

Happy Easter!



This Month's meeting:
Wednesday, April 17th

Lori MacCullouch;
Director Nursing Professional
Practice and Elder Care

Location:

Grantham Lions Club

(in the smaller hall)

732 Niagara St, (corner Parnell & Niagara St.) St. Cath.

Use Parnell Entrance

Doors open @ 7:00p.m.

Meeting starts @ 7:15p.m.

* fully accessible—no stairs*

(Ridgeway / Pt. Colborne meeting info on Page 4)

REMINDER!!

New dates and location for our meetings!



Meeting Location: The Grantham Lions Club, 732 Niagara St, St. Catharines, ON L2M 7W7 (corner of Parnell Rd & Niagara St) in the smaller hall at the Parnell end of the building (use Parnell doors)

Meeting day & time: Third **WEDNESDAY** of each month, doors open 7:00 PM, meeting starts 7:15 PM (excluding December, July & August)

INVITATION TO START UP NIAGARA'S GUSTY GANG SOCIAL CLUB

ARE YOU BETWEEN AGE 20 TO 40 WITH AN OSTOMY... AND... interested in occasionally getting together with similar folks for social networking and personal support in a fun setting?

Then... consider being part of a group to build **Gutsy Gang Social Club (Niagara)**, especially if you have expertise in applying social media, and call Dave at 905 327-2806 for more information.

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President's Message

Well its spring finally! It seemed to be a long winter, even though I managed to get away to North Bay ice fishing two times. Didn't catch much but had a lot of fun.



We are doing the Turkstra BBQ's again this year so we are looking for volunteers to help out. They are held each Friday from May 17th till August 30th. We're going to try a different time this year, from 11:30 to 1:30. Once again Turkstra supplies all of the food & equipment, we supply the labour & we get all the proceeds. It's a great way for us to raise some money & make ourselves known in the community.

We're looking at becoming Incorporated, the new governance model that Ostomy Canada seems to be heading towards will require us to be, and even so, it's probably a good idea to become a legal entity, rather than just going sort of willy nilly along as we have done since the beginning.

The June meeting is our annual Strawberries & Shortcake, Open mic night. Please try to attend. Oh, and it's our annual general meeting too, hopefully we will have some information by then on Incorporation. We need volunteers and anyone in-

terested in becoming a director, please let one of us know. Did I mention we need help to run this organization? Please consider spending a few additional hours per month to help out.

Thanks again to Ron for donating all the stamps for our newsletters, Cathy & Jim for picking up the newsletters from the printers & mailing them and Marlene for month after month creating the newsletters.

We had a good meeting in Port Colborne in March, with Jennifer Smith from the Local Health Integration Network (LHIN). She gave a talk on the services they provide the community, and we had ample time to discuss our concerns about the lack of Ostomy care we receive in Niagara. She made lots of notes & I'm sure she will be back in touch with us.

