, I was adjusting to a new medication, Cimzia. In a short narrative assignment meant to detail my family dynamic, I couldn’t help but look back to my diagnosis and reflect upon the impact it had on my entire family. As I reread it now, I remember my hopefulness, thinking that my new treatment would be the one to get me in remission. Spoiler alert: It did not.*

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The dynamic of my family growing up had always been normal. My house is right behind my elementary school, so every day when the bell rang I would walk across the park to meet my mom. She was always waiting there for me. As we’d walk home I’d try to crunch as many leaves as I could with my feet or I’d pick up acorns and pinecones to take home. Later I would ride my bike, watch TV, or walk the dog with my older sister. In the days before homework, this is all that would happen apart from a weekly violin lesson. I was free. There was nothing I couldn’t do. Around six o’clock my dad would come home from work, and we’d eat dinner together as a family. We were all content in our daily routines. This was a pretty standard day for us until my health deteriorated, and my idyllic family life followed shortly after.

When I woke up on my ninth birthday, I thought it would be an ordinary day. I had to wake up earlier than usual as it was the first day orchestra would meet. I’ve played the violin

ever since I was four years old, and I had joined the school’s chamber orchestra the previous year. I loved it. The only difficult thing for me was that it met at 7:30 in the morning and I hated waking up early. I remember feeling more nervous than usual as I walked into the building with my dad. I assumed it was just nervous butterflies flapping in my stomach. As the class went on and on I felt the butterflies more and more. They flapped their wings harder and harder, and I knew it wasn’t just nerves anymore. When orchestra ended, there were still twenty minutes before school officially started. I went to the nurse’s office and told her about the butterflies. My dad picked me up from school and I went home.

In the following months, the butterflies persisted and became part of my new daily routine. Quickly, I started to notice other strange signs. My already fair skin had grown paler, my already thin body became emaciated and I was always missing school. My parents and pediatrician grew concerned and I was sent to Children’s Memorial Hospital for a round of gastrointestinal tests.

When I was in the hospital, I didn’t fully comprehend the enormity of what was happening. While I was questioning what was happening to the butterflies, I paid close attention to the reactions of my family. My sister would always try to make me smile. She’d draw me pictures, make “Get well soon!” cards, and make paper flowers for my bedside table. My parents spent all the time they weren’t at my side researching my symptoms to try to figure out what was going on with my stomach. The mood of the family had grown gloomier. We didn’t really know what to do with ourselves until we knew my diagnosis. What I remember most specifically about my stay was the wretched smell of antiseptic that wafted into my nose as I woke up from my first colonoscopy. The fluorescent lights bore into my eyes as I regained my bearings. I was drowsy, but filled with hope. The doctors had diagnosed me.

I went back to sleep before I found out. Back in my hospital bed, my parents and doctors explained to me that I had something called “Crohn’s Disease,” which causes extreme inflammation in the gastrointestinal tract. Although I didn’t know what any of this meant at the time, and was *not* pleased that I’d have to take medication for the rest of my life, I looked around the room and saw the determined faces of my parents. I was scared for the new path my life was on, but I knew my family would protect me like they always have, and I became a much stronger and independent person because of it.

*September 2013, 17 years old*

**October 2014**

Author’s Note:

*“Some students have a background or story that is so central to their identity that they believe their application would be incomplete without it. If this sounds like you, then please share your story.” This was the prompt I chose for my college admissions essay. Rather than reflecting on the diagnosis itself, I remember wanting to strike a balance between “sick enough to have learned from my experiences” and “too sick to pay consistent tuition to your university.” Though I had dealt with even more health struggles in the summer months of 2014, I still remained optimistic that I would be healthy enough to attend college the following year. To tell my story, I reflected on my decision in seventh grade to become more open about my Crohn’s Disease, as well as my first experiences with self-advocacy.*

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*I’ve Got Courage, But I’m Jealous of Your Guts*

My home tutor arrived at my house with a bit of a problem. Apparently my extended absence from middle school had finally garnered the attention of my peers, who had begun to bombard my teachers with questions like, “*Is she okay?*” “*When is she coming back?*” “*Does she have cancer or something?*” “Or something” would be correct.

