

Appendix G: Sample SSDI Application

Thanks to Sari Jo Mogol Legge for allowing me to reprint her materials here. Sari was granted SSDI at the application stage, without the need to appeal, and without the assistance of an attorney. I reprint her materials here not so you can copy them, but so you can see the level of graphic detail that is required. Nothing is too personal or too private.

These days, the option of a face-to-face intake interview is limited, if not impossible. Whether you do an online or telephone intake, there won't be much opportunity to provide information beyond what is asked on the application. However, after you apply, there's almost always follow-up paperwork that you will be asked to complete. That is your opportunity to tell your story. Attach extra sheets as needed. Try to paint a realistic picture of what your daily life is like.

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THIS REPORT WAS USED IN THE PREPARATION OF THE FIRST SSA INTERVIEW DONE IN PERSON

My Crohn's disease started near puberty from 1972 onwards. I did not have a diagnosis until age 22. This was sporadic through early teen years and more frequent as I aged. My parents did not take me to the doctor for my condition. In **1983**, I was referred at age 22 to a Gastroenterologist in Brainerd, **Doctor Ronald M. Sorenson MD of Brainerd Medical Center**. Doctor Sorenson ordered several tests including blood labs, Endoscopy, Flex Sigmoidoscopy, and Small Bowl Follow Through with barium, Barium enema and Colonoscopy. The definitive diagnosis was **Crohn's Disease**.

My medications included Sulfasalazine, Azulfadine, Prednisone and occasional pain medications. Prednisone was the only effective thing to combat a flare at first, but I had bad side effects from long term usage. Through out a period from 1983 – 1987, you will see comprehensive hospitalization and clinic records. There are also episodes of Pancreatitis, depression and other auto immune illness conditions associated with Crohn's. My menstruation cycle would coincide with a Crohn's flaring episode with each ovulation.

1987. I was newly 27 years old. I weighed 87 pounds on average. I was hospitalized two weeks out of each month from January to July. **July 5, 1987** I was in St. Joseph's Medical Center in Brainerd. Dr. Sorenson informed me that my colon was destroyed. I was sent to Abbott Northwestern Medical Center on **July 15, 1987** and was operated on **July 17, 1987** by **Doctor Fredric Nemer, MD** a colon rectal specialty surgeon. I was given a total permanent Ileostomy. My appendix, entire large intestine, rectum, anus and 13 inches of Small bowel Terminal Ileum were removed. I was given a stoma for the Ileostomy on my right side.

I remained in good remission and health from 1987 to 1991. Sometime in the late 80's or early 90's I had a hospitalization for Pancreatitis – see records. In **1991** I was turned down for a BCIR continent ostomy operation due to the diagnosed return of Crohn's disease with an SBFT test at St. Joseph's. In **1993**, I gave birth to my son with a trouble free pregnancy but distressed labor of 17 hours. Due to my ostomy, the local OB/GYN preformed a vaginal sectioning which was about 100 stitches inside and out to bring the baby through the birth canal instead of cutting my abdomen area.

In the fall of **1993**, I had breast reduction surgery. My Crohn's condition affected scar tissue build up issues. See records from Dr. Smith of Midsota Plastic Surgeons. I had to go back and have some revision work done on one breast due to adhesions and Keloid scar factors.

I had/have an issue with dehydration due to the ostomy. There have been several hospitalizations or ER visits pertaining to becoming dehydrated from **1990** onwards. My records will indicate an ambulance call to my home in Nisswa sometime in 1993 or 1994 from complete and dangerous dehydration. In hot weather, even with all precautions, there are dangerous issues with hydration maintenance. This is a severe and on going issue in the present day and part of my reason for seeking SSDI qualifications.

1995 I started to have constant fatigue issues. My ostomy waste output became acidic and appliances would not adhere as they had before. My health quality was declining. Various attempts with doctors and medical supply to solve the increasing amount of problems were unsuccessful. This interfered with my job as a cashier at Walmart in Baxter. I was frequently late or sick towards the end of my work for them and they were not good at allowing me bathroom breaks as they had no understanding of my ostomy needs. At the time, I had continuous, acidic and painful water output into the appliance bag. I eventually quit working for Walmart and sought other employment. I went back to part time radio jobs and finally found secure employment at Cragun's Resort. I had no idea that the Crohn's was active again due to the lack of pain. All other symptoms were present and constant up to 1997. My constant appliance failure due to acidic waste was alarming and interrupted all aspects of work and home life. I blamed my fatigue and problems on pushing myself as a single mother with a full time job. This did not account for the bloating and weight gain when everything I ate was either vomited out or turned to water acid through my dying ileostomy stoma. Had I had the typical abdominal pain of years past, I would have sought answers for IBD sooner. I was naïve in thinking it was not Crohn's and was not educated enough at that point to understand that the illness can return after surgical intervention. It was determined that my stoma was no longer functional.

On **April 4, 1997** I had Pancreatitis and was hospitalized.

In **June of 1997** I had surgery for stoma revision at St. Joseph's with general surgeon Doctor Donald Wennberg, MD. It was to be a day surgery. I got abscessed at the surgical wound site and the stoma created by Dr. Wennberg failed. I was in St. Joseph's

for 4-5 days. With infections not responding to medications, and my Ileostomy infected so badly, I was transferred down to **Abbott Northwestern Hospital in Minneapolis** and Doctor Fredric Nemer did an emergency operation which included opening me up fully and removing another large section of diseased Terminal Ileum small bowel resecting back to healthy intestine to form a new ostomy site on the left abdomen side of my body. I now have only 17 feet of working small intestine.

I continue to have annual wellness Ileoscopic exams with Doctor Ronald Sorenson to check for Crohn's activity. It was again discovered in summer of **2002**.

1995-1998 I was treated for various gynecological and menstruation difficulties.

December 30, 1998 I had a partial Hysterectomy for Uterus removal done by **Doctor Stephen Larson, GYN/MD at Fairview Southdale Hospital in Minneapolis**. Doctor Nemer assisted in the surgery due to ostomy issue concerns. I had been diagnosed by Doctor Leland with bleeding into the uterine muscle wall. I had massive adhesions which stuck the uterus to various organs surrounding it and I had fibroids inside of it.

1998-present: I continue to have pain from inner adhesions and vomiting. I have constant fatigue and hydration/nutrition issues since the 1997 operation. I am frequently ill which upsets work situations greatly. *My ability to maintain a full time job that would bring a living wage to contribute to the well being of my family is something I can no longer do with any guarantee of consistent health.* When I work outside the home I seem to catch colds and viruses that others around me have due to the Auto Immune issues associated with Crohn's Disease. My ability to concentrate on several tasks at once has diminished due to interruptions for bathroom visits (3 an hour at times) and always seeking to replenish fluid intake. I can not eat properly in a work setting due to ostomy issues such as frequent bathroom visits after food intake and nausea. If I do not eat, I become dizzy or begin to dehydrate. Office clothing constraining my abdomen is difficult to tolerate during an eight hour work day. If an office is not properly ventilated during extreme heat conditions outdoors, I become very dizzy and have passed out in the work place. If I do not tell an employer that I have needs due to the Ileostomy, I quickly let them down with health problems that develop. If I am forthcoming with health information, I do not get hired. This has been a huge problem since the second surgery with the further loss of small bowel. I have insomnia, which contributes to fatigue if I have to keep to a strict schedule. All I do is sleep on the weekends. I can not care for the family or home when I work outside of it. Part of the reason we closed Europa in 2001, our repair garage is because I was too sick too often to help Peter run the office portion. I stated this during our Chapter 7 hearing so it is on record.

I had sporadic vomiting issues for unknown reasons. This problem increased greatly in **February 2002** and by early June with more testing from Doctor Sorenson, including an SBFT, Endoscopy and Ileoscopic exam concluded that I have a hernia in the small intestine close to the stoma, and **the return of Crohn's Disease** present from the stoma back into the small intestine by 40cm (**nearly two feet**). I am currently on Pentasa at 250mg pills, 9 a day.

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**THIS WAS AN EXTRA ATTACHMENT TO QUESTION E WITHIN PACKET
TO MAIL FOR ROUND TWO OF QUESTIONS THAT FOLLOWED FACE TO
FACE APPLICATION INTERVIEW**

August 21, 2002

Form ADL (Rev. 12/94) ES-80333-02 SSA Questionnaire.

DETAILED ATTACHMENT FROM SARI LEGGE

Question E. "What do you do on a typical day (include household chores, recreational activities, spending time with friends, etc.)? Be specific. Give an hour by hour description of a typical day, if possible.

My typical day is comprised of home based things these days. Usually, I will have gotten to sleep between 3 or 4 am depending on being finished with digestion from the ostomy and being done running to the bathroom to empty the pouch. There are nights when vomiting is a contributing factor to finally being able to lie down and stay in bed. I require some background noise such as a fan or our clock radio features 'nature' sounds in order to fall asleep. Most nights I will take 50-75 mgs of Benadryl to assist my insomnia. If left to sleep, I usually wake at around 6 or 7 to use the bathroom, smoke a cigarette and then go back to the bedroom. I will sleep for an additional 5 hours if I am allowed to depending on the needs of our son, or past work needs or appointment/commitments. Sleep is always something I look forward to but do not do very well. The ostomy seems to have hardwired itself into my subconscious as I wake up with a need to empty it if it has become full. Very seldom do I have an accident in bed from a leaking or blown appliance.

Sexual relations with my husband are catch as catch can in good moments. I do not have pain which prevents sexual intimacy, but if you tried to make love and feel sexual with water pouring out of your body into a little bag ...it is rather hard to be spontaneous. Getting up during sexual intimacy to use the bathroom is also a challenge. My husband is ready for Sainthood for several different reasons. I tell my new ostomates that their sex lives are better after surgery, for the most part that is true, but, for my own circumstance of late with active disease in a short gut, I will say that sex comes with new challenges.

I have to wonder what's in it for my husband, but he seems to love me regardless so, that endears him to my heart every day I wake up to find that we have an excellent marriage and are very much in love with each other.

Since the vomiting incidents have increased in March 2002, I have unfortunately been having some urination leak/urgency issues. Both Dr. Li and Dr. Sorenson feel that this is a result of straining and pressure on the body to vomit. So, there are times when I need to wake up to urinate too. Most of the time, I pee when I am in the bathroom to empty the pouch. In the day, the pressure to urinate is greater than the need to empty the bag of waste from the ostomy.

Once I am awake for the duration of the day, I have a cigarette, use the bathroom, come back to the bedroom, make the bed and then brush my hair and teeth in the upstairs bathroom. I also take my first Pentasa and some vitamins from upstairs. If my son is at home, I check in with him to see to his needs. If he is not home, I check the answering machine and return telephone calls. I will then come to the computer, turn it on and check email. I drink water and then will attend to the bathroom shortly thereafter. I do not handle food well several hours after waking up. If I eat at rising, I usually do end up vomiting.

I go retrieve email from the computer and start to correspond to people from www.ibdsucks.com, or MN (Crohn's and Colitis Foundation of America) or National CCFA messages and duties. I also belong to an IBD Quilt Project organization in which I handle the PR and Marketing as a volunteer person. This is due to my media background and I can be effective for the CCFA, IBDSucks or the Quilt from my home. I make calls as required or not by the emails I receive. I check the IBD Sucks website for "Dear Baggy" my ostomy discussion folder to help other ostomates and IBD patients. This may take the remainder of the day at times until I begin to prepare dinner for my family. I do not get paid for these services as they are all volunteer based or non profit organizations. If I had to leave the house to 'work' for any of these things, I'd let them down greatly.

