

---

# Cecostomy produces many positive life changes

By: Tara M. Person

For the past 21 years, I have lived my life centered around my bowel incontinence. At a very young age, my mom and I began trying different bowel programs such as suppositories, stool softening drinks, enemas and even a biofeedback evaluation. Enemas were the only thing that did work, but only if we did them religiously. I hated the enemas because of the rush of water going into my system. The enemas hurt so badly that at age 12, I stopped doing them.

From that point on, I became the classic spina bifida teenager. I did not have enough fiber in my diet. I would go one and a half weeks with no bowel movements and then have a huge “explosion.” At first, I thought this was manageable. I had one and a half weeks with no interference and then a few days that I had to isolate myself from everyone. It was a never-ending cycle, which eventually affected every part of my life. I couldn’t go out to eat. I couldn’t do anything active. I also couldn’t be honest with friends when I canceled on them. There are only so many times you can say to friends, “I don’t feel good” before they start to wonder.

I was at SBAA’s 2001 Conference in New Orleans when I had had enough. The spicy food in New Orleans did a number on my system. I was probably sick for 90 percent of that conference. I made the decision to fix this problem. I didn’t want to turn 21 and still be dealing with my bowels.

First, I met with Karen Rauen at the Spina Bifida Clinic. She told me about a surgical procedure called a Continent Cecostomy (ACE Procedure). It sounded perfect for me. Karen explained that my appendix would be attached to my belly button creating a “tunnel” to the outside of my body. A catheter is inserted to give an Antegrade Continent Enema. The enema cleans

out the large intestine (colon) from the top down.

A few months later I came back to the Spina Bifida Clinic to meet with Dr. Balcom. He explained all the risks, all the options, and each step to this procedure. I could really tell that Dr. Balcom loves when he can help one of his patients by doing a surgery like this. That day I went home and scheduled the date for the surgery. From day one I made all the decisions. I was the one who communicated with Dr. Balcom and his nurse, Rick. I wanted this to be a surgery that was done for me and not to me.

During the months leading up to the surgery, I was very excited. As the date got closer I became more scared than excited. Dr. Balcom and his office staff were very helpful. Rick answered the smallest and biggest of my questions. During the week before my surgery I probably talked to Rick everyday. He made me feel very comfortable with having surgery.

The day before surgery I had to do a complete cleanout. This was the worst part of the whole procedure. I started the cleanout at home. I had to drink Magnesium Citrate. On the bottle it says, “A Sparkling Laxative”. Believe me, there is nothing sparkling about it. The cleanout at home wasn’t working so I checked into St. Joseph’s Hospital. I had an NG tube put in to feed the Go Litely into my system. Go Litely is stronger than Magnesium Citrate. I heard from Susan Andrasko, a young adult with spina bifida, who had the cecostomy done a few years ago, that Go Litely tastes like cement, which is why I wanted to use the NG tube.

The next day was the day of surgery. I was really scared. I was very surprised to see Dr. Balcom stop by my room prior to surgery. He wanted to make sure I was okay. That meant the world to me. I went into surgery

around 1 pm and was out by 7 pm. I remember being in the Holding Area, before surgery, watching all the nurses in the room. I was given something to relax me, which I really needed.

The next thing I remember is being in the recovery room, after surgery. I remember telling myself to stay awake in case Dr. Balcom came into the room. A few minutes later, he did. He told me that the surgery went great. He was able to do it laproscopically and there were not any complications. Before he left he asked if there was anything else that he could do for me. I asked him for some ice chips. I wanted to see if he would take care of Tara, the person and not just Tara, the patient. He fed me ice chips! I was very impressed.

I was in the hospital for three days—one for pre op, one for the surgery and one for post op. I hated not being able to do things by myself so I wanted to go home as soon as possible. I believe I was able to go home so soon because I was determined and motivated throughout this process to take control of my life and my bowels. Post op has consisted of a lot of rest, taking off work, a few doctors appointments and training my system to work in the opposite way it has for the past 21 years.

Currently, I am still training my system, which can be frustrating. I realize how I need to change my diet. Without fiber all the bowel programs in the world won’t work. Everything has healed and my tube has been removed. I do an Antegrade Enema every other day, by feeding a catheter into my belly button and then attaching it to the enema tube.

There are countless reasons why I am so happy with my cecostomy. On the outside I don’t look any different because the hole is hidden inside my belly button. The horrible rush of

*(Continued on page 11)*

## Gifts from our friends

A sincere thank you is extended to the following organizations and individuals for continued support of SBAWI.

### In honor of Dick Roskopf on his 60th Birthday

Ken and Cookie Helman  
Allan and Toni Frantl

### In honor of Carla Frantl on her 36th Birthday

Ken and Cookie Helman

### In honor of Susie Horter on her 35th Birthday

Ken and Cookie Helman

### In Memory of Kevin Helman

Allan and Toni Frantl  
Ken and Cookie Helman

### In Memory of Mary Ann Potts

Lt. Col Jim Dollar and Mrs. Jane Dollar  
Sheldon Russell

### In Memory of Matthew Moersch

Marilyn and Dick Krouse

## Scholarship recipient extends appreciation

I would like to take this opportunity to thank the Board of directors and the family of Mary Ann Potts for the Mary Ann Potts Educational Scholarship for the 2001-2002 school year.

I appreciate the financial assistance as I work to achieve my goal to obtain a degree in radio/television/film with a minor in journalism. I am hoping to work in the public relations field someday.

I really enjoyed this semester. I completed the last math class and the only speech class I will ever have to take, as well as, two classes which are core courses in my minor. I am looking forward to next semester.

Sincerely,

Tara M. Person

(Continued from page 8)

## Cecostomy produces many positive life changes

water that came with an "old fashion" enema has been eliminated. The cramping with an antegrade enema is minimal with great results.

I realize how important communication with my doctors is. Each one has played an important role in my life. Dr. Dunn has saved my life when I needed my shunt

replaced. Dr. Tometz has made sure my gate stays nice and there aren't any problems with my legs and feet. Dr. Balcom, on the other hand, has given me something no one else has ever given me — my life back. Finally, I am able to go out with friends and not worry about my bowels. A part of me still does worry because that's what I have done for

so many years. It has been challenging to break myself of that habit.

If I could turn back the clocks, I would get the cecostomy again in a heartbeat. This surgery is ideal for someone with spina bifida who wants to be more independent. It is one of the best decisions I have ever made.

## Variety of sports events will keep participants active

For these and other opportunities, please contact Kathy Mohar at IndependenceFirst (414-225-2918).

**Youth and Adult Water Skiing** is for people 6 years of age and older with a need for adventure. Limited to eight participants so sign up early.

Where: Oaukachee Lake.

When: Wednesday, August 14, 2002.

Time: Call to schedule a time between 1 and 6:00 pm.

Cost: \$5.



Other opportunities available through IndependenceFirst this summer and fall include:

- Softball June – August
- Street Hockey June – July
- Tennis June – August
- Volleyball June – August
- Basketball September – March