Soon after I turned nine years old, I began to deal with some peculiar health problems. I stopped retaining nutrients from food, lost weight, and became drastically pale, rendering me an emaciated ghost. After seeing my pediatrician and a few specialists, a series of gastrointestinal tests were ordered. It was my first colonoscopy that diagnosed my Crohn’s Disease.

Fast forward to seventh grade. I was enduring an extended flare of symptoms, which made attending school impossible. Since there is currently no cure for IBD (Crohn’s Disease and



Ulcerative Colitis), the main goal of treatment is to control the inflammation in the digestive system (with meds), and to manage daily symptoms (with even more meds). At this point, my medication had failed to keep me in remission, and the next medication on the list would take about three months to start working. These months were spent at home trying to catch up on missed schoolwork and attempting to retain my sanity while isolated from society in my house.

It became clear to me that I could no longer fly under the radar—I had to explain to people what was happening to me. I’d always been private about my Crohn’s Disease. Maybe it was because I was so young when I was diagnosed. Maybe it was because it is an illness commonly associated with the bathroom. Or maybe it was because the awareness for Crohn’s Disease is so low that even now, as I type, my computer does not recognize “Crohn’s” as a word in the English language. But when I thought about the confusion my peers were facing regarding my absence, I realized what an incredible opportunity I had been given. A problem I’ve faced since diagnosis has been coping with the massive lack of awareness for my disease. In that moment I realized I had an opportunity to educate my peers and teachers. I turned to advocacy.

I created a slideshow presentation in which I tell my story and explain the severity of my illness. At the end, I make a promise to my teachers that I will try my hardest during the year, no matter what my Crohn’s Disease may throw at me. I’ve continued to edit and share this presentation with my teachers and peers for six years.

Advocacy reached its high point for me when I was able to attend Camp Oasis this past summer. Camp Oasis is sponsored by the Crohn’s and Colitis Foundation of America, and is for kids with Crohn’s Disease or Ulcerative Colitis. Part of camp tradition is to hold “IBD Panels” by age group in order to discuss our illnesses freely, and, as a Leader in Training, I was given the opportunity to serve on these panels. Shortly after sharing my story, I was approached by a

camper named Natalie. Having just been diagnosed with Crohn’s Disease, Natalie was struggling with many issues I had experienced and we bonded very quickly. Knowing that I can be a role model for her has made me realize that I can make a difference. Working at Camp Oasis helped me recognize that I was part of a significant IBD community—one that I feel grateful to be part of. Crohn’s is emotionally and physically debilitating, but my experiences give me the power to aid others through similar struggles. I have guts, no matter how inflamed they may be.

*October 2014, 18 years old*

**May 2015**

## Author's Note:

*In May of 2015 I had committed to DePaul University, but the constant unpredictability of my Crohn's symptoms came to a head with an enormous flare. I was out of school for several months, first in homebound tutoring, and then involved in a program to help students return to school after extended absences. This transition program helped get me out of the house, but I was not back in the classroom. For the last several months of my Senior Year, I went to school for half of the day. I attended my music classes, but instead of academic classes, I went to the Special Education offices to work individually on my remaining assignments, before leaving around one o'clock each day. One of these assignments was to reflect on my own persona, but my depression and isolation from normal classroom activities led me to take a less-than-optimistic tone. At this point in my disease, I had missed out on an enormous amount of social events to celebrate graduation, and the darkness was setting in. While I was eager to begin college, I was no longer optimistic about the future of my Crohn's—at the time I could only see the pain it had brought. I remember thinking about how tired I was of trying to be optimistic, and that in general no one really wanted to hear about the negative impacts of my illness. I was tired of school, tired of Crohn's, and tired of hoping.*

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I'm not an average teenager. When I go to bed at night I'm not obsessing about my appearance, or if a boy noticed me in the hall that day. I'm not thinking about whether I'll have time to stop for coffee on the way to school the next day. I'm worrying about if I'll even *make it* to school. I've lived with a debilitating and unpredictable chronic illness since I was nine. Crohn's Disease is an autoimmune disease of the digestive system that has taken an enormous

toll on my life and has altered my perception of the world. Because I was so young when diagnosed, IBD (inflammatory bowel disease) played a large role in shaping who I am, and learning to cope with my illness has become an essential part of my everyday life.