In the evenings, I try not to get back on the computer after dinner to be on www.ibdsucks.com. This is a patient to patient Crohn's and Colitis website for support that I am known as Dear Baggy on. I am on this website nearly daily as a veteran ostomate voluntarily using my time to help others in the same situation. I used to sign back on the computer onto Sucks nightly, but find that I can not get off the computer with patient needs sometimes taking a few hours to discuss and resolve where ever possible. I have given this duty to others who are on in the evening. We are a global website and usually there is patient help available from another patient. I used to be worried no one else could handle the duties of ostomy help, but over the years, we have quiet a few good veteran patients whom I trust to mind things in the evening.

In the midst of all this, I do varied tasks such as eat something, take meds, clean the house a bit – like dusting or vacuuming if it is needed. I do laundry loads once a week and tend to that. I may, pending on weather go out and water the garden and pull a couple weeds or bring flowers in if there are any suitable. I do garden as my main hobby when the energy is there for me to enjoy. I have a perennial garden which requires little maintenance once established. With all that going on, there are required bathroom breaks, at least 2 an hour to empty the ostomy appliance pouch. I parent my son during all this too. He's a good kid, I am very lucky in that regard but worry about my ability to keep a strong and connected parental eye on him as he approaches his teen years. He is 10 in January of 2003. Auto pilot mode will not suffice in keeping a teen safe and directed from hazards they face. My husband can not be expected to take up all the slack, can he? No, he can not.

What I notice most is that I used to be able to talk on the telephone and correspond with email or do bookwork (family bills) at the same time. I can no longer concentrate on two things at once. I get a little frustrated when I get a phone call that is social in nature when I have things that I must concentrate on to finish or answer back in a timely manner. The telephone seems to put back my timing in accomplishing things. I can do dishes or empty the dishwasher, fold laundry or house

clean while on the phone, but I keep my house pretty orderly and my husband and son also help with the housework – so usually, any business minded thinking or more formal writing in answering letters or tasks can not be done while I am on the phone. Pending on who it is on the phone, I have been known to take the cordless into the bathroom with me. Certain callers, I must by necessity tell them that I will call them right back to excuse myself to the bathroom.

I drink water or tea during the day. Mostly I like water best because it stays down and hydrates me best. Medication schedules are adhered to for the daily instructions even if they are not at the same time each day. I still get them in me properly. I think.

When I prepare a family meal to coordinate with my husband's return from work, we 3 like to sit down together. This is a very important time to us as a family. I pop up at least once a meal to the bathroom. My son, who is healthy, seems to have picked up this habit for some strange reason too. It's a family joke. After any meal, I do not like dishes in the sink or food items not cleaned and put away properly. I will do this either alone or with my husband and son helping out too. I clean the stove and counter tops and wipe up floor spills.

After dinner or any big meal, there are several times an hour bathroom visits. With 17 feet left of my intestine, any meal I eat will immediately push out old food left from earlier meals from the intestine into the pouch. That's the first empty during the meal. Likely 15 minutes later, I will start eliminating the food I just ate minutes earlier. At home, this is not a problem. At work place situations or social situations, this is a little bit of a dance to coordinate eating and bathroom. I used to skip lunches at work places because it is just too hard to continue to press on with any productivity after a full meal is consumed. I will eat smaller snack items if possible. Some work places do not allow this on non-break times, some do. I do not work at a job if there is not water allowed at the work desk I am at. I dehydrate and become quite ill if not allowed water. If I eat small snack items, there are times when I don't have to pop up and down to the bathroom. Sometimes it works, sometimes it doesn't. Dietary changes or adjustments don't matter. One day a food that was thick enough to stay in with out coming right through, will not be successful another time. I never know. There are absolutely foods that I avoid at all costs at home or out of the house.

In the evening at home, I like to watch television. Usually it is the soap operas I have taped earlier in the day. That comes later in the evening when the house is quiet because I will be up and down frequently to stop the tape to go to the bathroom. In the hours when my son and husband are home with me, that time is spent together if possible. We will watch a program, talk, and play with the 2 cats we have or the boys will make model planes in the hobby room Peter has. After 8pm, I really do not like phone calls, but will take them from a patient or friend because that is when they can talk.

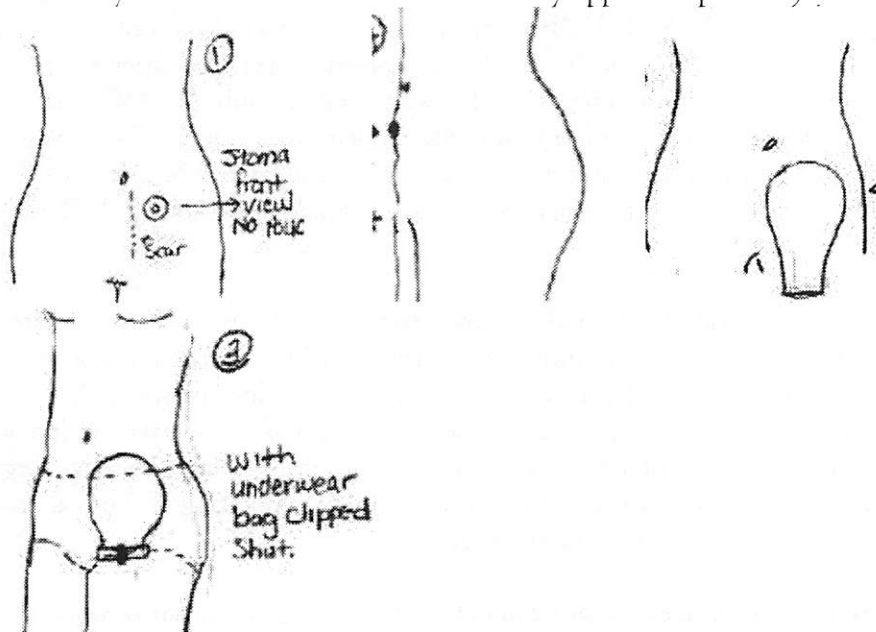
Sometimes, I don't have any mental juice left to talk and I feel guilty, but have learned to let the machine pick up the call. We don't have caller ID or Call Waiting.

On days when I am required to leave the house, I usually try and make the appointment for later in the day. This allows for sleep from the night before to be covered and it also gives me some lead time to make myself ready to leave. The Pentasa and Crohn's itself has been very cruel to my skin. I usually have some form of break out evident on my face or chest. Not only is this painful, but it

takes time with to cover with cosmetics. Showering with an ostomy is not that big a deal, but it does take some time to dry and insure that the seal is still 'watertight' to put clothing on and go out. Clothing is something I really do not like any more. At home, I am 'deconstructed' by wearing loose tee-shirts, no bra or underwear, and I wear boxer shorts that are loose or sweat pants. The bras I wear now will never be considered for Victoria's Secret. I wear a sports type bra with no underwire and can not contend with any clothing item that binds me in the least. When I dress to go out, the minute I hit the door at home, I go and put on my comfort clothing.

In recent months there have been more incidents than I care to recall where I have had to call and cancel or reschedule an outing because of either a rough night or deep fatigue or that I did eat that day and was having runs.

Diarrhea to an ostomate may seem redundant, but I can tell you that it isn't. To a person *with* a colon, the definition of diarrhea is fairly straight forward. This is not the case with a person who has an Ileostomy. A person with a colostomy which is hooked up directly from the colon usually has thicker waste that comes into the appliance from the stoma (intestine that comes to the outside of the body to stick out to frame with an ostomy appliance product) see illustrations:



For an Ileostomate, the stoma is created from the **small intestine**. Without the colon to absorb the water and digestive acids which are made in the stomach and small intestine to distribute food to the body, the Ileostomate always has LOOSE stool. The colonic process of serving as the body's waste plant is not available to the Ileostomy patient. The normal waste consistency from my ostomy may be that of a milk shake. When an Ileostomate gets the runs, the waste into the pouch is much more like acid water. *Much of the time, now, this is what my output consists of.*

An ostomate can not eat roughage without the danger of obstruction in the intestines. We try to balance our food intake to ensure that it is used as nutritional fuel before the body eliminates it. This is where MY case has become very difficult to maintain.

The SHORTER the small intestine is in the body, the faster food I consume runs through my stomach for distribution to the body. I have 17 feet of the normal 21 feet of small gut a healthy adult has to work with. I no longer have a colon. This further speeds up the elimination of waste before my body has gotten any worth from what I eat. Vitamins are not absorbed properly either before they are expelled. Sometimes they are expelled whole as I swallow them unless it is a gel vitamin which has a chance to be used somewhat more effectively.

In 1987, with the first surgery, I lost my entire colon, rectum and anal passage. As well, a foot and a half of small intestine was removed to cut out disease which had begun to attack my small intestine at the Terminal Ileum. My surgeon spliced back to healthy gut to create a stoma that ran back to healthy small intestine. I functioned at a reasonably high rate of lifestyle with little to slow me down for the very first time in my whole life. I actually HAD a life for the first time!

Until 1995.

I began to have acid runs all day and appliances would fall off daily when they are supposed to (and had) lasted 5-7 days for each appliance. I did not realize at that time that Crohn's was again present. I did not realize that it CAN AND DOES come back even after a radical surgery to eradicate it. I had no pain as I did in the years before the first surgery. I had deep fatigue and hydration issues. I passed this off to life as a single mother with a full time job. In 1997 after a botched stoma revision surgery at St. Joseph's Medical Center in Brainerd by Donald Wennberg (see records) I was rushed down to Abbott Northwestern where Surgeon Fredric Nemer (see records) had to cut out several more feet of Ileum and recreate a working stoma to the LEFT side of my body.

Since this time, I have found that daily life is much different from the first surgery which was life giving after nearly a whole life of Crohn's infirmities. Since 1997, my life is vastly different and difficult to maintain any levels of sustained activities and full schedules. Now, in 2002, Dr. Ronald M. Sorenson has found not only a hernia by the stoma, but also of Crohn's flare including the stoma and two more feet directly behind it. This greatly explains the even larger lack of energy and ability to gain nutritional value from the foods I consume. And, the vomiting of foods also is deeply problematic on several medical and emotional levels.

I have had to come to terms with the reality that I can not work at a full time or part time job outside the home where I can not be close to water, toilet, and replacement foods or a bed if I have to lay down. Further, if I throw up or need the bathroom, the only interruption or disappointment to meet deadlines is my own personal problem and not that of a productive work place.

When Peter, my husband and I owned our own family business from 1997-2001, I can tell you with absolute certainty that part of the reason our business ended up failing was that I could not be relied upon to be consistent in keeping that office running to keep Peter's mechanics hands on the job in order to repair vehicles. As I was absent more and more, Peter was interrupted with phone calls and customer billing needs to the point where he could not work on the cars with any speed to get the jobs out in a timely manner. We did not lose our business due to bad work! We lost our business because one man was over-run and over worked in being unable to do it all ALONE. We lost our business August 2001. We filed and were discharged of Chapter 7 bankruptcy (see

records) as of January 8, 2002. Much of this occurred because of my IBD illness becoming unstable.

I have become consistent with daily inconsistencies. I am reliable to let myself down and others around me.

So, now, today, I don't do much in the way that earns our family money, but I do what I can on a volunteer basis for IBD awareness and patient to patient interaction from the safety and convenience of my home. That way I do not let anyone down but myself.