Cheers,

John Molnar



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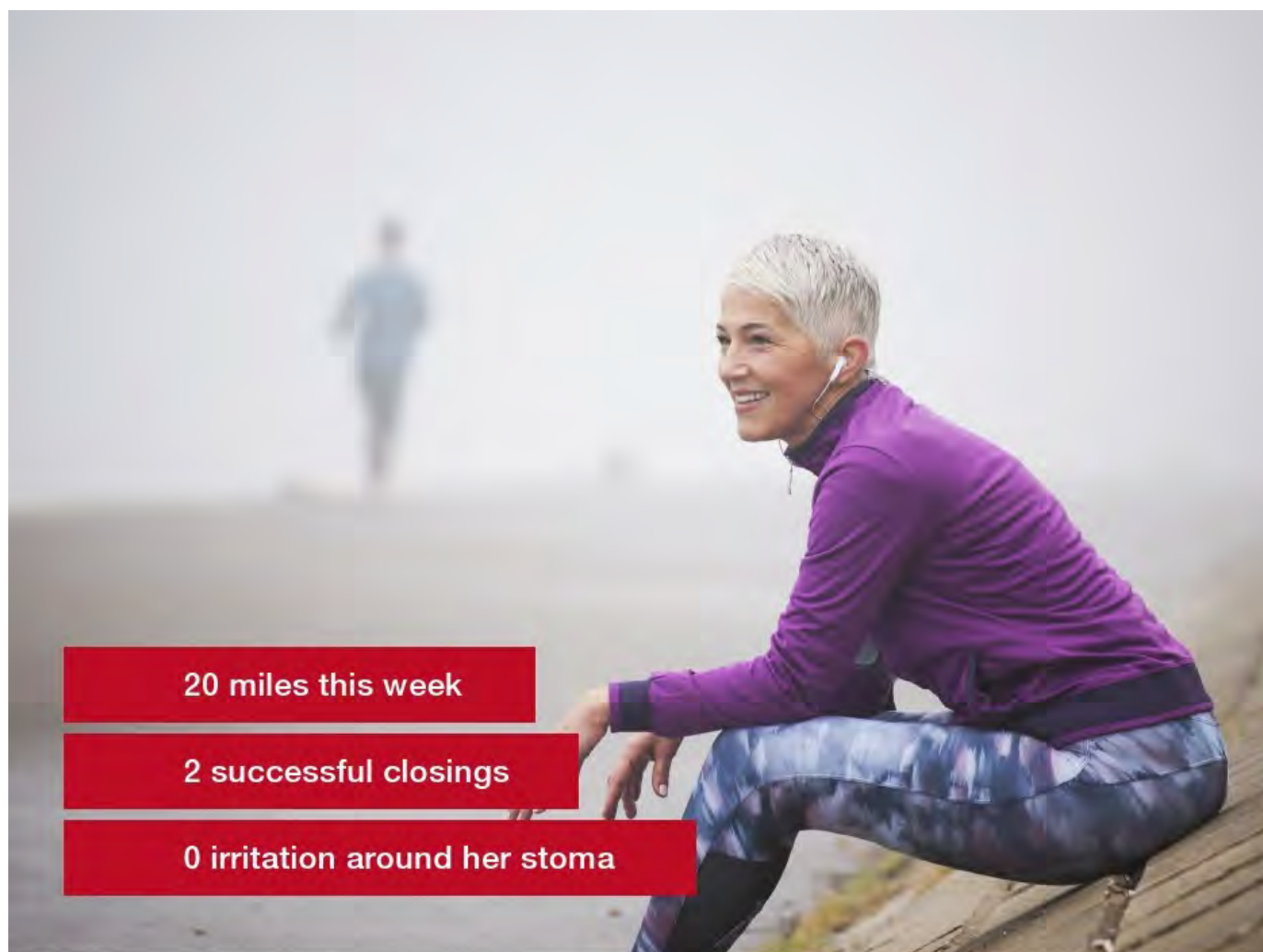
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Keep your face always
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and shadows will fall
behind you.

— WALT WHITMAN



GH



20 miles this week

2 successful closings

0 irritation around her stoma

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Doors Open 6:15pm, meeting at 6:30pm

Please note that the meetings are held after business hours when the pharmacy is locked. To keep the pharmacy secure, the front door is attended by staff and unlocked only to admit attendees between 6:15 and 6:30pm. No-one else will be admitted after 6:30 because the staff are also involved in the meeting.

Meetings:

Wed, March 27th — Niagara Local Health
Integration Network

Topic: Home and community care support

Wed, May 29th — TBA

2018/19 Board of Directors

Title	Name
President	John Molnar
Treasurer	Beth Harwood
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CALENDAR OF EVENTS

Our Website: www.niagaraostomy.com

Our Email: info@niagaraostomy.com

2019 Dates

Mar 20-SafenSimple Ostomy

Apr 17- Lori MacCullough; Director
Nursing Professional Practice and Elder
Care

May 15

June 19

Telephone Numbers:

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Coloplast: (866) 293-6349

ConvaTec (800) 465-6302

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NOTICE TO READERS:...

Products and methods mentioned in this newsletter are not endorsed by the Niagara Ostomy Association and may not be relevant to everyone. Consult your doctor or ET nurse before deciding to use any of them.