Living with Crohn's Disease is a never-ending battle, and early on in my diagnosis I learned to "go with the flow." Immediately I had to get over any fears I had of doctors, needles, and blood, and quickly learned how to hide any sign of weakness. I never wanted to be the little girl crying in the doctor's office. Soon after this realization, I developed "the mask." Before being diagnosed I had always been a happy, healthy child, and with "the mask" I could pretend everything was okay once I left my house. I wanted to be a student, and considering Crohn's is an invisible disease, I could pretend to be one as much as I wanted. Sometimes hiding the pain was the best option for me, especially around people that didn't know about my illness. I didn't want anyone to worry about me, so the mask stayed on. While I'm a little more open about my disease today, the mask stays on in public for the most part. I understand that this isn't the best coping mechanism, but with a relatively unknown illness with a stigma like Crohn's Disease, it was a decent option when I was in third grade and it played a huge role in shaping who I am today.

For me, living with Crohn's Disease makes me more appreciative of my life and a more independent young adult. From nine-years-old it was necessary for me be able to talk openly with my doctors about the symptoms of my illness. Though it can be embarrassing to discuss the details of a digestive disease, I was taught at a young age how important it is to be honest and comfortable talking to adults. This skill translated into my life as a student. I can now understand the importance of advocating for myself as well as for other people that suffer from the constant complications of Crohn's Disease. I'm always mindful about keeping up with my school work in

case my disease flares unexpectedly, and I am in constant communication with my teachers when I'm out of school for long periods of time. Despite some positive experiences, I have *plenty* to say regarding the negative. While I've learned a lot from having this disease, it's important to recognize how much I've lost. It is hard for me to know what I would be like today without Crohn's, and impossible to tell if the skills I've acquired could have been obtained in other ways. I wouldn't be the same person, but would I be as independent and responsible?

With such a difficult disease, it's important to be positive and optimistic, but I still feel angry and frustrated. I don't want to associate my persona with a chronic disease, but it's hard not to when everything about my life has been altered by Crohn's Disease. My social life, my academic life, my mental and physical health, are all dependent in some way on damaging inflammation in my digestive system. I feel like I'm supposed to say that it's worth it because Crohn's Disease has taught me to advocate for myself and be responsible, and I can appreciate the smaller things in life. But how can I do that when there are days I can't leave the house? Or have to sleep in my parent's bed because it's closer to a bathroom than mine? Can I appreciate the world when I'm so frail from not absorbing nutrients that I can't walk? How am I supposed to educate and support younger patients when I'm still not in remission after being treated unsuccessfully for half my life? Am I supposed to tell them they will be cured one day when *I don't know that it will ever happen?* There are good days and bad days. Living with something so unpredictable can take a massive toll on every aspect of your life, and learning to cope with my illness is something I struggle with every day. Until I feel comfortable, my mask will remain.

If my persona is a mask, my shadow is what resides underneath. I find it necessary to hide my pessimism, resentment and anger in order to set an example for other patients as well as to avoid alarming others of the severity of my Crohn's Disease. To appear positive and healthy, I

use my mask to deliberately hide my shadow so I can have some privacy when coping with my illness.

It is difficult to remain optimistic and positive about finding a cure when I don't believe it will happen in my lifetime. Why should I be optimistic that things are going to get better one day when they never have before? I resent my peers for not having to worry about things like this. They are able to have normal lives. I hear students complain about trivial things like their hair or how upset they get when their parents won't buy them a new phone and I wish things like that could be the most difficult parts of my day instead of what I deal with. It's hard for me to make lasting friendships because it's impossible for my friends to understand what I experience.