When I have to absolutely make it out of the house to pick up Jake from school or an activity such as Day Camp this summer, there have been several days when I had to call Peter from work at the very last minute before the 6:30 deadline crying because I was too ill to even do that 20 minute task. I have had to interrupt my husband taking him off a repair, away from work and go pick up our son. Thank God the company he works for is sympathetic towards our family and does not penalize Peter at such times. They have participated in CCFA fund raisers. This summer, during an especially hot spell, I was on my way to pick up Jake from Day Camp. It was 5:30pm; the deadline is 6pm to retrieve the kids. Pete's work is between our house and the Day Camp location. The humidity and heat index were quite high and I'd felt sick all day from dehydration despite being in our air conditioned home and drinking fluids with vitamins added. I was driving and started to feel as though I was driving on marshmallows instead of car tires. The car AC was not producing enough cool air. I got scared and made it to the garage, got out of the car, went into the shop, and was feeling faint. I could not spot my husband but spotted his supervisor, Brian. I made my way over to his desk and started to speak to him, but was later told I was deadly white and then fainted in front of the desk.

Fainting was not the best move to make on a dirty and hard cement garage shop floor, but I did it anyhow. I was revived by the mechanics and began to panic as I knew I had to get Jake and did not know the time, nor did I know where my husband was. I was told that Day Care was called, and Peter who was out on a test drive did not go get Jake, but that Jim Pace, the boss went to get our son. Mr. Pace drove me and Jacob back to our home leaving my car parked at the garage lot.

THAT is what my days have become in 2002 with the disease back and active.

Let me tell you that on a good day where I feel energy and health, I try to make the best of the day in some activity like gardening or boating in season or going to a movie, going out to dinner with Peter, maybe a social visit to friends or cleaning house in a burst of frenzy so I can get something, *ANYTHING* accomplished. What usually follows after is deep fatigue and diarrhea again so that I pay for my good day with several bad ones. On Sunday's Peter is home and lets me sleep as late as I need to, sometimes the whole day. It's a great way to spend his only day off. NOT. His taking extra jobs for car repairs in our home garage after he works a 14 hour day is also because of me and my Crohn's becoming no longer manageable.

This is what OUR daily lives are all about.

Your questions to daily living in Question E went on to ask me what was life like BEFORE my "impairment" began and I am here to tell you that there has been no BEFORE in my life. I have

always managed to fake my way through life with Crohn's Disease. Past years, I have managed to do very well. I neglected to add earlier my 1998 partial hysterectomy surgery because of the uterine adhesions (from Auto Immune based IBD) caused. I had organs sticking to intestines and other body organs (see records). Chalk up another loss to Crohn's. These days, as I age, and due to further loss of intestine in 1997 along with the Crohn's Disease returning time and again to what intestine I do have remaining, *I can no longer fake appearing normal and productive in my day to day life.*

If you think that I like it this way and that I enjoy not participating in my son or husband's life at full tilt, you are mistaken. If you think that I enjoy not working at a career I loved dearly, you are mistaken.

If there was *any other* way that I could financially help my family rather than apply for SSA, I would do it.

You wanted a picture of my day to day life, and I have done my level best to give you that picture with honesty and integrity.

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THIS WAS SENT IN THE SECOND ROUND OF QUESTIONS AFTER FIRST INTERVIEW AND WAS MAILED TO THE OUT OF TOWN CASE WORKER DECIDING THE CLAIM

To Whom It May Concern:

I HAVE DONE MY UTMOST TO FILL OUT THESE FORMS AS THEY ARE WRITTEN.

MOST OF THESE FORMS DO NOT FIT WHO I AM IN ANY JOB OR PERSONAL SITUATION.

I HAVE BEEN SICK ON AND OFF SINCE AGE 13-14 (PUBERTY) WITH CROHN'S DISEASE.

IN MY WORKING CAREER BEGUN IN 1979, I HAD PROBLEMS DURING TIMES OF DISEASE FLARE, BUT THERE WAS ALWAYS A DIFFICULTY IN MAINTAINING A BALANCE OF NUTRITION OR MANAGING PERMANENT DIARRHEA UNTIL 1987 WHEN I HAD THE FIRST ILEOSTOMY SURGERY REMOVING SOME SMALL INTESTINE (AT TERMINAL ILEUM), ENTIRE LARGE INTESTINE (COLON), RECTUM AND ANUS.

AFTER THE 1987 OSTOMY SURGERY, NUTRITION AND HYDRATION WAS ALWAYS A CONCERN. BATHROOM BREAKS WERE FREQUENT DUE TO HIGH ILEUM LOOSE STOOL RELEASED INTO THE OSTOMY POUCH WHICH MUST BE EMPTIED OR AN ACCIDENT WILL OCCUR WITH THE POUCH LEAKING OR BURSTING. SOME EMPLOYERS DID NOT RESPECT OR HAVE REGARD FOR NON BREAK TIME BATHROOM NEEDS. SOME EMPLOYERS WOULD NOT ALLOW WATER TO BE PRESENT IN WORK STATION.

IN 1997, AFTER BEING SICK FOR NEARLY TWO YEARS PRIOR, I HAD FURTHER SURGERY TO REMOVE MORE TERMINAL ILEUM SMALL INTESTINE. I NOW HAVE 17 OF THE NORMAL ADULT 21 FEET. THIS MADE PHYSICAL WORK SOMETHING TO PROTECT MYSELF FROM AND MOST EMPLOYERS DO NOT UNDERSTAND BECAUSE MY ILLNESS IS INSIDE, MY OSTOMY BAG DOES NOT SHOW OUTSIDE CLOTHING. I "LOOK" HEALTHY, AS A WOMAN I CAN WEAR FACIAL COSMETICS TO FURTHER "SELL" THE LIE OF HEALTH. SINCE THE 1997 SURGERY, I AM ALWAYS FATIGUED. I HAVE MALNUTRITION ISSUES AND HYDRATION

PROBLEMS DUE TO SHORT INTESTINE AND FOOD DIGESTING AND BEING ELIMINATED TOO QUICKLY AFTER EATING OR DRINKING.

I DO NOT HAVE AN 'AFFLICTION'. I HAVE A CHRONIC DIBILITATING ILLNESS WHICH CONTINUES TO DESTROY REMAINING INTESTINAL FOOTAGE. I HAVE HAD CROHN'S SINCE PUBERTY. *AT AGE 41, I CAN NO LONGER FAKE IT OR MANAGE EVEN PART TIME WORK ON A REGULAR SCHEDULE* OUTSIDE THE HOME. **THE CURRENT SSA DEFINITIONS FOR CROHN'S DISEASE ARE NOT CURRENT WITH LEGAL MEDICAL FACT** AND I FEAR THAT I WILL NOT MEET WRONGLY SET PARAMETERS TO QUALIFY AS DISABLED. THE ILLNESS IS NOT COMMONLY KNOWN AS 'REGIONAL ENTERITIS' AS YOU HAVE IT LISTED IN YOUR RULES. IT HAS NOT BEEN CALLED THAT FOR AT LEAST 30 YEARS.

PLEASE READ ALL SUBMITTED PERSONAL MATERIALS TO PROVE TO YOU THAT I TRULY AM ILL.

I WISH I WAS HEALTHY. I WISH I WAS HEALTHY BECAUSE I HAVE A YOUNG SON I FEEL IS STUCK WITH A MOTHER WHO CAN NOT DO ALL THE THINGS MOST MOMS CAN DO. I HAVE A WONDERFUL HUSBAND WHO WORKS HIMSELF TOO HARD TO MAKE UP FOR MY LACK OF DECENT FINANCIAL CONTRIBUTION. I WOULD WISH FOR HEALTH TO NEVER BE IN A HELPLESS POSITION TO BEG FOR SOMEONE ELSE TO JUDGE ME AS DISABLED. I WISH I WAS NOT DISABLED.

BUT CROHN'S DISEASE *AS IT HAS ATTACKED MY BODY* HAS DIMINISHED **MY** CAPACITY TO BE CONSIDERED ABLE BODIED TO CARRY FORTH A FULL TIME JOB OUTSIDE THE HOME.

Appendix H: Sample Request for SSDI Reconsideration

Thanks to Mary White for allowing me to reprint her request for reconsideration here. In addition to noting the extraordinary level of detail, note, too, that the request is organized to match the listing of impairments for her particular disabilities. In addition, after the detailed explanation of Mary's disabilities, she then addressed her ability (or lack thereof) to work. This is critical – you need to explain not only that you are sick, but that you cannot work at any job in the economy, including a light-duty secretarial position.

Believe it or not, I have taken the liberty of eliminating some of the detail. The actual document is 35 pages long.

Please note that the Social Security Administration has been phasing out the reconsideration step. Instead, you can ask for review by a Federal Reviewing Official. Whether you are writing something to support your initial application or your request for review by a Federal Reviewing Official, this sample is a good indication of how to tell your story and connect it up to what it has meant for your ability to work.

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Social Security Administration
Maryland

**Re: Notice of Disapproved Claim dated October 28, 2004, Claim Number:
12345678**

Dear Sir or Madam:

I am writing this letter to seek reconsideration [or review by a Federal Reviewing Official} of your decision to deny my claim for Social Security disability benefits. Your notice stated that the determination was arrived at based upon the medical records you received along with the forms I completed. Your conclusion was that my condition is not severe enough to prevent me from working. Also, based upon my personal data and description of my past work, you further conclude I am able to do that or other "same type work."

Respectfully, I strongly disagree with your determination. My condition constitutes a severe impairment in that it significantly limits my physical and mental capacity to perform basic work-related functions, as evidenced by the extensive medical care I have received in an attempt to treat the most severe level of Crohn's disease itself, and all of the resulting complications arising from those attempts. As I will demonstrate below, I have a number of impairments that, especially when taken together, are severe. I am unable to work in my former position, or in any position available in the economy, because I spend literally hours every day dealing with ongoing issues related to my colostomy, often involving a form of incontinence. I cannot be in a workplace at all, and

no employer would tolerate the time I would need to deal with the steady stream of uncontrollable fecal matter. Thus, I ask that you reconsider your decision.

What follows is a detailed narrative of the course of my numerous impairments and their effect on me.

My illness requires that I be a full-time patient. For example, during the period covered in my Disability Report, November 26, 2002 through August 26, 2004, I spent a total of 85 days being treated directly in medical facilities:

- Hospitalized 9 times, 8 times being on an emergency basis, for a total of 61 days
- Underwent 3 major abdominal surgeries, 2 being unscheduled
- Underwent the insertion of 6 drains to treat post-op abscesses
- Underwent 2 wound debridements to treat skin infections caused by fecal matter
- Had 17 doctor's visits with 7 different doctors, outside the hospital, throughout this period
- Had 6 diagnostic tests or outpatient procedures, not including those done while in the hospital

It is difficult to imagine any employer being willing to tolerate this many absences. Even working at home did not resolve the problem because clients would not tolerate such delays, either.

In addition, I have been unable to work while having bouts of pain not treated in the hospital, recovering from my many hospital stays and surgeries and while suffering with the debilitating complications from those surgeries. I am still suffering from these complications with no clear remedies in sight. More tests and doctor's appointments are scheduled in January 2005 at the Johns Hopkins Outpatient Center.

Even though the local SSA office is only a few blocks from my home, I was not, and still am not physically able to come in for a face-to-face interview. I did not even have the mental capacity to get beyond the second page of the online form when I started this process more than a year ago, on December 6, 2003. It was very difficult for me to complete the many forms required to file the initial claim although I forced myself to do the best I could, and managed to meet all of your requests and deadlines.

Similarly, it has taken weeks for me to write this letter to submit with my request for reconsideration. I am easily fatigued and find it hard to concentrate, especially when I am in pain and working between episodes of incontinence and the need to maintain my colostomy. This is a good example of why I believe my claim should be granted. I am at a loss to understand how you possibly could deny a disability claim from someone who has been as devastated, physically and mentally, as I have been.

