

**Portland Maine
Ostomy Support
Newsletter**

The Visitor

September-October 2008

**Next Portland Meeting:
Sunday, September 21,
2:00 PM**

Mercy Hospital Auditorium

We meet on the third Sunday in
March, May, July, September, &
November

^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^

**An ostomy support group is now
meeting at the Goodall Hospital in
Sanford!**

When: The Third Monday of the Month
7:00 to 8:00 pm

Where: Founders Room,
Goodall Hospital

Contact: Kathleen Parsons @ 247-5774
for more information



Our Website: www.uoaportland.com

From the Editor – Peter McGinn

Two quick notes:

Chris Chapman wanted to pass along the following thank-you to those who sponsored her in the "Take Steps For Crohn's & Colitis" walk that took place on May 30, 2008.

With everyone's help I raised \$109.00. Even though it was a rainy gray day there where 24 teams, 175 walkers, and 200 participants that came out in support. Here in Maine there was a grand total of \$20,000 was raised! Thanks again your support!! **Chris Chapman**

Also. Last year Chris told us about a symposium held at Maine Medical Center on issues around Inflammatory Bowel Disease. Some of us were interested, so info on this year's event is on the next page. Please note that you have to register in advance to attend.

Portland Support Group Contacts	
Paul Brady, Treasurer	934-4055 pbrady@maine.rr.com
Sally Hinckley, Secretary	799-2235 Hhinckl1@maine.rr.com
Peter McGinn, Website/Newsletter	854-1741 narrator@maine.rr.com
Peggie Delparte, Mercy Hospital	879-3190
Kate Hill, Mercy Hospital	879-3190
Barbara Gardner Visiting Nurse	780-8624

A full day of IBD Educational Programming!

This program aims to give patients the necessary knowledge to feel more in control of their disease. In addition to the basics and special pediatric topics, lectures will address current IBD medications and what's in store for the future, the role of nutrition, complementary and alternative medicine and how they fit into inflammatory bowel disease treatment, and more.

Date: Saturday, October 4, 2008

Time: 9:00 a.m. - 3:30 p.m.

Location: Maine Medical Center, Dana Center, 22 Bramhall Street, Portland, ME 04102

INDIVIDUAL REGISTRATION FEES:
\$10 for CCFA members, \$15 for non-members, under 18 is free (breakfast and lunch will be provided)

You can register online at
<http://www.ccfa.org/chapters/ne/#PortlandIBD> or

For more information or to register for this program, please contact CCFA Education and Support Manager, Stacey Snyder at: ssnyder@ccfa.org or via phone at: 1- 800-314-3459 ext. 13

Please note: day-of registration is not available for this program; pre-registration is required.

(All of the remaining articles are from the Chicago New Outlook newsletter)

Instructions for Life

Forwarded By Peggy Bassrawi

- Take into account that great love and great achievements involve great risk.
- When you lose, don't lose the lesson.
- Follow the three R's . . . Respect for self, Respect for others and Responsibility for all your actions.
- Not getting what you want is sometimes a wonderful stroke of luck.
- Learn the rules so you know how to break them properly.
- Don't let a little dispute injure a great relationship.
- When you realize you've made a mistake, take immediate steps to correct it.
- Spend some time alone every day.
- Open your arms to change, but don't let go of your values.
- Remember that silence is sometimes the best answer.
- Live a good and honorable life. Then when you become older and think back, you'll be able to enjoy it a second time.
- Share your knowledge. It is a way to achieve immortality.
- Be gentle with the earth.
- The best relationship is one in which your love for each other exceeds you need for each other.
- Judge your success by what you had to give up in order to achieve it.
- One moment of patience may ward off great disaster. One moment of impatience may ruin a whole life.
- Why choose to assume a negative outcome in an unknown situation?

Thoughts on Odor Management

By Rosemary Van Ingen, CWOCN

Is it not interesting that people with normal intact bowel tracts and urinary systems manage odor problems in an acceptable manner in our society? But when disease or trauma strikes and the person is the owner of an ostomy, the biggest concern he/she has is the fear of offending society with an odor.

Ostomy Collecting Receptacles. When ostomy surgery was first developed, people with ostomies wore anything to collect output. Tin cans, rubber gloves, cups of all shapes and sizes, bread wrappers, and plastic margarine cups, just to mention a few, were standard equipment for the person with an ostomy. Not only the feasibility, but also the odor problems this type of equipment produced, was enough to give ostomy surgery and people who had ostomies a very deplorable place in our society. Presently, virtually all the pouching systems available to us today are made of odor-barrier materials.