A crucial factor of living with a chronic illness is that it can be very easy to lose your temper. Coping with something that has no end in sight can be extremely frustrating and I have days when I am furious. With no one to blame, it's hard to find a way to deal with this anger. My disease has had one problem after the other for almost ten years. It's almost laughable that every time one symptom or side-effect ends, another takes its place. In the last year I experienced medication-induced psoriasis, a painful abscess in my upper leg, horrible depression, and a five-week long bout of walking pneumonia. Early last summer I spent nine days in the hospital after a complication occurred during a colonoscopy. The chances of the micro-perforation transpiring were 1/4000, and I came extremely close to needing emergency colostomy surgery. When I was finally released, I came home to a massive pile of schoolwork from my junior year of high school that I didn't complete until early October of my senior year. There is never a break for a patient with Crohn's Disease.

The image I project is calm and optimistic, but it isn't an accurate representation of who I am. I don't always feel comfortable showing my true feelings unless I really know my audience.

It's difficult to hide such a large part of who I am, but it's hard to explain myself when most people haven't gone through the same experiences. Crohn's Disease is extremely isolating and challenging, which is why I compensate with an ever-present sunny disposition.

*May 2015, 18 years old*

**November 2016**

## Author's Note:

*The following was not written for an assignment, but rather for my own records. The day of my ileostomy surgery was an extremely stressful and overwhelming time for me, and I wanted to make sure all the details were written out somewhere for me to come back to years later. At this point in time I weighed 104 pounds, and was struggling to walk even before the surgery. I'm still not sure how I got through this recovery, but I wouldn't be where I am today without it. What follows is the story of how I met "Squishy."*

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The night before the big surgery was the last bowel prep I would ever need, but it was probably the most difficult to keep down. The combination of anticipatory anxiety about major surgery, as well as the physical pain I had all throughout my body, was enough to break me that night. I remember sobbing to my parents that there was no way I could drink any more prep fluid, trying not to throw up the progress I had made, and debating if it was worth going into the emergency room to get an NG tube to do the rest of the work for me. I was done. I didn't have the physical or emotional energy whatsoever to get through that prep, but somehow I did it, and I know it was because of my parents supporting me. They've been known to give some pretty amazing pep talks when I need them, and boy did I need one to get through that prep. Once I was done, I was able to get a few hours of sleep before getting up to head over to the hospital. I put on a pair of leggings, my Great Bowel Movement "IBD Can't Stop Me" sweatshirt, and took a few "before" pictures of my belly before leaving. I still had a blue Sharpie splotch next to my belly button, where my stoma nurse had marked the spot for my stoma a few days earlier. It was



covered in Tegaderm, a clear medical dressing, which was just itchy enough to remind me it was there, making me worry if my bag would be itchy too.

Most of the time in pre-op is a blur. My parents always said they know my pain or anxiety is really bad if I stop talking. I was silent. I remember being drawn on by nurses, signing things, IVs going in, bracelets going on. A white one with my name and birthdate, a seafoam green one with my allergy, “SULFA” on it, and a pink one for the anesthesiologists. At this point I had been under anesthesia countless times, but never general anesthesia. I signed some more things. I waited. I watched my parents try not to look nervous. I spoke with my doctor. I was wheeled away.

I do not like waking up from anesthesia. I especially do not like waking up from anesthesia when my parents are not there. When I woke up in post-op recovery, the only person in the room was a nurse typing away at a computer. I think I asked if it was over. It was. I went back to sleep. This repeated a number of times, but I remember thinking “do I mean ‘Is the surgery over?’ or ‘Is the pain over?’” I still don’t know what I was asking, but I do remember summoning the energy from my sleepy body to move my right hand up to my belly, feeling that the bag was there, and going back to sleep. Over and over.