Perhaps this decision was arrived at because you did not receive all of the medical records that support the severity of my condition. While reviewing some of the medical records that I have gathered, I can see how major medical events in a patient's life are

reduced to a paragraph or two in clinical terms, with pain and residual effects being minimized or omitted altogether. Even my own answers were too brief to fully explain my situation in the space provided on the forms. I tried to convey the extent of my disabilities assuming that, for example, constant pain or draining fecal matter is self-explanatory in its severity. The symptoms I face on a daily basis are not normal, healthy occurrences. They are indicators that I cannot function outside my home, or work from my home, due to the need to deal with these issues.

This letter and attachments should prove, beyond a reasonable doubt, that I cannot work. Although I wish I could get back to having a professional life, the daily demands of caring for myself preclude it.

Because I am in such desperate financial need of the disability benefits, I am expending most of the scant energy I have, while in distress, to show you why I am unable to work in any capacity. I hope to make it as easy for you to see how disabled I am as it is for anyone who has experienced my illness along with me over the past two years. I ask you to please appreciate the tremendous effort this is for me by giving your time and attention to the additional information I am presenting. I trust that you will agree that I do indeed qualify as being disabled, according to your criteria, and approve my claim at this time.

I. My History of Crohn's Disease (regional enteritis)

Unlike a lot of unfortunate people, I was quickly and properly diagnosed with Crohn's disease after having persistent abdominal pain for only a few short months in the summer of 1990. I was divorced and living alone at the time in Gaithersburg, Maryland. At age 35, I was at the upper end of the age range when this disease was diagnosed. I'm grateful that I didn't get this disease earlier in my life. However, when I did get sick, my disease was so aggressive that it was easily detected with the first upper GI series I had. There was so much inflammation that lengths of small intestine were seriously constricted and very obviously narrower than the rest of my bowel. I was immediately put on Prednisone and other medications, Azulfidine and 6-MP, used to treat the disease. I blew up on the steroids like a puffer fish, and within a few months, I was hospitalized for 2 weeks for bowel rest due to an obstruction.

A couple of months after that, in late 1990, I developed pain around my hip that soon caused me to limp. My gastroenterologist ("GI") could not locate the source of the pain, yet it persisted. He finally sent me to a rheumatologist in February 1991, thinking it might not be bowel related. After a long examination, the rheumatologist finally found the source of the pain. He left the exam room and came back after a few minutes. He told me I had an abscess and that he had just made arrangements with my GI and the hospital to place a drain in my right side immediately.

It took 2 weeks to get the abscess under control and get the rest of my body ready to undergo surgery. After a 6 hour surgery on February 28, 1991, performed by my excellent surgeon, Dr. Robert Fox, I woke up to pain I didn't know was possible. Pain control continues to be a big challenge for me to the point that I am constantly in pain on

some level. Also, IVs are very difficult to start and maintain in my case, sometimes exacerbated by Prednisone, which is known to constrict blood vessels. These two things become huge issues for me while being treated for this disease and its complications.

When I saw Dr. Fox the morning after my surgery, he said my insides had been a mess. I had multiple fistulas, bowel looped in strange ways, and my appendix was way up high under my rib cage. He had to resect my terminal ileum and remove my cecum, a portion of my ascending colon and some small intestine. A resection of the mid-transverse colon was also necessary. (2/28/91 Dr. Fox operative report). I spent another week in the hospital recovering, another few weeks at home recovering, and was then able to return to work. I had pain in my heels for a few weeks following surgery but that was treated successfully with Naprosin. Aside from chronic diarrhea of the rapid transit variety, I was lucky to have no active disease for the next 11 years.

II. Current Qualifying Conditions

In July of 2002 -- the onset date of my current disability -- the disease became active again. Due to the severe symptoms described below, I have been unable to work with any regularity since that time, and ultimately became unable to work at all.

The SSA's criteria for Crohn's disease provides a number of alternative sets of symptoms, any one of which could form the basis of a finding of disability. Certainly, when taken together, it is clear that I cannot work at all. I will discuss each alternative basis for finding that I meet the criteria as being disabled, although all of my impairments should be viewed together. In general, the SSA criteria for digestive disorders sounds exactly like a description of my disease. Section 5.00 of the Blue Book states as follows:

A. Disorders of the Digestive System which result in a marked impairment usually do so because of interference with nutrition, multiple recurrent inflammatory lesions, or complications of disease, such as fistulae, abscesses, or recurrent obstruction. Such complications usually respond to treatment. These complications must be shown to persist on repeated examinations despite therapy for a reasonable presumption to be made that a marked impairment will last for a continuous period of at least 12 months.

I have included two letters addressed to the SSA from prominent physicians discussing the need to revise the sections regarding regional enteritis and its effects not properly recognized in the current criteria.

As explained in detail below, the complications associated with my Crohn's disease "persist on repeated examinations despite therapy" Thus, I should be found to be disabled.

5.07 Regional enteritis (Demonstrated by operative findings, barium studies, biopsy, or endoscopy). With:

A. Persistent or recurrent intestinal obstruction evidenced by abdominal pain, distention, nausea, and vomiting and accompanied by stenotic areas of small bowel with proximal intestinal dilation

In July 2002, I was sick with vomiting and abdominal pain. My boyfriend at the time and I had both eaten pizza the evening before. He had some mild symptoms the next day and I thought it was the pizza that caused our problems. However, my symptoms of pain, diarrhea and vomiting lasted 4 days while my boyfriend was fine within 24 hours. I didn't think too much of it at the time, but over the next couple of months I had similar episodes and I then began to realize this was the return of active Crohn's disease.

The third serious bout of pain was much more intense. I was on vacation and just a couple of days into a week-long stay at Nag's Head, when I suddenly started vomiting with extreme force and kept doing so until there was nothing left to throw up. I couldn't eat much over the next few days and my abdomen was so swollen and distended that it hurt to the touch. The only time I left the rental house was to be driven to the pharmacy so I could try and find something to relieve the pain, nausea and extreme bloating. Nothing helped. I could barely stand the ride home. The pain was due to an intestinal obstruction.

The episode in Nag's Head started on September 20, 2002 and I did not have relief from these extremely painful obstructions until I underwent a second bowel resection on September 25, 2003. This surgery followed more than 12 months of recurring abdominal pain, distention, nausea and vomiting.

And not just normal vomiting during these many episodes. I was actually vomiting fecal matter because food above the obstruction had nowhere to go but back up and out. Food that was below the obstruction came out as sudden diarrhea. Luckily, my bathroom is so small that I could manage to hover over the toilet while I vomited in either the sink or the tub. This was better than standing up and vomiting into a toilet full of, and splashed with, explosive diarrhea. I had to make it to the bathroom in time to contain the mess, but I didn't always succeed. It was so hard to clean up myself, my clothes, my bedding, my bathroom, and other rooms where I was sick, but I had no choice. When I wasn't in the bathroom, I was in bed or on the couch moaning as waves of extreme pain ebbed and flowed over me every few minutes. During the ebbs, I thought "I can make it this time" but during the flows, I thought "there's no way." I couldn't even keep down anything to help with the pain or nausea. After suffering hours and hours of this torture, I was so weak from pain and dehydration, it was all I could do to pick up the phone and call 911.

On November 29, 2002 at 7am, I was treated for the first time at Frederick Memorial Hospital's ER by ambulance. The x-ray taken in the ER was inconclusive but the abdominal ultrasound showed gall bladder sludge. I was admitted to the Hospital and subsequent radiological testing showed dilation in some areas of my small bowel and inflammation of my colon. I was released several days later on December 2, 2002 with prescriptions for the pain medication Percocet, two types of antibiotics and Bentyl for abdominal pain. (11/29/02 – 12/02/02 hospital reports). Ultimately, I had to undergo a dual colon resection because of recurring obstructions on September 25, 2003.

On March 21, 2003 I was taken by ambulance around 3am after suffering more than a week with increasingly severe abdominal pain that came in waves and caused a burning sensation. I had also been vomiting and having severe diarrhea along with the pain. The radiological testing confirmed the presence of active Crohn's causing a bowel obstruction. (3/21/03 – 3/24/03 hospital reports). I was then placed on a regimen of steroid therapy starting with 60mg per day of Prednisone which was to be aggressively reduced over the next few months. I also had to start wearing diapers for days at a time because of accidents.

These less severe but frequent episodes of pain, while trying to adjust the level of Prednisone, were bad enough to keep me from working but not severe enough to warrant another expensive hospital stay costing well over \$1,000 per day. I had to increase my dosage of Prednisone and take enough Vicodin in order to tolerate the pain just enough to preclude a trip to the emergency room and subsequent hospital admission for several days. (4/28/03, 5/02/03 Dr. Miller progress note). These episodes were not only physically debilitating, but also not being able to work and mounting hospital bills greatly added to my stress and anxiety over having active Crohn's once again. I knew that surgery was in my near future because it was the only effective treatment I had experienced in 1991.

On July 11, 2003, I had a fever and was unable to get relief from the Vicodin during the previous night. I had to have my neighbor drive me to the ER because I could not afford another charge of \$325 for the ambulance. I carried a pink hospital bucket with me and vomited several times while in the car and in triage. The CT scan showed a definite obstruction this time. After the usual course of fluids and bowel rest, I was released on July 13 with Azulfidine and Tums added to my list of medications. Azulfidine is frequently used in treating Crohn's but it would again prove, as in 1990, to have no appreciable success in slowing down the advancing disease. I was later put on another standard Crohn's medication, 6-MP (6-mercaptopurine or purinethol, a chemotherapy drug that suppresses the immune system). As before, I had little hope of this medication helping much.

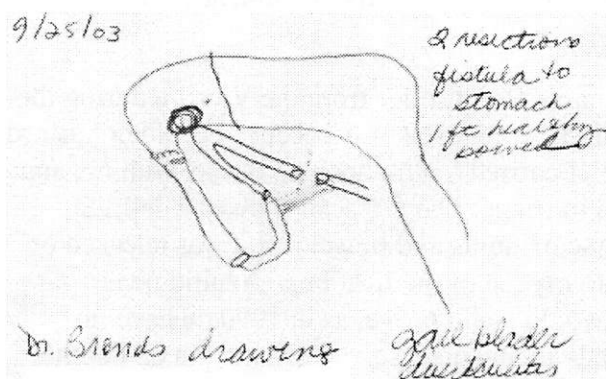
On August 16, 2004, I was again taken by ambulance to the ER a little after 1am complaining of acute abdominal pain. While waiting for treatment, I spent hours on a gurney in the hallway vomiting and having diarrhea without any relief or attention whatsoever. I felt so bad for other patients having to listen to me vomit and constantly moan with pain. This time the vomiting was so severe that I had to endure the horribly uncomfortable and difficult insertion of a nasogastric or NG tube. It took the nurses 3 attempts to get the tube up my nose and down to my stomach, finally listening to my advice of using a pediatric size tube. Even moving from the gurney to get x-rayed and scanned during these many hospital stays is very, very hard to manage while in so much pain. At this time, a surgical consult was necessary and I met Dr. Steven Brand. (8/16/03 – 8/22/03 hospital reports). By the end of this five day stay, I managed to respond to treatment without having to undergo surgery. My insurance coverage would not begin until September 1, 2003 so I was greatly relieved on that particular score, although surgery was inevitable. The obstructions were so frequent now and not

responding to medication. Azulfidine and 6-MP were discontinued, but the Prednisone was not.

