

**BERRIEN COUNTY CANCER SERVICE**

**7301 RED ARROW HWY.**

**STEVENSVILLE, MI 49127**



**OSTOMY  
NEWSLETTER**

*July - August 2009*



what matters.™

## **CELEBRITY OSTOMATES**

**Via: Sherman Area Ostoline**

My curiosity has always been aroused by the fact that the necessity for ostomy surgery is no respecter of position or lifestyle. Because we know that this surgery is more common than most would believe, there are probably many people in the public eye who are ostomates. Like many of us, they want to keep this information private and we respect this desire. However, some mention does come to light from time to time and knowing these people have lived active lives of great accomplishment, can serve as an inspiration to all of us. Among those we could mention in the past were: former Vice President Hubert Humphrey and President Dwight Eisenhower. The late Queen Mother Elizabeth of Great Britain who was over 100 years old before passing away and the late Moshe Dayan, former Defense Minister of Israel. Rolf Bernischke, ex-kicker for the San Diego Chargers has an ileostomy. So does senior PGA Golfer Al Geiberger. You may never be a queen, king, President of the United States, or a top athlete, but whatever you do, you can see that your ostomy should not keep you from trying.

## **SOME OF THE BEST BASIC OSTOMY HINTS**

**via: The Right Connection, San Diego**

Don't believe as if having an ostomy makes you less of a person or some freak of nature. There are lots of us and most of us are glad to be alive. Build a support system of people to answer questions when you have a problem. Consider our ETs and your officers who are listed in this newsletter. Don't play the dangerous game of making your appliance fail by over taping or putting off a change. There aren't any prizes given for the longest wear time except accidents. Don't wait until you see the bottom of your supply box before ordering more. Always count on delays in shipping, holidays, etc. when calculating what is needed. Zip-lock sandwich bags are useful and odor-proof for disposal of used ostomy pouches. Don't get hung up on odors. There are some great sprays and some internal deodorants...Remember— everybody creates some odors in the bathroom. Don't feel you are an exception. Hydration and electrolyte balance is of vital importance. Be sure to drink enough fluids to maintain good hydration, ileostomates especially. Read and learn all you can about ostomies. You never know when you may find an opportunity to educate someone about the life-saving surgery that has extended so many lives. Learn to be matter of fact about this and never embarrassed. Few folks get out of this life without some medical problems and unpleasant situations with which to cope. You may be amazed at how people will admire your adaptability and courage. In the beginning after surgery, almost everyone experiences some depression. If you fit into this category, you are certainly not alone. But it need not be a lasting condition. Try something as simple as walking...long walks. If the depression seems to linger, don't be afraid or ashamed to seek help. There is help out there! The bottom line is— We are alive! In other times, in other countries, we might not be. Medicine and techniques today have given us an opportunity to experience this second chance. It is certainly an opportunity worth accepting and exploring. The most important part of you as a human being has not changed.

**Rolf Benirschke** was taken as the second-to-last pick in the 1977 NFL draft, few people could have imagined the football career that would unfold. He became the placekicker for the San Diego Chargers for the next 10 years and set 16 team records before retiring as the third-most accurate kicker in NFL history. But what makes Rolf's career so remarkable is that he played while battling ulcerative colitis and after undergoing ostomy surgery midway through his third season. In 1979 he collapsed on the team plane on a flight home and required emergency surgery that removed most of his large intestine and left him wearing two ostomy appliances. As he wrote in his autobiography, *Alive & Kicking* (1996), Rolf found strength in his faith, the love of family, friends, and teammates, and the support of his doctors and nurses. Rolf amazingly returned to professional football the following season healthier and stronger than ever. Benirschke received such honors as "Comeback Player of the Year," the Philadelphia Sportswriters Association's "Most Courageous Athlete," the NFL Players Association's "Hero of the Year" and the NFL "Justice Byron 'Whizzer' White Award."

**Mary Ann Mobley** is a Miss America, a humanitarian, a motivational speaker, a documentary film maker, an award-winning actress, best friend to her husband and a proud mom. Mobley held her own starring opposite Elvis Presley and held her breath when shot at by Guerilla forces in Mozambique. "I was diagnosed in my early 20's, during a magical time in my career - I felt like the sky was the limit. I began experiencing fever, chills, diarrhea and excruciating abdominal pain. After many tests, the doctors finally determined that I had Crohn's disease. Because in the first stages of my illness about an hour after I would eat, I would have intense intestinal pain. Uh, that's rather embarrassing when you're dating someone. Most people who suffer from these diseases have to also deal, until they get some kind of guidance, with their guilt. It's either the guilt as a mother, that you don't feel like getting up and being with your children, taking them to the park, reading to them, playing with them. Guilt over that maybe you're not fulfilling all of your obligations as you should as a wife. Or as a friend. There is a lot of guilt involved. And I think that your friends and your family and your children have to understand."