My ileostomy surgery was on November 21, 2016, the first official day of my 6-week-long winter break and what would have been my Grandfather’s 101<sup>st</sup> birthday. I am still surprised that I was only in the hospital for about three days after the surgery. It felt like I was there the whole month. I do not like having to rely on others to help me with basic needs. I do not like being weak. I do not like having to lie on my back. My first mission post-op was to sleep on my side, which I eventually did with the help of a homemade pillow and some corgi stuffed animals to help prop me up. My nurses were wonderful, but I still didn’t like having to ask for help with

everything. I don't think the severity of what had happened hit me until it was time for my first bag change. My bag was made of clear plastic, so I could see the stoma through the bag, but it's not the same as when the bag is off. Having my bag off for the first time was about as exposed as I have ever felt, something that is strange to think about considering how many times I've been, as comedian and fellow Crohn's patient Ben Morrison calls it, "probed by a team of specialists." For the first 5 days after this kind of surgery, there was a plastic rod running through the stoma. I have a loop ileostomy, so for these first several days this rod was helping keep my stoma from resisting my fresh stitches and trying to slurp back into my abdomen. I remember hating my stoma nurse as she peeled off my first bag—I had done enough research beforehand to know that there was a thing called "medical adhesive remover spray" that she really should have been using considering this was an open wound. Imagine peeling a huge Band-Aid off of an open wound. That's what it was like. I think I cried a little bit when she left, not from pain, but from it sinking in that I would have to change my bag myself. Every three to four days. Forever.

Once I had time to digest (pun intended) the initial shock of seeing the stoma, I decided to name it. Originally, my plan had been to refer to it as "Rosie," because my surgeon had previously told me that the colorectal surgeon she trained under taught her how to make stomas look like "a little rosebud" blooming out of the abdomen. When I met Rosie, I didn't feel that this was the right name for her. For a few days I simply referred to my stoma with feminine pronouns, "She's awake," "She's noisy," "When is she going to shrink?" I later decided to refer to her as "Squishy" and continue to call her this today.

*Surgery: November 2016, 20 years old*

**May 2018**

Author’s Note

*After a difficult start to my undergraduate career, I was finally able to attend classes somewhat consistently during my third year at DePaul. For an assignment for my Honors Program Junior Seminar in Multiculturalism, I wrote the following brief essay assessing my positionality in the world, specifically what advantages/disadvantages did I have based on privilege. The paper gives a brief overview of the first few years with Crohn’s Disease, and goes on to describe the complications that led to my decision to have elective surgery.*

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I grew up in Glenview, Illinois and attended New Trier Township High School. Even in my third year at DePaul, whenever someone asks me where I grew up, they have trouble placing “Glenview,” but “New Trier” tends to elicit a response. My high school is in Winnetka, Illinois but the district also includes towns like Wilmette, Northfield, and Kenilworth. The area is overwhelmingly affluent and white. Growing up I did not feel “wealthy” compared to my peers, but at the same time I never worried about having enough food, having money to go back-to-school shopping, or possibly most important in my case—access to health care.

At the beginning of third grade, I started losing a significant amount of weight and growing pale. I was having diarrhea several times a day, often very soon after meals. I remember feeling relieved that my classroom was directly across the hall from a girl’s bathroom because I had very little time to run there once I knew I had to go. My dad is an internist at Northwestern Memorial Hospital, and my mom was a registered nurse at RIC until I was born, so they had always taught my sister and me to be open with them about any health-related questions or concerns. They also instilled in me a trust of doctors from a young age. I remember telling them

that I wanted to go see my pediatrician because I was having diarrhea constantly, “even when I’m not nervous about something.” My pediatrician was concerned about the possibility of an eating disorder, but my parents knew that I was eating my meals – everything was just going right through me. My pediatrician referred me to a pediatric gastroenterologist and in the week that followed my appointment with the GI doctor, I had an upper GI (x-ray of the stomach), upper endoscopy, and colonoscopy. I was diagnosed with Crohn’s Disease the same day as my colonoscopy, around three months after first showing symptoms.