Therefore, if a person with an ostomy does have a fecal or urinary odor about them, some detective work should be done: Check out the application of the pouching system to the body. Is it leaking? Check out the closure of the pouching system—is it closed properly so that no fecal matter is oozing out after the closure? Do not put holes in the pouch, as gas will seep out continuously.

Urostomy Odor Cautions. A person with a urostomy should rinse or wipe off the spout of the pouching system with a bathroom tissue after emptying. Those few drops left in the spout after closing the pouching system can cause a urine odor under clothing. It is interesting to note that most urostomy pouching systems on the

market are odor-proof, but the connecting tubing and bedside and leg bag are not. You must dispose of and replace these products when they take on urinary odors, or else your entire living quarters will smell.

Elimination in People with Ostomies versus Others. Emptying a pouching system is comparable to a person with an intact bowel or urinary tract having a bowel movement or emptying their bladder. How does the person without an ostomy handle the odor produced by the normal function of their body? Room deodorizing sprays are popular, a quick flush of the toilet when defecation occurs and opening a window are some acceptable methods that have been used for odor management. Just remember, there is not a man or woman on this earth whose wastes do not smell

Doctors, Learn to Listen

Contributed By Jane Michnik

Studies shows doctors rarely let a patient finish what he/she is saying, and most interrupt in a matter of seconds of the patient's starting to speak. Researchers specializing in communication studies, say surveys of doctor-patient exchanges found about a third of those polled were reluctant ever to question their doctor's opinions.

"We're ultimately responsible for our health," researchers say. "We can find another doctor, we can get second opinions but psychologically that reality doesn't exist for many people." It is the patient who speaks up who lives longer and gets the treatment he/she needs. Their advice: "Before your doctor's appointment, write down all of your questions so you'll remember what to ask, and don't hesitate to ask plenty of questions."

Urostomy Concerns

Germs are all over the world. Nevertheless, when they are in the urinary tract, either in the conduit, the ureters or the kidneys . . . they are in an abnormal location. This is what causes a urinary tract infection.

What causes infection? Mostly, the reasons are unexplainable. Why do some people get more colds than others do? Infections can be caused by obstructions, kidney stones, tumors, cysts or scar tissues. Almost synonymous with urinary obstruction is infection, and then along with this comes stone formation.

Once you have stone formation, it is hard to get rid of the infection. It is a kind of a cycle that goes around and around. Infection can be caused by urine being forced back to the kidneys through the conduit. This could happen if you fall asleep with the appliance full of urine and accidentally roll over on the pouch, causing urine to be forced back through the stoma and the urinary tract with tremendous pressure.

Invariably, the urine in the pouch is contaminated. In general, to prevent and treat the infection, you need a good flow of urine, much like a stream. That not only dilutes the bacteria or germs in the urine but also helps wash them out. Two quarts of fluids daily are required for the average adult but if you have had problems with infections, you need to drink more water. Night drainage is necessary for everyone with a urostomy. Otherwise, one runs the risk of urine backing up into the kidneys, which can cause irritation or infection. This is especially important for people with urostomies with only one kidney.

It is important to be aware of the symptoms of a kidney infection . . .

elevated temperature, chills, low back pain, cloudy urine, and decreased urine output. It is normal for people with ileal conduits to produce mucus threads in their urine, which give a cloudy appearance. However, it will be different with an infection. Moreover, be aware that bloody urine is a danger sign. You must see your doctor if any of these symptoms occur. He/she will usually prescribe an antibiotic—which will be very efficient—to clear a bacterial infection in the urinary tract. This will not prevent future invasions but will cure the immediate infection.

I haven't bought a thermometer recently, but the story goes that.....

If you were to purchase a rectal thermometer made by Johnson & Johnson (it has to be this brand) and open the package to remove the thermometer, you will find some literature.

If you take out the literature from the box and read it carefully, you will notice that in small print there is a statement: "Every Rectal Thermometer made by Johnson & Johnson is personally tested and then sanitized."

Be thankful you do not work in the thermometer quality control department at Johnson & Johnson. There is always someone else with a job that is worse than yours is.