

Published in the Asbury Park Press 8/10/03

By CAROL GORGA WILLIAMS
COASTAL MONMOUTH BUREAU
LONG BRANCH –

Connie Haber is not ordinarily a risk-taker, but she is gambling that a trip to Germany can give her back her life. Haber, of the Elberon section, is scheduled to have surgery today for the removal of a painful type of scar tissue, commonly called an adhesion. She has to travel to Seligenstadt, Germany, because the procedure she wants is not performed in the United States. "Many people don't have options," said Haber, describing a community of fellow adhesion patients she has met through her research. "Once we're educated, we can make the best decision we can."

Adhesions are bands of tissue -- which form commonly after trauma such as surgery or infection -- that connect organs that usually exist separately in the abdominal cavity. When adhesions connect organs, they can cause chronic pain, infertility or bowel obstructions, experts say. Adhesions can pull an organ out of shape to "tether" it to another organ or the abdominal cavity, according to the American Adhesions Support Group. Once the adhesions are removed, they tend to recur, sometimes only weeks later. "I have abdominal discomfort. I have fatigue. My belly feels like it is being punched from the inside," Haber said last month during an interview at her home. "It is just a magnitude: one problem after another."

For Haber, who rarely had health problems in the past, gastric-bypass surgery started the cycle in November 2000. A year later, she began to feel the stabbing and pinching pain that characterizes adhesions, she said. In June 2002, she had to have additional surgery for a bowel obstruction. That is when she learned there was a name for her symptoms: Adhesions Related Disorder.

In January, she had her third surgery. "I've been diagnosed with this for a year," Haber said. "I've had two bowel obstructions, and I'm not waiting for a third. I'm going to Germany to seek treatment, so I can be a wife and mother again." While the cost can be daunting -- about \$10,000 by Haber's estimate -- it is worth every penny to her to be without pain. Insurance probably won't pay for it, but Haber intends to submit her bills and see what happens. She wishes she didn't have to leave the country for help. "I'm so angry," she said. "Maybe they'll do something here, so people don't have to go to Germany." Her main reason for coming forward is to educate others about their options, she said. "I'm a modest, humble, private person," she said. "But I want to make a difference in someone else's life." Haber doesn't want to be defined by her illness. The mother of five fought back by working toward greater recognition of ARD. Through her work, New Jersey has become the fourth state to recognize ARD -- after Wisconsin, New York and Louisiana, according to Anthea Nesbitt of the American Adhesions Support Group, a branch of the Australian Adhesions Support Group Inc. The group runs www.bombobeach.com, an electronic information and support forum. Although Haber already was in Europe when the resolution designating Sept. 25 as Adhesion Related Disorder Awareness Day came through sponsor Sen. Joseph A. Palaia, R-Monmouth, it is no less an achievement, Nesbitt said. "Bless her heart," Nesbitt said of Haber. "We just have to hope and pray" that Haber's surgery is as successful.

Haber's surgery will be performed by Dr. Daniel Kruschinski who will use a specially designed scope to lift the abdominal wall. Once inside, he will cut the adhesions and apply a barrier called SprayGel, which is not yet available in this country, Nesbitt said. Another adhesion barrier, Intergel, was voluntarily pulled from the market after patients complained of pain and inflammation.

There are other adhesion barriers approved for use in the United States, but Kruschinski does not favor them because they are liquid and can slide off the organs, he said.

Dr. John Davis, a surgeon at Jersey Shore University Medical Center, Neptune, said physicians have been concerned about adhesions "forever," and a topical agent like SprayGel needs to be subjected to rigorous testing before it is allowed in this country. "The theoretical value of an adhesion preventee is a good one," Davis said. But there is a "but."

"The agents that are used to block adhesion formation are going to impair the host in many ways," Davis said. "Scarring is the normal process for healing a wound. If you impair that, it sets up a dangerous situation." Kruschinski, director of the Institute for Endoscopic Gynaecology, said he has pioneered the use of gasless laparoscopy because the carbon dioxide commonly used in such procedures creates an acidic environment that can lead

to the formation of adhesions. Adhesions result from inflammation, including endometriosis, chemotherapy and pelvic inflammatory disease. In surgery, everything from blood, talc from gloves, lint from sponges and stitches can cause enough irritation for scar tissue to form, according to the American Adhesions Support Group. More than 300,000 people a year are hospitalized for treatment of adhesions, according to the group.

About 500,000 surgical procedures are performed annually to remove adhesions, which start to form within three hours of surgery and will stop forming when the surgical site heals, experts say on the adhesions Web site. Of the 2,500 or so adhesion-removal procedures Kruschinski has performed, he says he has a 95 percent success rate in terms of patients not suffering from a recurrence of their adhesions. Ten percent of his patients, however, complain of pain even when they have no adhesions. "That might be related to another issue -- such as an infection," he said.

So far, 30 Americans have had the procedure in his facility in Germany. Another seven Canadians and seven people from the United Kingdom also have been patients, he said. When Haber visualizes the adhesions, she thinks of a growing cancer, and she just wants to be free. "The pulling, stabbing, twisting feeling is a reminder something is not right with your system," she said. "I'm very fortunate that I'm catching this before another recurrence and emergency surgery in the middle of the night. I'm so lucky I'm not as bad as some other people."

Haber, 44, said she wishes she had educated herself about surgery before she found herself on the operating-room table. "I'm lucky that I have my family to support me, my friends who listen to me," she said. "I wouldn't be able to do this without my family and friends and my husband to lean on. I'm trying to do what I can for my family. I want to be pain-free and adhesion-free, so I can start moving on with my life without the feeling that something is growing and strangling my insides."

Carol Gorga Williams: 732-643-4202 or carolg@app.com