Many patients with inflammatory bowel diseases (Crohn’s and Ulcerative Colitis, IBD) suffer with symptoms for years before diagnosis, and I will always be grateful that I was diagnosed so quickly. Over the next ten years or so, my symptoms would wax and wane, though they would never resolve entirely. When symptoms were worse, I would receive a course of steroids to stabilize my inflammation. Steroids like prednisone can have intense side effects including insomnia, mood swings, and weight gain—especially swelling of the face, commonly referred to as “moon-face.” After treatment with steroids, I would be placed on a new medication that would act as what I call my “lead actor.” The main medication changed often, but others, including immunosuppressants and anti-inflammatories, were always backstage trying to help keep things under control. After a few months, the main actor remembers what their lines are and starts performing, but soon after, the side effects creep in, and the main medication stops working altogether. The cycle repeats itself. Meanwhile, I was trying to get through middle school and high school, often missing months at a time and retreating into homebound tutoring. As the years went by with no medication making a lasting impression, anxiety and clinical depression set in, and the permanent damage caused by inflammation made itself known.

On January 1, 2016, I went to the ER with pain near my groin. After being admitted and having an MRI at 10:00 at night, doctors discovered a fistula and anal stricture. During that hospital stay I had a seton placed (a permanent drain) and in the following months had to return many times for colonoscopies and exams under anesthesia to monitor the stricture and fistula. The stricture was caused by a buildup of scar tissue and problems with my pelvic floor muscles. After so many years of stress on the area from going to the bathroom, my pelvic floor muscles lost the ability to relax, which made it extremely difficult to control bowel movements. Even with months of pelvic floor therapy, I struggled day to day with fecal incontinence. At this point, I was in the middle of my first year at DePaul, and I was needing to wear a diaper to class. Some days I couldn't get to class at all because I was unable to leave the bathroom in my dorm. I went on medical leave that spring term and took some online classes from home.

For years I was both extremely lucky and unlucky. On one hand I was gravely ill, often losing weight, dealing with side effects from medications, and suffering from chronic pain and fatigue with no end in sight. On the other hand, there were many things I did not worry about. I never worried about health insurance. I never worried about not getting the proper accommodations at school. I never worried about being sick and home alone because I was privileged enough to have a stay-at-home mom. Once I was at college, I was able to receive housing accommodations through the Center for Students with Disabilities. My entire time at DePaul I've lived in a room with no roommate and a private bathroom equipped with a bidet toilet seat I provided and the housing department installed. I have been able to take online classes over the summer because the added tuition is “not an issue” according to my parents. I am extremely grateful to be privileged to have these resources, as they allow me to focus entirely on my health in the midst of a Crohn's flare.

The biggest piece of luck though, was that my illness was invisible. No one had to know how sick I was unless I wanted them to. Over the years I had developed an excellent mask—a way of hiding my feelings and symptoms so I don’t cause others to be uncomfortable. Even today, if people knew the amount of pain I am in on a daily basis it could be particularly upsetting. I never wanted my parents to worry about me more than they already did, and I certainly never wanted to be the little girl crying in the doctor’s office, so my mask has remained an effective way to separate myself from my illness. With the appearance that everything is fine, I could pretend that I was a normal young woman and not have to address that I was not as able-bodied as my peers.