I met with Dr. Brand in his office on September 4, 2003 to discuss and schedule surgery. He was not available until October 1, so I was scheduled for that date to have my second bowel resection.

I engaged another gastroenterologist in Frederick, Dr. Tina Sukumar, and saw her for the first time on September 15, 2003. Since surgery was already scheduled and the findings of obstructions due to Crohn's were evident in my hospital records, she saw no need to put me through further diagnostic tests, such as a colonoscopy, prior to the surgery. Dr. Sukumar introduced me to a new medication specifically to treat inflammation of the bowel, Pentasa.

On September 23, 2003, I was back in the ER for the 5th time due to an obstruction. My surgery had been scheduled for October 1, but it became clear that I could not wait that long and was admitted once again. It took 2 days to prepare me for surgery on September 25.



Dr. Brand drew this simple diagram and gave it to my sister to explain what had been done during my operation. The notes were written by my sister. She questioned the gall bladder and diverticulitis.

As with my first surgery in 1991, I actually underwent a dual colon resection. This refers to two sections of colon or small intestine that must be

removed and the bowel on either side of the missing section is sewn together. The drawing attempts to show what Dr. Brand told me and the operative report confirms; there was a segment about 1 foot long of healthy small bowel that could be saved so it was decided to perform the dual resections. The healthy bowel was located between the dense adhesions from my previous resection, on the lower left between my large and small intestine, and diseased bowel that was connected to my stomach by a fistula. It is the segment looping up from the colon on the left side to the area of diseased bowel. The diseased section and fistula were removed, and then the remaining foot of healthy bowel was connected to the remaining intestine. Numerous adhesions and severely inflamed portions of bowel were also removed because they had contributed to the many partial and full obstructions. The pathology reports states that I lost a total 35cm of bowel. My gall bladder was also diseased and contained a polyp, so it, too, was removed at this time.

It is important to note that the operative report describes a bowel leak at one of the resection sites and it was thought to be corrected during the surgery. I was unaware of this fact until I requested Dr. Brand's records for review by my new gastroenterologist at Johns Hopkins Hospital in January 2004.

However, another category of qualifying disability (8.04) was about to begin, as set forth below, in section E.

B. Persistent or recurrent systemic manifestations such as arthritis, iritis, fever, or liver dysfunction, not attributable to other causes

Prior to my phone interview with the SSA on August 27, 2004, the pain in my left shoulder and down my arm had been noticeable but largely masked by the higher level of pain medication I had been on during the months following the corrective bowel surgery and subsequent emergency colostomy on May 26, 2004. The pain increased dramatically as I began to wean myself off the narcotic pain medication. By the end of the first week in September 2004, I had to seek the help of an orthopedist. Not only did I have shooting pains when moving my left arm in almost any way, but there was a kind of burning ache in my shoulder blade, up my neck, in my shoulder and all the way down my arm to my wrist. I wake up with both of my hands aching and it hurts to get them to move.

I was treated for an inflamed rotator cuff and bursitis in my left shoulder with a cortisone shot. This helped with most of the shooting pain, but did not completely alleviate it. I still have to take Vicodin in order to just tolerate the pain from the inflammation enough to type this letter a little at a time. I sometimes have to move my left arm with my right hand as gently as I can to free it up. I will also cradle my left arm with my right when it aches so horribly. Narcotic pain medication usually only helps to take the edge off.

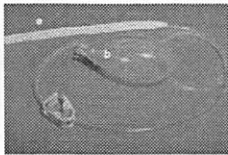
Because I had not been lifting anything heavier than about 3 pounds, and had not been doing much housework or any other type of work and there had been no trauma to my arm, it is fair to assume that the joint pain and inflammation are due to the Crohn's disease, which can cause inflammatory events in joints, as well as other "systemic manifestations." Since I had developed arthritis in my heels following my first bowel resection in 1991, I was not surprised that I had the same type of secondary complication this time although the joint pains are more widespread, severe and persistent.

I have arthritis in my neck, joint pain in the fingers of both hands, both shoulder blades and the bottom of my feet hurt. I can't walk around without cushy shoes or slippers, and can't stand or walk much more than a half hour before I have to get off my feet for a little while. I will also be seeking the help of a Pain Management specialist as well. My inability to walk or stand for a considerable period of time is yet another reason why I cannot work.

C. Intermittent obstruction due to intractable abscess or fistula formation

As set forth above, I have suffered from many intestinal obstructions. In addition, fistulas were found during surgery on September 25, 2003 with one attached to my stomach. It is unclear to me whether the fistulas played a role in the many intestinal obstructions, together with the inflammation, adhesions and other abnormalities caused by the Crohn's disease. In my case, I experienced multiple abscesses and an enterocutaneous fistula *following* the surgery to remove the obstructions and diseased bowel.

On September 30, 2003, 5 days after the major abdominal surgery, detailed above, I was released from the hospital. During the follow-up office visit with my surgeon, Dr. Brand, on October 9, 2003, I complained of pain that was different from any pain I had felt before when I was obstructed. During the evening of October 11, not only was my abdominal pain increasing, my temperature was escalating. My condition continued to get worse throughout the night and when my temperature reached 102 on the morning of October 12, 2003, I called my gastroenterologist. She told me to get to the ER as quickly as possible to undergo a CT scan. The scan showed what appeared to be multiple abscesses, and a CT guided percutaneous drain was immediately inserted. Not only had I been in a great deal of pain due to the abscesses, this procedure was excruciating because an IV could not be started successfully in the ER. Immediately following the drain procedure, I had a PICC line placed in my left arm. Only after this procedure was I able to get pain medication, antibiotics, etc.



Despite being on antibiotics during this long hospitalization, I developed Cellulitis at the drain site 5 days following the drain insertion. On October 17, 2003, I was again taken to the OR, this time it was for debridement of the area and placement of a "Jackson Pratt" drain. A Jackson Pratt Drain or "JP" is also called a bulb drain. The white portion at the end of the tubing is perforated with very small holes and is inserted into the abscess. It is cut-to-fit the size of the abscess cavity. The tubing continues up the tract and outside the body to the bulb. At the incision site, the tubing is attached to the skin with a loose suture or two. The soft bulb is kept squeezed together to create a low level of constant suction. There are measurement lines on the bulb so the amount of drainage can be assessed and a cap on the bulb allows the drainage to be emptied into the toilet or specimen jar as needed.

Besides the JP drain, I now had a fairly narrow but very deep wound about 3.5 inches long on the right side of my abdomen. The disabling effect of the skin conditions that developed as a result of having abscesses and open wounds is discussed in detail in section E, below.

Immediately following my release after the surgery on September 25, I had started using canes that my neighbor loaned me. To help me get in and out of bed or up and down from the couch or chair, I used a four-footed cane because it was stable enough to put most of my weight on it. I used a regular cane to lean on while walking around my house and took it with me to the hospital every time following my initial surgery. In the hospital I also used it to help me get in and out of the bed. I would either hang it on the bed or my IV pump to keep it within easy reach. These canes were invaluable over the months to come as I had to use them in the house and every time I went to the doctor's or hospital.

Recovery from the bowel resection and adjusting to an open wound, with a drain emerging from it, was proving to be extremely slow and difficult. The simple act of sitting up and getting out of bed was a major hardship. I quickly learned to ask nurses in the hospital to tuck my bedding in tightly so I could pull on it to help me sit up. I later asked my sister to do this for me at home. The cane helped once I got to an upright

position and I could lean on it to get out of bed. Every single type of movement involving my abdominal muscles was hindered by pain. My diarrhea continued to be a serious problem and I was now resigned to living in diapers. Night sweats and chills forced me to change my nightclothes and bedding several times each night. It was all so exhausting, debilitating and depressing.

I had ordered a tub chair after my surgery so that I could get in the shower to wash my hair. Now I also depended on it to sit on while letting the water gently wash the packing from my wound until I got used to removing it using saline lying on the bed. Otherwise, I would just sponge bathe the parts I could reach. I had to forego shaving my legs and trimming my toenails for the longest time. Getting proper nutrition in order to heal and get some strength back was a huge challenge. My appetite was suppressed and everything tasted bad. Even water tasted horrible. I was very weak but kept fighting to take care of myself.

Additional disabling fistulas and abscesses are discussed in detail in section F, below.

D. Weight loss as described under 5.08.

Because my intestine had gradually repaired itself over 11 years and was able to absorb B12 again and most other nutrients following the resection in 1991, I did not lose much weight prior to being put on Prednisone in March 2003. Again, I puffed up and even gained some weight. Side effects of steroid therapy cause many difficulties in coping with the disease, such as insomnia, and actually inhibits the body's ability to heal. Being on steroids was a significant factor that delayed further surgery to correct the bowel leak caused by the resection on September 25, 2003. I had abdominal pain every time I tried to reduce my dosage and it took months to finally get off of it completely in February 2004, and get it out of my system. Prednisone was the only medication that may have helped reduce the frequency of the obstructions during the previous year but it causes many other problems as well.

Thus, as my medical records indicate, the Crohn's disease itself has been disabling. In addition, I suffer from numerous disabilities secondary to Crohn's, related to the surgeries described both above and below.

E. Disability due to Cellulitis, Open Wounds, Enterocutaneous Fistula – October 2003 to May 2004

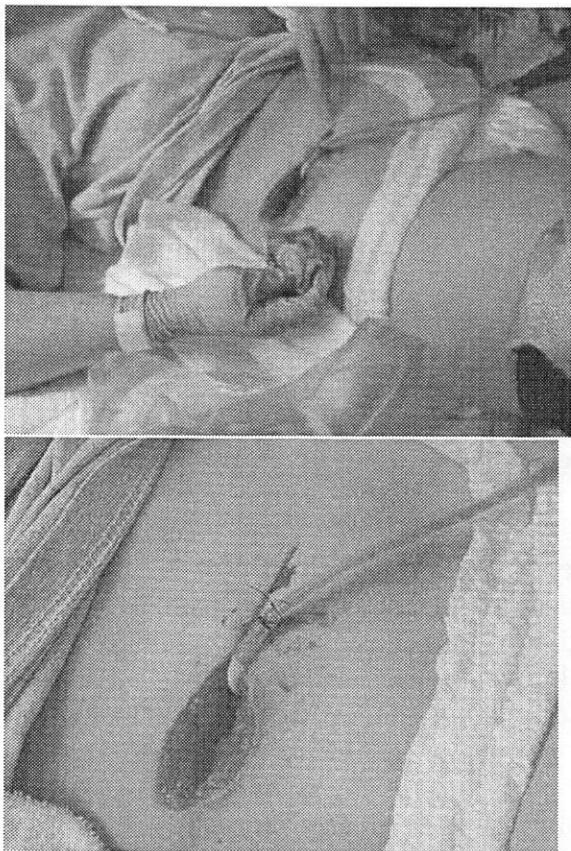
Following my second bowel resection on September 25, 2003, I suffered the debilitating effects of post-op abscesses and the subsequent complications that traumatized my skin. All the procedures to treat the abscess failed, because I actually had a continuing bowel leak, causing me to endure pain and severe limitations each and every day. Thus, at this point, I developed a second impairment described in the following SSA listing of impairments:

8.04 Chronic infections of the skin or mucous membranes, with extensive fungating or extensive ulcerating skin lesions that persist for at least 3 months despite continuing treatment as prescribed.

Not only was I still recovering from major abdominal surgery, I now had to clean, pack and bandage my open wound daily. I also had to track the output of the drain and figure out how to avoid pulling on it so I wouldn't further damage the wound or the skin. The home healthcare nurse reported to the surgeon that my output appeared to be fecal matter. He disputed this declaring it was only pus.