Application for Membership

Name: _____

Address: _____

Postal Code: _____ Phone: _____

Email: _____

Type of Ostomy(optional): _____

Dues are \$30.00 per year, renewable by December 31 of each year. Membership is open to all ostomates, family members, medical professionals, health professionals and other interested parties. Includes monthly newsletter. We do not wish to exclude anyone because of inability to pay dues. If payment of dues is a hardship, please inform the treasurer or president. They have the authority to waive individual dues. This information is kept in the strictest confidence. We will never share your email address. It will be kept strictly confidential. Completed application along with your cheque or money order (payable to Niagara Ostomy Association) should be mailed to:

Beth Harwood, 16 Greenhill Dr.,
Thorold ON, L2V 1W5

EXPECT MORE – TAKE CONTROL OF YOUR HEALTH CARE

BY UOAA ADVOCACY COMMITTEE

This first article is about finding your voice as you take the initiative to speak up, or act on your own behalf, to encourage change that will bring improvements in your quality of ostomy care, and ultimately, your quality of life.

We are all unique individuals and regardless of having a medical condition such as an ostomy some people by nature are outgoing while others are more naturally shy and timid. Some people are overly confident while others lack self-esteem. We are who we are; however, when it comes to your health and well-being, if your gut is telling you “this isn’t normal” or something is wrong or you just don’t plain “get it”, don’t be afraid to

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or email at ConvaTec.Canada@convatec.com

(Continued from page 6)

speak up. There is power in your words. Yes, this can be easier said than done for many, but realize there is no shame in asking for help. It can be a challenge to balance being assertive while not being overly demanding.

Ask yourself the question – do you think you are capable of producing a change? How do you create change in your life? For example, if you are experiencing pain and sores on the skin around your stoma – are you accepting this as normal and trying the best you can to manage it on your own because you don't want to bother anyone? In contrast, are you someone that would call your doctor, seek resources to find help and not accept this as normal? It is good to try to be self-sufficient but if you are still suffering and in pain then a positive change has not happened. What can you do to strengthen your voice, and be a participant in your self care? The belief that you can make a change is called self-efficacy. It is a little different than being self-confident in that you truly believe a change will happen and you won't stop seeking help until that change has happened.

Some people also fear that by speaking up and questioning their healthcare providers, that they will find them annoying, stupid, needy or unlikeable. Healthcare professionals are held to high medical standards and they want to help their patients. They understand that this is new to you and

that you are trying to understand your medical condition. They also need you to understand your treatment plan, so that it can be a success. There is absolutely no reason to feel embarrassed. Remember, if you do not ask your questions or express your concerns, you remain uninformed and that is a fearful place to be. You want things to get better not stay the same.

When it comes to medical situations, many people become tongue-tied or have difficulty expressing themselves. UOAA recognizes that it is not enough to just tell ostomates to self-advocate, but rather we need to provide you with the tools to do so. Self-advocating can be a positive experience.

Below are 10 questions and simple solutions that will help you find your voice:

1) Are you nervous, anxious or confused about your medical condition?

People who do not feel confident in their understanding of their medical condition feel fearful. Once they are educated about their condition, they are more confident to speak up. The information in this blog post and UOAA's ostomy information and educational resources can help you gain confidence and if you are just starting your ostomy journey it can give you a sense of control in a time of uncertainty. “

(continued on page 9)

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(continued from page 8)

2) Do you just defer to the expertise of medical professionals or do you participate in decision making?

Many people assume they have no role in their care. They just leave it in the professionals' hands. In reality, you play a very important role. Medical "lingo" is very new to people – people who don't understand it do not feel confident in speaking up and feel intimidated by medical professionals. Most people are afraid to say – I don't understand what you are saying. Make a list of what you do and don't understand to generate the proper questions to ask.

3) Do you think you are the only one in the world having these issues and concerns?

People who feel alone do not speak up – once they find others such as with a support group – they feel more confident and less isolated and alone. Here you can get a role model or peer to guide you along the way. It's comforting and insightful to hear from people who share similar experiences. Chinese proverb: "To know the road ahead,

ask those coming back."

4) Do you have low self-esteem and sometimes feel that your life doesn't matter?

People with low self-esteem tend to not speak up. They tend to remain silent or let other people do the speaking for them. When someone has low self-esteem, it is hard to see his/her own worth or recognize that his/her opinion matters. Self-esteem is further affected by a life-altering/body altering illness such as ostomy surgery. Take steps to feel better about yourself or if needed, seek counseling.

5) How can advocating for your healthcare needs (or other things in your life) really change your life in a positive way?