The summer before my sophomore year of college, I had to come to terms with the fact that it was quickly growing impossible for me to function day to day. After an overwhelming amount of research, I began to entertain the idea of elective surgery. My quality of life had been suffering from the social isolation of being on medical leave, and my eyes were finally opened by a friend of mine with Ulcerative Colitis I had met a few years prior at the Crohn’s & Colitis Foundation’s Camp Oasis, a camp for children and adolescents with IBD. Natalie had recently undergone colectomy and subsequent ostomy surgery, and had seen tremendous improvement in symptoms, peer relationships, and her clinical depression. Knowing that a similar surgery could give me my life back, I met with a colorectal surgeon in the Fall to discuss my options and schedule a date. I was able to get through about half of Fall Quarter before having to finish my courses online from home. I had laparoscopic loop ileostomy surgery on the first day of Winter Break, a surgery considered “temporary” due to the possibility of reattachment at a later date, but permanent for me as the damage and scar tissue is too severe for future reversal. It was also a

feasible option for me, as the recovery was about six weeks as opposed to a much longer, more painful recovery period after a colectomy and permanent ostomy surgery.

After six weeks of Winter Break, I was back at school. Now I had added the ostomy to my complicated equation—a physical symbol of the invisible illness. One that can be hidden from view somewhat easily, but serves as a constant visible reminder to me of the storm brewing just a few inches below the surface. It is hard to say if the physical manifestation of my illness puts my mind at ease, or if it merely adds to the confusion and anxiety I associate with my illness. If I am still able to hide my ostomy bag from view, I still benefit from the privilege of appearing able-bodied. With my perpetual awareness of my bag, it is harder to use my mask to shield myself from the chronic nature of my disease and the fact that while my surgery alleviated some symptoms, it did not cure my disease, and with it came a whole new chapter of complications.

Crohn’s Disease has been and will always be my biggest obstacle, but I am immensely grateful for the resources I have access to because of my privilege. I have returned to Camp Oasis as a cabin counselor and have applied to go back this summer. After DePaul, I am planning on getting my Master’s in Social Work in order to become a licensed clinical social worker and work with children suffering from chronic illnesses. I do not take my privilege for granted, and I hope that others do not take their health for granted, because I would not wish the physical and emotional pain of this disease on anyone. I am lucky to “pass” as able-bodied, but my mask can be extremely isolating. The only way I have been able to make peace with my health on some level is to be open about it, and use my privilege to help others that are struggling with IBD.

*April 2018, 21 years old*

### Conclusion

It was an honor to have the opportunity to complete this project. As I reflect on my own story, I feel a sense of closure to some extent on this chapter of my life. Crohn’s Disease has no cure, and I will have it for the rest of my life, but as I look back I feel confident in my ability to push back against the endless complications. As I prepare to enter graduate school, I feel somewhat at peace with my disease, knowing it has prepared me to face anything that comes my way and strengthened my drive for academics, health, and educating others about my illness. On June 24, 2019, one week after I graduate with a B.A. in Psychology from DePaul University, I am having a total colectomy. Although having my colon removed will not cure my disease, it will greatly reduce my risk for developing colorectal cancer, as well as eliminate some of my ongoing symptoms. My ostomy will be made permanent, as I am not eligible for future reattachment due to both the severity of my disease and existing damage after 14 years of disease activity. I’ve known this surgery was necessary for a long time, and I’m grateful that I have a window of time this summer to recover before beginning graduate school in August. I will be attending Loyola University in Chicago to pursue a Master’s of Social Work. I plan to become a Licensed Clinical Social Worker specializing in pediatric chronic illness (unsurprisingly with a focus on IBD) in order to help children and adolescents cope with their illness and learn how to advocate for themselves.

On June 15, 2019, my graduation cap will read “Life Takes Courage, But This Degree Took Guts”—a fitting message as I prepare for surgery and my academic career beyond DePaul. I would like to dedicate this project to my beloved Papa Paul Reibman, who passed away April 30<sup>th</sup>, 2017. Papa Paul attended DePaul for his Bachelor’s degree and later worked with DePaul’s



“Gear Up” program. Papa Paul struggled with illness since childhood, and had a variety of gastrointestinal symptoms that some doctors diagnosed as Ulcerative Colitis, while others believed it to be related to severe Irritable Bowel Syndrome. My grandfather and I had a special bond because of our constant stomach pain and GI symptoms, and I hope he would be proud of the work I’m doing now to help others who struggle with chronic illness.