**The Ostomy Support Group will meet with the Cancer Support Group at BCCS on July 21<sup>st</sup> and August 18<sup>th</sup>.**

**Dwight D. Eisenhower** (1890-1969) the 34th President of the United States. Bringing to the Presidency his prestige as commanding general of the victorious forces in Europe during World War II, Eisenhower obtained a truce in Korea and worked incessantly during his two terms to ease the tensions of the Cold War. On June 8, 1956 Eisenhower developed vague, ill-defined discomfort in the lower abdomen at 12:30 am. His physician arrived at the White House 30 minutes later and found moderate distention and tympany, but no particular point of abdominal tenderness. The President slept fitfully for the next few hours. Tap water enemas in the morning gave no relief. The pain became colicky and centered on the umbilicus and right lower quadrant. Without surgery, Eisenhower's bowel obstruction could easily have killed him. Even so, the decision to operate was contentious. Eisenhower had had a serious heart attack just nine months earlier, and this made surgery risky. As you might expect, it is difficult to decide to operate on the President of the United States when he might not survive the operation. At operation, the terminal 30 to 40 cm of the ileum had the typical appearance of chronic "dry" Crohn's Disease. An ileotransverse colostomy (internal ostomy) was performed, bypassing the obstruction. The post-operative course was smooth as well. He began conducting official business on the fifth post-operative day.

**Theoren Fleury** was picked 188th in the 1987 National Hockey League draft. In the 1998-99 season, he scored 53 assists, the sixth highest number of assists in the league. He placed seventh in the league for goals and points, with 40 and 93, respectively. He was acquired as a free agent by the Rangers in July, 1999. At 5 foot 6 inches tall, he has become a role model for hockey players under 6 feet tall (considered to be the standard size for the NHL). Theo is known for his fierceness on the ice, and his determination.

Diagnosed with Crohn's Disease in 1996, he has been determined not to let the disease rule his life. Theo Fleury said: "When you live in a hotel and travel from place to place keeping a close eye on what you eat and always remembering to take your medication is a hard task. But Crohn's Disease is something that I have come to terms with and have adjusted my lifestyle accordingly."

**Carrie Grant** is known to millions as the flamboyantly dressed teacher who coached the Fame Academy students' singing voices. But behind her smiles and words of encouragement, the 38-year-old has a debilitating disease. For the last 20 years, she has battled against Crohn's disease - a potentially life-threatening bowel condition that has seen her undergo regular operations, left her unable to eat for weeks and means she is in almost constant pain. Despite all this she remains philosophical: "Having Crohn's has made me a more thoughtful and considerate person, and I am grateful for every day when I'm not in too much pain." Carrie is married to David Grant, 47, who is also a singing coach on Fame Academy. The couple have two children, Olivia, eight, and Talia, one. "My Crohn's improved with each pregnancy," Carrie says, "but no one knows why - I was even able to eat chocolate for the first time in years, which was wonderful!" "I've since managed my Crohn's by diet and painkillers. I still have colonoscopies and, when I'm in really bad pain, revert to my liquid diet for weeks on end." Carrie laughs at the idea that David Blaine is going without food for 44 days: "At the time of Fame Academy, my bowel condition flared up and I had to survive on four pints of a special vitamin drink a day. I didn't eat for 90 days!"

**Marvin Bush** son of former president George W. Bush was born in 1956 in the oil boomtown of Midland. Marvin worked primarily in mergers and acquisitions and investment management. In 1985, Bush's life changed forever. At odd times, he found himself doubled over in pain; blood began appearing in the toilet. An active 29-year-old, by then married to college sweetheart Margaret Conway Moister, Marvin thought the pain might be an ulcer, or even hemorrhoids. It turned out to be ulcerative colitis. Almost a quarter of a million Americans suffer from the disease, and for 25 percent of them, the only remedy is major surgery. Bush was part of that 25 percent. Telling his mother he would be home the next day, Bush checked into Georgetown University Hospital and didn't emerge for five weeks. His entire large intestine was removed, and he now wears an external ostomy pouch, which collects waste and fits under his trousers. In 1991, the CCFA named Marvin Bush as its spokesman, hoping he could use his natural speaking ability and his family's public profile to raise awareness of the disease and, perhaps more important, give it a public face. "Walking around with a pouch around your waist is not an easy thing to talk about," says Marvin. "And yet, when you think about this insidious disease that really robs a lot of people of their pride, it really was not that challenging to visit hospitals or see kids or call as many people as I can. In a way, it's been part of the healing process for me."