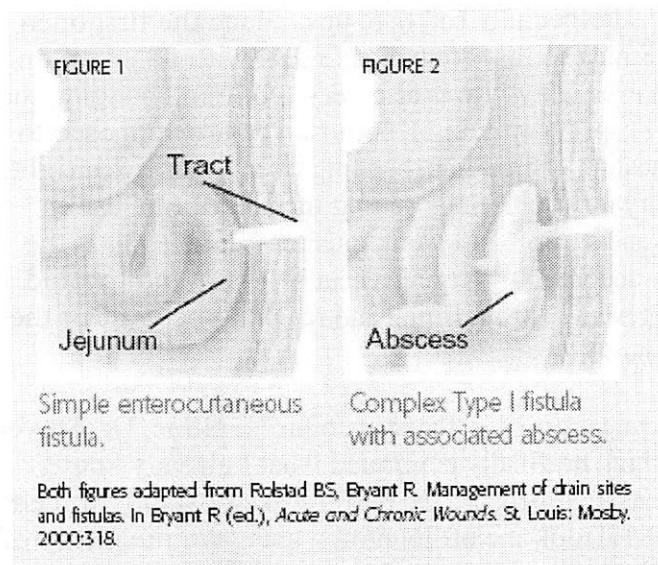
On November 25, 2003, about 6 weeks after the last drain was surgically placed, I developed a low grade fever and had to undergo another drain replacement as an outpatient. A Van Sonnenberg sump catheter was placed by the radiology department at FMH. (11/25/03 drain exchange report). I don't know what the technical difference is because I was only aware of having another Jackson Pratt drain on the outside of my body. See section II.C, above.

Only 5 days later, on November 30, 2003, I was back in the ER with a fever and a large area of tender, red skin around the drain and under the closed wound. The infection had come on suddenly the previous night. Now, it was necessary to have the Cellulitis taken down again and a 4th drain inserted surgically by Dr. Brand. This was another JP drain. This second open wound was much larger because the infected tissue had been about the size of an egg, as he described it. (11/30/03 – 12/03/03 hospital reports).



While still in the hospital following the insertion of this last drain, I became very alarmed when fecal matter gushed out of the open wound around the drain. Tiny plastic sutures were also found in the packing when the nurse changed the bandage. My surgeon dismissed the problem. Because of this and many other difficulties I was having with Dr. Brand, I called Johns Hopkins from my hospital room to make an appointment with their gastroenterology department. The photos above were taken that night because I was very concerned that something was horribly wrong. Note the hospital ID still on my wrist, diapers and the packing in my gloved hand soaked with fecal matter.

Very quickly, the fecal matter began to erode the skin around the wound. Not only is fecal matter draining uncontrollably out of your abdomen really disgusting, but it stings and burns horribly. I had also lost my diseased gall bladder on September 25, 2003, so caustic bile was draining into my intestinal tract at much higher levels. The pain was almost constant, burning under the wound, in the tract and on the skin. As the wound healed, the tract that had been formed by the drains was kept open by the continuous flow of caustic fecal matter. The only way to stop the flow would have been to ingest nothing at all. That would have eventually killed me. My condition was now labeled as an Enterocutaneous Fistula.



The illustration above shows that my fistula was the Complex Type. The photo on the right was taken on January 9, 2004, the day following what was to be my last visit with the surgeon, Dr. Brand. He had put silver nitrate on the wound again to cauterize it. This only further irritated the skin that had been excoriated by the burning fluid draining through the wound. The circular area with the little dark spot is the opening of the fistula tract. The straight scar to the left is from the first open wound of October 17, 2003. The brownish areas are where the silver nitrate stuck to the excoriated skin, burning it further.

Despite my efforts to protect the skin around the wound up to this point and in the months to follow, nothing could adequately heal the skin or treat the pain effectively. I had been taking Questran to help 'bind' the bile and using acid reducers to help ameliorate the burning under the wound, in the tract and on the skin. After losing my gall bladder during the surgery on September 25, 2003, bile is no longer being processed properly and is not being absorbed in the intestine. This continues to burn my skin today.

By now, my tiny makeshift bedroom on the first floor, next to the bathroom, also doubled as a wound care center. I was surrounded by bags filled with bandaging of various types and a host of related supplies. I had to put together a plastic carry-all with dividers and a handle to keep the gauze, syringes and other supplies in that I used on a daily basis, and place it next to me on the bed while I was tending to the draining wound. I would often have to change the bandage 6-8 times a day. It's good that I got to be something of a wound expert because I would have 2 more to deal with in the coming months.

To treat the skin and contain the flow of burning liquid, I tried different types of bandages and bandaging techniques. I tried ointment and creams finally using Balmax on the ulcerated skin more than anything else to provide a protective barrier although it would get washed away fairly quickly. Balmax is used for diaper rash and contains zinc oxide. I even tried cold gel wrap swatches to cool the burning. The gel only irritated the skin further. I had to constantly switch out cold packs every 20 minutes and keep them on the wound to get any relief when I had especially bad flare ups. Since the first open wound I had been using Montgomery Straps so that I only had to deal with adhesive on my skin twice a week or so rather than every day. I was also very gentle in changing the packing over the months, as this can be especially painful, because you are supposed to be tearing off dead tissue to promote healing. Sitting up, bending over, walking upright, reaching and sleeping are also very, very difficult. So is getting in and out of a car or being driven on bumpy roads, starting and stopping. I would push my cane against the floorboards to reduce the jarring to my abdomen. Wearing a seat belt hurt and I would try to cushion my wound. I was also prevented from lifting and reaching because of the pain and risk of further damage to my bowel.

On January 12, 2004, I saw a preeminent gastroenterologist at Johns Hopkins, Dr. Steven Brant. During my extended visit with him, he finally confirmed what I already knew. The fistula was never going to heal on its own because the bowel leak constantly forced caustic fecal matter to drain through it. He took me off Ibuprofen and gave me plenty of Percoset. He also gave me a regimen to slowly reduce the dosage and eventually eliminate the Prednisone completely. I had had abdominal pain each time I tried to decrease the dose 5mg at a time. I had to go down by 2.5 mg then back up if I had pain and so on. It took 5 weeks to taper off the steroids, taking my final dose on February 19, 2004.

Dr. Brant consulted with, and then referred me to a wonderful physician and person, Dr. Susan Gearhart. She wasn't available until February 24, 2004. In the meantime, they had me get a barium enema on the morning of January 23, 2004 to confirm the location of the bowel leak. It was between the large and small intestine. That afternoon and all

evening long, the entire bag of contrast drained through the fistula. It saturated my clothes and all the bandaging material I had with me before I even made it home. I had to repeatedly place the padded area of diapers over the wound to absorb the watery contrast all evening long.

During my first visit with Dr. Gearhart on February 24, 2004, I learned that I could not undergo surgery to mend the bowel leak and take down the fistula until she was confident the steroids were out of my system. She performed a colonoscopy on the morning of March 8, 2004 and I had an MRI later that same afternoon. The MRI showed a 5cm uterine fibroid and several ovarian cysts. I then had to wait until April 13, 2004 to see Dr. Rene Genedry, the gynecologist referred to me by Dr. Gearhart. To learn more about the condition of my reproductive organs, I had a pelvic ultrasound on April 20, 2004, and a mammogram as well. Despite the ultrasound, it was unclear if I needed to have a hysterectomy or any other surgery only he should perform, so I had to wait until the two surgeons could schedule a mutually available surgery date, all while I was still suffering daily from the draining fistula.

After waiting for 8 excruciatingly long months of pain and excoriated skin from the fistula, the corrective surgery was finally scheduled for May 20, 2004. Dr. Genedry was to be the first surgeon to operate if his expertise was needed. Although the fibroid and cysts were verified upon exploration, he decided to leave the organs intact to serve as blocks against future fistulas to other organs, such as my bladder. He also thought it best that I not have to cope, physically and mentally, with a hysterectomy at this time unless it was absolutely necessary.

F. Disability due to Another Post-Op Abscess and Emergency Colostomy – May 2004 to Present.

From this point forward, my condition relates to two impairments listed by the SSA, 5.07(c) (obstructions, fistulas, and abscesses) and 8.04 (chronic skin infections). Because the intestinal and skin issues are inextricably intertwined, I discuss them together here.

Several days after the scheduled surgery on May 20, I developed another abscess and endured the painful insertion of 2 more radiological guided percutaneous drains. Because fecal matter was again draining into the bag, I had to undergo emergency surgery on May 26, 2004. Dr. Gearhart told me I would probably awake with the colostomy. Not only did I awake with a Sigmoid colostomy, but my mid-line incision was a huge open wound. I now had the smaller open wound on my right side that once was the fistula, the colostomy bag on my left side, and there was a huge, bloody, messy gash right down the middle of my abdomen. This new wound started about 2 inches above where my navel used to be and ended about an inch above my pubic hair line. It was the shape of a canoe, tapered at the ends, deeper and wider in between – way over an inch wide and an inch deep.

Controlling my pain and nausea was very difficult. I had to have an NG tube put in while sitting in my hospital bed, a procedure I absolutely hate. I had also been on oxygen the

entire time so my nose and throat were almost as sore as my belly. The two major surgeries, stabilizing me, getting me used to caring for the bag, 2 wounds and eating again took a total of 17 days. Recovering this time was even more difficult and slower than in September.

For the third time, I had to have home nursing care, this time with 2 nurses. On her first visit, the RN saw how much distress I was in and called the surgeon's nurse to get me some relief from the unrelenting nausea. I could not keep anything down. She also suggested I drink Gatorade and Ensure so I could get some hydration and nourishment. I had lost 20 pounds in just a few weeks while in the hospital. I had been on high doses of antibiotics and couldn't even get down the horse pills I was prescribed upon being released. Getting anti-nausea suppositories and Gatorade did help but my appetite was still dangerously low. Nothing appealed and nothing tasted good except for graham crackers. After being home a week I couldn't even bathe myself properly and my hair hadn't been washed in almost a month. I was so weak, fighting pain and very depressed but I had to take care of myself, attend to my ostomy bag and treat my two open wounds twice a day. This all wore me out.

This skin problem started immediately upon using the colostomy bags, because the fecal matter seeps under the seal and erodes the skin. The problem continues to this day, despite trying everything prescribed or found by my own research, to both treat the skin and alter the consistency of the output.

After the last surgery on May 20, 2004, I was left with only 6.2 feet of small intestine after having lost my ileum and cecum in 1991. It is not clear whether I have Short Bowel Syndrome (SBS), but my output is like 'acid water' and excoriates the peristomal skin. I may also have dumping syndrome because waste runs through me very quickly. Even one bite of food can send diarrhea rushing out into the bag.



This photo was taken sometime in late June of 2004. The open wound from the mid-line incision (used a total of 4 times now) is only partially healed. The skin fold is where my navel used to be and the skin around the wound is so drawn up, it has formed two rounded pouches of fatty tissue on either side.

These features make it difficult to get the bag to seal well on that side. The stoma itself is outlined in blue. The red areas outside the stoma are where the skin has been eaten away and the fecal matter sits and burns. You can even see the pink ring where the bag irritated the skin. Although the skin itches a lot, it burns when I scratch it. The smaller open wound from the fistula, on my right side, is not shown here.

For many weeks, the wounds needed cleaning and bandaging twice a day. The visiting nurses, one of whom was an enterostomal therapist or ET nurse, helped me with the wound care and bag changes, but the nurses were only able to come every other day or so for 8 visits. I had to coordinate changing the bag with bathing so I could sit on the tub chair and remove the bag under running water at first. And the amount of bio waste is incredible. I was still a human biohazard as with the fistula. My wound center was now a wound/ostomy care center as well as my bedroom.

On July 12, 2004 I hit bottom even though I had tried really hard to feed and take care of myself. Luckily, my father called and hearing how weak and worn out I was, offered to drive up and take me to the hospital. I hadn't eaten for several days and had nothing to drink that day. The surgeon's nurse arranged for my admission so I didn't have to go through the ER. I was seriously dehydrated and my condition was described as "failure to thrive." I thought for sure I would have to go on Total Parenteral Nutrition (or TPN) in order to survive. They managed to get me hydrated and nourished to the point where my chemistry showed that I didn't absolutely need TPN. I spoke to the specialist and discovered that it would be next to impossible for me to manage the feeding line by myself or even store the bags of nutrition in my home without a second refrigerator. Still, it took 4 days to get me in shape to be back home on my own. The crisis was over, but severe problems remained.

The only support I got was a booklet on how wonderful my life would be following the colostomy. Nothing could be further from the truth for me. Nobody told me it would take 8 solid weeks just to adjust to having a colostomy. It takes a lot of adjusting, physically and mentally, even when things go right. Everything continues to be difficult because of the pain – like sitting up, standing, walking and sleeping. Fecal matter, everywhere but where it should be, and pain continue to dominate every facet of my life.

I had been having severe pain below the stoma, particularly when waste passed through the area. Dr. Gearhart was quickly able to schedule a CT scan and see me on August 20, 2004. The scan revealed inflammation of the bowel in the descending colon. I then resumed my prescription for Pentasa, taking 16 capsules a day. Bowel pain comes on if I miss even one dose.



This photo was taken in mid-November 2004. The open wound is healed, although it's a mess. The stoma is again outlined in blue. The red areas outside the stoma are where the skin continues to be eaten away by the fecal matter or 'acid water' and has not improved over the months, despite all efforts to treat it.

My surgeon and ostomy nurse have suggested many things that have not helped or changed the condition. They are

great and have really tried to help. Even taking 8 Imodium tablets a day has no effect at all. I've tried fiber and even eating 2 big marshmallows before every meal to firm up the stool. Nothing that I have tried or continue to try so far helps. The one thing that was abundantly clear was that I could not be in a workplace with burning lesions like the ones around my stoma and leaking ostomy bags.

With the excoriated skin from the fistula lasting 8 months and the excoriated peristomal skin lasting 7 months through today, I have suffered with this qualifying condition for more than 15 months with no clear remedy in sight, other than more surgery. I am not strong enough to undergo surgery at this time and that is only one factor. There are many others. I anticipate that the next surgery will be in the Spring of 2005 at the very earliest.

G. Ongoing Disability Due to Secondary Complications – May 2004 to Present

Aside from the skin problem caused by this watery, caustic stool is that it eats through the bag seal and leaks out all over my clothes. This happens without notice and not because I don't change the bag often enough or apply it properly. I have had many such accidents often while sitting up and in bed. Being awakened with diarrhea all over my night clothes and bedding is just awful. Making things even worse is the high amount of gas passing into the bag and blowing it up. This sometimes happens so quickly and to such a great extent that when I sit on the toilet to empty the bag, the air pushes the diarrhea out so fast that it goes all over my legs, my clothes and the bathroom floor. I have to strip off my clothes and put them in the bathtub, then get on my hands and knees and clean the toilet and hardwood floor as quickly as possible - while naked. Getting up and down is really hard for me. I then have to hose my clothes off in the bathtub and drape them over the tub chair so they will be dry enough to put in the laundry sack. This has happened 3 times in the two weeks from November 13 - 26, 2004 alone. I am at a loss to understand how anybody could think that an employer would allow me to be in a workplace as long as I have these sorts of problems, nor would it be safe for me to be exposed to more germs when my immune system is compromised, or safe for other employees to be exposed to my fecal matter on a regular basis.

I also have to 'burp' the bag many times a day because it quickly blows up with gas and becomes very uncomfortable, pulling against the skin. It is hard like a baseball and sticks out about 3 inches. I tried vents but they don't work because stool just pops out along with the air. Obviously, the gas is malodorous and I constantly have to use a special air freshener. I cannot do any of this in public.

If I was out and the bag seal broke, diarrhea would pour out all over my clothes. Even if I had a complete change of clothes and all the necessary supplies to put on a new bag, I cannot go through this process in the bathroom. I know some ostomates can do this but I can't. I have to lie down on the bed with a bed protector under me and my supplies right next to me with a little tub of hot water. Mainly this is because it takes me a while to ease the bag off with adhesive remover. My skin is so sensitive that removing the bag can be quite painful. The shape of my stoma is irregular, so I need 'cut to fit' bags. I

have to cut the new bag right before I remove the old bag so the newly cut seal does not get dirty while being handled or stored. Usually I'm lucky and the stoma doesn't spew liquid stool all over me when I change the bag. Once it did this to the extent that I had to make my way into the shower and hose myself and my clothes off, not once but twice during that one bag change. If a bag change goes smoothly, it takes about 20 - 30 minutes, if not, it can take much longer.

These problems are bad enough at home and in private. Aside from the pain, this would be too difficult and embarrassing and, more importantly, unsanitary to deal with in an office or public setting. Not only is it somewhat of a biohazard, it is downright gross and smells really foul. So when I do have to go out, I don't stay out more than an hour or two. I also get fatigued very quickly and suddenly.

III. Effects of Impairments On Ability To Work

A. Self-Employment

As I stated on the Work Activity Report, I have attempted to, but have been unsuccessful in, doing any substantial work on a regular basis since July 2002. Once I got very sick in July 2002, I became unable to complete work in a timely manner in light of the delays due to my illness. Because I have been suddenly hospitalized so many times without being able to give any notice to my clients and have had persistent painful complications, I quickly lost what once was a critical part of my former success: reliability and responsiveness.

A couple of clients wrote me some fairly unkind and threatening emails because I would promise to get work done and was then unable to either do the work or even notify them that I was too sick to work. I couldn't get on the computer or the phone to deal with any work-related issues despite my best intentions. I had been honest about my health, but it was a delicate balance between losing business by explaining the severity of my illness and trying to maintain any business at all, when I so desperately needed the income – any income at all. Although I hoped to make up for some of the time lost, I found that I could not deliver work product because there were too many days I was unable to perform at all for too many months. My most understanding clients had no choice but to seek other firms after waiting months for me to recover. I have yet to recover.

It has been an extremely difficult thing to admit to myself, but the truth is that I am no longer in business, nor am I able to work. I had been so proud to have made it on my own for 10 years, officially, but I have had to accept the reality of my persistent disability.

The only reason my bills are being paid to this point is that I knew early on that I was going to be financially devastated by this illness and I took measures to prepare for the situation the best I could. I managed to sell the condo I owned for twenty years, although I hated to displace my great tenant of seven years. I also refinanced my home mortgage in order to lower my monthly payments. Fortunately, I was able to get these two

processes far enough along to complete them by my 4th hospital stay in August 2003 but not my 3rd in July 2003. I will have to withdraw the remainder of my IRA very soon to make the payments on my many medical bills totaling about \$27,000 so far. At one point I was making monthly payments to 12 different health care providers. My excellent credit has always been precious to me but it is now in danger, too. Despite doing what I could to weather the storm, this storm has not abated and I am living off of unsolicited cash gifts from my father and one of my uncles. This can't go on. Taking charity is so emotionally distressing for me that I can't even allow myself to think about it much. I have always been self-sufficient, independent and taken care of my responsibilities and other people.

B. Work As Accounting Manager

Before starting my own business, I worked as an Accounting Manager. The total number of hours just engaged in work activities for this job was 40 to 60 hours per week. It was more than a full-time job. The time to get bathed, dressed and ready to work as a professional added 5-6 more hours per week. Commuting to and from the workplace involved an additional 9-10 hours a week. The total number of hours required to fill this position near my home was 56 to 76 hours.

As Accounting Manager and Benefits Administrator, I designed and prepared certain daily, weekly, monthly, quarterly and annual financial reports, attended meetings and provided information to management, employees and outside auditors. In effect, I was the Controller for this company. There was no financial position above mine.

The centerpieces of my work as an Accounting Manager, as in any other accounting position, were the ability to perform extremely detailed work, and the ability to meet deadlines. I cannot adequately describe the extreme level of detail and accuracy, as well as creativity, skill and hours of tedious work, it took create the scores of reports and schedules I produced from scratch while in this position and in every other accounting related position I ever held, before or since.

Aside from being accurate and adhering to legal accounting principles and practices, the overriding pressing responsibility of anyone in the accounting field is that all functions be completed on time. Customers, employees, vendors, corporate officers and especially government agencies require timely reporting and payments. Accounting is one of the most intensive deadline-based fields one can work in. Extremely serious consequences result for the company if deadlines are not met.

Attending meetings with the corporate officers and other managers occurred at least weekly. No other person on my staff could take my place at these meetings due to the wide-ranging and confidential information that I alone possessed. Providing information to management and employees on a less formal basis took place throughout the day and the time devoted to this often required that I work uncompensated overtime, when the office was fairly empty, so that I could concentrate on the detailed work I had to constantly complete.

In addition, the job was physically taxing. Each day, of course, was a little different but working in the busy and demanding field of accounting required a great deal of walking and standing to exchange information with people, make copies, supervise my staff in an adjacent office and walk to and from the ladies room. It requires many hours of sitting in front of the computer. I was constantly handling papers, files of all descriptions and weights. Boxes of archived files were in excess of 20 pounds. Bending over and reaching into file cabinets occurred throughout the day.

I also supervised 3 people who performed these assorted tasks: accounts payable, accounts receivable, collection, payroll, contract invoicing, sales tax reporting, etc. I had to constantly make decisions about work assignments, getting the staff level I needed and seeing that they had the equipment and supplies needed to do their jobs efficiently. Not only do you have to teach a staff, personally oversee their activities and be there to answer their questions, you have to discipline and counsel them from time to time. I also provided cost analyses of employees throughout the company to management whenever it was time for downsizing. Making decisions about personnel and having to let people go was the hardest thing I had to do in some respects.

In short, this work was both intellectually and physically demanding. Now, I can concentrate only in short intervals a couple of hours at a time (which is why it took me weeks to prepare this document with a great deal of help from my friend). My illness affects my cognitive ability due to dehydration and poor absorption of key nutrients. One side-effect of my disabilities is that I am unable to pay the necessary attention to detail that was, and would be, a critical element of a job in the accounting field or any other job in the economy.

C. Why it is Impossible for Me to Work in Accounting or any Other Job in the Economy

Because I still have a painful skin lesion around my stoma, and because my colostomy bag leaks so often without warning that I have to change my clothes on a regular basis, it would be unsanitary and impractical for me to be in any workplace. First, it would compromise my health by exposing me to germs or other possible irritants in a workplace. Second, my co-workers could be exposed to my feces. I would need a private place to lie down in order to change my bag and have to empty the bag as often as needed. I know of no workplace that will allow this. Fecal matter is considered a biohazard by OSHA.

Even working from home becomes impossible when spending so much of my time dealing with fecal matter as I have over the past two years. In addition, because of the near constant pain and fatigue, having had high levels of IV narcotic pain medication, anesthesia during many surgeries and procedures, and taking oral narcotic pain medication on a continual basis, I have had a hard time concentrating or remembering what I was about to do. These factors have only compounded the mental capacity difficulties brought on by age. I became 49 years old on December 16, 2004.