**According to medical records**, former President John F. Kennedy was in far greater pain and taking many more medications during his presidency than previously known. Kennedy was sick from age 13 on. In 1930, when he was 13, he developed abdominal pain. By 1934 he was sent to the Mayo Clinic where they diagnosed colitis or it was called colitis. By 1940 his back started hurting him, by 1944 he had his first back operation, by 1947 he was officially diagnosed as having Addison's Disease. And he was basically sick from then on through the rest of his life. He had two back operations, in '54 and '55, which failed. And he needed chronic pain medication from '55 through his White House years, until he died in Dallas. He was never healthy. I mean, the image you get of vigor and progressive health wasn't true. He was playing through pain most of the presidency. By the time he was president, he was on ten, 12 medications a day. He was on antispasmodics for his bowel, paregoric, lamodal transatine, he was on muscle relaxants, Phenobarbital, Librium, Meproboamate, he was on pain medications, Codeine, Demerol, Methadone, he was on oral cortisone; he was on injected cortisone, he was on testosterone, he was on Nembutal for sleep. And on top of that he was getting injected sometimes six times a day, six places on his back, by the White House physician, with Novocain, Procaine, just to enable him to face the day. He had compression fractures in his low back, he had osteoporosis. He had a lot of surgery. In 1954, they put a plate in because the pain was so bad he needed, or they felt he needed to have his spine stabilized. It got infected in '55, they took the plate out. By the late '50s there were periods had he couldn't put his own shoes on because he couldn't bend forward.

**Anastacia** is a rare talent. She is a songwriter, a singer and a dancer. Born in Chicago, raised in New York City, Anastacia came from an entertainment-oriented family: her father was a singer, her mother an actress in musical theater on Broadway. She was diagnosed with Crohn's disease at age 13. "I have a big scar on my stomach and would never hide it" - Anastacia said. "For those with Crohn's, holding in our emotions fuels the symptoms. What is seen as a curse for some, is a gift for me, because it has helped me to discover who I really am as a person. The disease has given me a clear window to my own emotions, which causes me to live each moment and to understand exactly how I'm behaving in a particular situation. Crohn's can be debilitating, but I am lucky to be in the two to three per cent of sufferers who are relatively healthy. I think I got it so young that I incorporated it into my way of living, enabling me to become stronger."

BERRIEN COUNTY CANCER SERVICE  
7301 Red Arrow Highway – Stevensville MI 49127  
Stevensville: (269) 429-3281 Niles: (269) 683-7460

OUR MISSION: To provide free skilled home nursing services, equipment, information and supplies at cost for cancer patients and their families in Berrien County.  
FOR YOUR INFORMATION: at BCCS, we accept donations of ostomy supplies. We would be happy to give these supplies to anyone who can use them. Please have your supply numbers ready and call our Stevensville office to see if we have what you use!

WOULD YOU LIKE TO HELP . . .

Contributions to our non-profit 501(c) (3) corporation are tax deductible.

Donations to our General Fund help to balance our current budget.

Memorial contributions are made in memory of a friend or loved one who has passed away. For memorial contributions, we need to know the name of the person being memorialized as well as the name and address of their next-of-kin so that we may send them a tribute card.

Honorary contributions are made in honor of someone yet living. For honorary contributions, we need to know the name and address of the person being honored so that we may send them a letter of recognition.

Any contribution may be mailed or brought to our Stevensville or Niles offices.

ENDOWMENT FUND

The Berrien County Cancer Service has its own Endowment Fund to ensure that we will be available for as long as needed. Donations to this fund may be mailed or brought to our Stevensville or Niles offices. We have partnered with the Berrien Community Foundation and the Michigan Gateway Community Foundation to enable donors to take full tax credit advantage from the Michigan Community Foundation Tax Credit.

To make this type of donation, please send payment directly to:

Berrien Community Foundation	Michigan	Gateway	Community
Foundation			
2900 South State Street, Suite 2 East			111 Days
Avenue			
St. Joseph, MI 49085			Buchanan, MI
49107			

A letter to be used as a receipt and for tax purposes will be sent for all donations.

*Before you follow any medical advice in this newsletter, or any other publication . . . check first with your doctor or ET.*

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