Recovering was a lot easier during my first and much shorter episode of active Crohn's when I was 36 years old, in 1991.

In addition, as set forth below, my cognitive abilities are compromised by dehydration and other secondary effects of my disabilities.

Due to the almost constant pain, along with being easily fatigued, I cannot sit up for more than two hours, walk and stand for more than about 20 minutes at a time on good days. When not recovering from surgery or procedures, I still have to rest often in between tasks. Even taking a shower and getting dressed can wear me out and I rest while being driven somewhere by somebody else. Prior to and after my surgery in September 2003, I was often and suddenly very sick for several days and was frequently hospitalized. I was hospitalized for 21 days in 2004 for both surgery and then dehydration.

Everything is different now except for living alone. I lost my health insurance coverage because of my divorce in December 2001. It was impossible for me to get insurance coverage in the private sector when I needed it most. I had to wait until Maryland got its new program up and running to cover those of us not able to otherwise get coverage, mainly because of preexisting conditions and being self-employed, etc. Crohn's was a qualifying condition. I have no family member living closer to me than 45 minutes away. I have no one to help me with anything on a daily basis, other than when I was just out of the hospital following each of the surgeries, including open wounds. Managing my healthcare, taking care of myself and the basic necessities of living is even more than I can handle most of the time.

D. Ability to Perform Normal Daily Functions

Given the high number of days that I have been treated in various medical facilities, the subsequent recovery periods and dealing with the secondary conditions I have stated so far, it is difficult to describe a typical day in my life. The answer I gave on the Function Report form was only applicable to what I was doing at that particular time -- a snapshot. It was a feeble attempt to convey the challenges I have faced over the last 2 years and continue to face today. I was able to lift a gallon of milk that week only.

My use of the word "work" is very misleading. Reading and writing a few emails, paying bills online, ordering supplies, and doing health related research are what I now consider "work" on the computer. Phone calls and paperwork related to medical bills and contacting doctors for any number of reasons is what I consider "work" not done on the computer. Writing this letter is the hardest "work" of all.

On a really good day, I can do some "work" for a couple of hours, rest for several hours, and if I am able to, I will "work" for a little while later in the evening. None of these efforts generate any income.

What I failed to mention on the Function Report is that I usually wake up because of pain, as well as sometimes soiling myself. Prior to my colostomy, I was awakened by

pain in my abdomen, or the draining fistula, and having to get to the bathroom quickly or change my diaper. Now I am awakened by pain in my arm and/or at my colostomy site and have to empty the bag before it gives way. Oral pain medication does not last more than a few hours. I am on no pain medication other than Vicodin and on nothing to fight the joint pain on a continuous basis. I will usually wake up several times a night and often cannot get back to sleep only after having slept less than 2 hours. I can't remember the last time I had a good night's sleep.

My functionality is dictated by the level of pain and fatigue I have each day, depending on what phase I was in during this illness. Acute, chronic, and persistent pain have all applied and still do. I do the best I can in spite of it. It is a part of my life and may always be. Being handicapped in some way runs through all of the days with some level of severity. There are many things I either shouldn't do or can't do at all.

Getting my basic needs met is an ongoing challenge. Managing my healthcare directly and administratively takes a lot of time and effort. Everything connected to food is a major issue; getting it, putting it away, preparing it and cleaning up after a meal. Money issues never stop and neither does the paperwork, dirty dishes or the trash. All of these things take more energy to handle than I usually have.

In addition, due to my illness, I am unable to do house or yard work. I have no choice but to do what I can when I can because there is nobody else to do it. However, everything takes longer and I have to take a break often. Everything that was not at waist level was off limits for weeks at a time. I couldn't bend over, often dropping things that I could not pick up. I finally ordered some pick up sticks. I'm not a fanatic about having my house sparkling clean by any means, but if things get out of hand, I can't function.

Generally, I do not leave the house unless I have to due to the need for medical care or food. Hospitals, doctors' offices, imaging centers, outpatient centers and the 7-11 convenience store at the corner are my usual destinations. When someone else or the grocery service is not delivering food to my house, going to the grocery store, even with somebody, is a treat because I can choose my own food. However, it can only be done with considerable difficulty. I have only visited my sister's home on a few holidays and gone to a restaurant with her if we go to a place that serves us pretty quickly, and if she gets me home immediately after eating.

The stress of all of this has been tremendous. I have very few outlets that I relied on before I became ill. I haven't been able to garden, do home projects or walk very far and I miss all of that. I haven't been out with friends in ages and don't drink anymore. I haven't had any sexual encounter, even a good kiss, in too many months for me to admit and I have had no drive for sex. It has fallen way down the list of things I think about. One thing I really miss is being able to take a bath and relax. It is too hard to get in and out of the tub and I don't yet have a good way of keeping my ostomy bag from getting soaking wet.

The primary reason why it is so difficult to deal with all of the things that are not encountered by healthy people as well as those who are, is the Crohn's itself. My life has been severely altered because my body cannot process food and waste properly. It has leaked onto my office chair, my sofa and my car seat. It has been in a diaper, down my legs, on my clothes and on the floor. My waste ends up being everywhere it shouldn't be; it has been obstructed in my bowel, in my mouth when vomiting, leaking from my bowel through a fistula onto my abdomen or through my stoma into a transparent bag. It has even splashed into my face on rare occasions. I hate it, but it inspires a lot of laughs as well as a lot of tears.

E. The Toll My Disabilities Have Taken on My Loved Ones

The saddest part of all is that I was unable to spend time with my mother during these last two years of her life. I can't make up for losing time spent with her. Ever. Mainly, because I have worked at home for most of the last decade before I was critically ill, I was the one to take care of my mother, rather than my sister. She depended on me to take care of her life for her and I pretty much did.

By the time she had been through independent living, assisted living and finally into the nursing home in 2002, I myself was in need of some rest. She was getting the best care 24/7 and I had also managed to get her on Medicaid. I finally had a little peace of mind. It wasn't very long after she got settled and, in her own way, accepted where she was, when I started getting sick.

My sister and I managed to visit our mother a few times when we could in between my hospital stays before my surgery. I used to call the nursing home from the hospital all the time. Even if I couldn't speak to my mother directly I could check to see how she was doing. When I started having open wounds in the fall of 2003, I dared not go to visit her due to the risk of infection. She had one of her nurses call me in the hospital during my stay in August of 2003. It touched me so greatly that she was that concerned and tracking on the situation. After that, she didn't really remember I was sick at all.

During the whole month of September 2004, my arm hurt so badly that I couldn't do much of anything at all. I finally got a cortisone shot in my shoulder on October 1, and was told on October 3 that my mother had been taken to the hospital with pneumonia. We all knew this was the beginning of the end. Knowing it was now or never, my sister drove me to the hospital and later to the nursing home, when I could manage to leave the house, so we could visit our mother together those few last times. She was being given nothing but comfort care and was no longer recognizing us but we tried to let her know we loved her anyway.

Writing this letter is taking weeks and so much effort, but the only good thing is that having to expend all of my scant energy on it might be staving off some grief. I still have to take care of my mother's final responsibilities and paperwork, including *her* medical bills. It would have been even more difficult if I had gotten sick before she was living in

the nursing home. I am just grateful my mother had the level of care she needed when my sister and I could not take care of her.

My father is 83 years old and lives 45 minutes away from me in Rockville, Maryland. Although it is scary and nerve racking to drive with him, he also came up to take me to Johns Hopkins for testing twice and took care of me the week following my most recent surgery. He's not the greatest nurse but he has been as supportive as any good father could be in all other ways. His financial generosity has saved me and he has been the one to come up and take care of my car so it wouldn't rot in the driveway. My father also came up to take me to the MVA to get my license renewed when I couldn't drive there or stand in line. I know my serious and prolonged illness has been very hard on him and causes him great concern.

There is no way to measure the amount of stress and strain my illness has cost my loved ones. I wish with all my heart that I could say it's all over now and we can all relax, but I can't. More is yet to come.

IV. Conclusion

In sum, my life is dominated by pain, fatigue and feces. I cannot be around a lot of germs with a compromised immune system, less than optimal nutrition and the ulcerated skin around my stoma. I cannot expect an employer to put up with fecal matter leaking into the workplace because I often have sudden colostomy bag leaks, accidents when emptying the bag, and I have to empty it many times a day. If I had to suddenly change the bag, lying down in a private room to do so poses another impossibility in the workplace. Even if I found an employer who would accept all of this, my cognitive abilities are not what they were. I am unable to concentrate for sustained periods of time. I am thoroughly exhausted, often spending more hours resting during the day in between struggling to get simple chores done. In short, I am not competent to perform a job that requires high cognitive ability, memory, and stamina. I also am not competent to perform work that requires sitting up for hours at a time, bending, reaching or lifting – I don't have the energy to stand for very long, and bending and lifting are compromised by the painful ostomy site. My restrictive joint and muscle pains make moving around very slow.

I am an independent person. I had my own business and was proud to be able to maintain it. I would rather work than spend the last several weeks writing this. If I could work, I certainly would. I cannot.

For all of the reasons set forth above, I respectfully request that you reconsider your initial determination and find me to be disabled as defined by the SSA. Thank you.

Sincerely,
Mary Virginia White

Appendix I: Social Security in the Courts

This Appendix will provide summaries of selected court decisions relating to SSI or SSDI that are important for patients with chronic diseases.¹⁰⁴ Primarily, I will be showing how different jurisdictions follow slightly different rules of law. Again, a large number of the cases I summarize involve inflammatory bowel disease (IBD), although many relate to other illnesses, or IBD in conjunction with other illnesses. Substitute the disease mentioned in the case summary with your disease – the law is the same regardless of diagnosis.

The following cases demonstrate how the courts around the country have treated SSDI and SSI cases. In particular, I have tried to provide examples of how the rules differ from one jurisdiction to the next. Some cases that involved a number of issues are cited more than once, for the various points the case illustrates.

1. Chronic Diseases that Remit and Relapse

In *Barnhart v. Walton*, 535 U.S. 212 (2002), the United States Supreme Court considered a claim for SSI. The claimant suffered from schizophrenia and depression. Due to his illness, he lost his job, but had begun to work again (in a different, far less well-paying job) within 12 months of his job loss. The SSA interpreted its definition of “impairment” to require that the impairment “has lasted or can be expected to last for a continuous period of not less than 12 months.” The Court explained that the 12-month phrase relates to the impairment, not to the incapacity to work, although the impairment must be sufficiently severe so as to prevent the claimant from engaging in substantial gainful work. Although one might have a chronic illness like high blood pressure for at least 12 months, it might not render the claimant incapable of gainful employment during that time. Thus, the Court found that the 12-month duration applies both to the impairment and to the inability to work.

Interpreted literally, *Walton* could have harsh results for patients with chronic illnesses. If we cannot qualify for benefits unless we are totally disabled for every day of a 12-month period, most of us will be ineligible for benefits.

Despite *Walton*, courts – especially the Eighth Circuit – seem to understand that chronic diseases are disabling even if they are not acute and active all of the time:

Forehand v. Barnhart, 364 F.3d 984 (8th Cir. 2004) – a claimant with fibromyalgia appealed a denial of benefits. Without discussing or distinguishing *Walton*, the court said that, in deciding whether a person has residual functional capacity sufficient to be able to work, the courts look to whether the claimant has the ability to perform the requisite physical acts day in and day out, in competitive and stressful environments “in which real people work in the real world.” This language would seem to allow for the possibility of providing benefits when the claimant is not disabled for a

¹⁰⁴ The cases discussed here are selected illustrations and are not intended to be exhaustive.