Consider the impact on your life. Make a list of pros and cons for speaking up. If the pros outweigh the cons, it may be worth it to speak up and improve your life in a positive way.

6) Do you have a concern or health issue with your osto-

my, but your doctor or nurse pushes it aside and tells you not to worry about it?

Are you the type of person if you are worried about something, but your doctor doesn't mention it, then you assume it must not be a concern so you remain silent? If you are unsure or disagree and it is affecting your quality of life, then get a second opinion by another expert. Listen to your gut. It's important for you to feel safe and secure in your own body, and you certainly don't want the problem to get worse (or it might truly be nothing to worry about!). It always

(Continued on page 10)



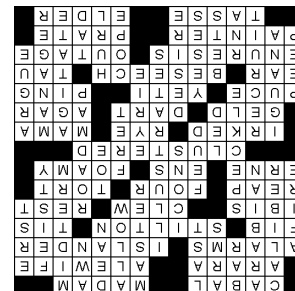
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(Continued from page 9)

feels better to have your concerns addressed in a way that makes you feel that you have been heard.

7) Do you find yourself rushed or brushed off when you are at an appointment with a medical provider?

We all agree that medical professionals are busy and are often running behind schedule. The good news is that often this occurs because other patients were asking questions during their appointment! They were speaking up! You deserve their time too. Write down your questions before you arrive and be sure to take out your list and go over every single question you have. Remind yourself – this is your visit, this is about YOU, not the doctor. Also, the next time you call to make your appointment tell the office staff that you will need some extra time to discuss all of your concerns and evaluate your situation especially if it is a complicated issue.

8) Do you feel like you are just another ostomy patient in a long assembly line and feel that there is no real care for YOU, a unique and individual person?

If you consistently leave the office feeling worse than when you entered and with unanswered questions, then it is time to consider finding a new provider and seeing someone else who will make you feel comfortable to ask questions and take the time to listen and respond. This holds true even if it's a referred provider who is supposedly the "best" in the field. It's important to have a good relationship with your provider. Quality ostomy healthcare is a team effort and communication is critical.

(Continued on page 14)

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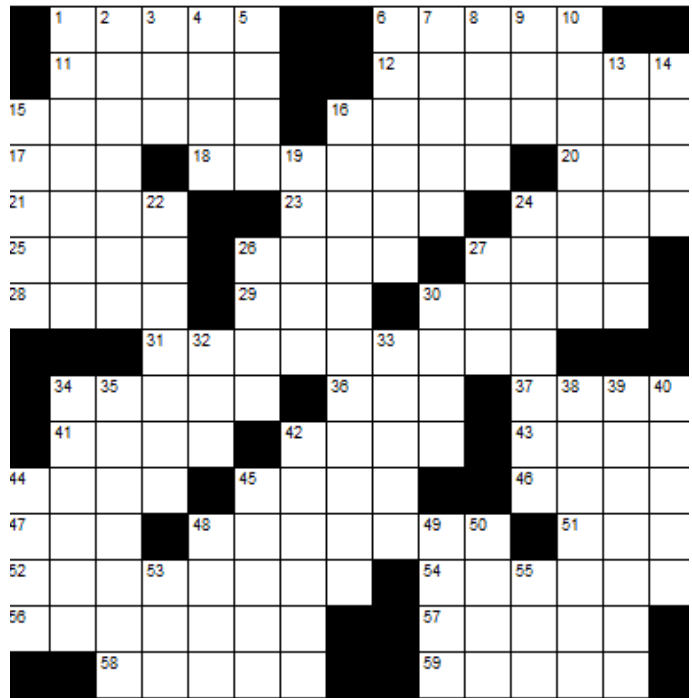
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ACROSS

- | | |
|-----------------------------|--------------------------------------|
| 1. A clique | 37. Mother |
| 6. Gentlewoman | 41. Neuter |
| 11. A kind of macaw | 42. Flit |
| 12. Shad | 43. Food thickener |
| 15. Warning devices | 44. Brownish purple |
| 16. Inhabitant of an island | 45. Abominable Snowman |
| 17. Lie | 46. Engine knock |
| 18. English blue cheese | 47. Hearing organ |
| 20. It is (poetic) | 48. Entreat |
| 21. Nile bird | 51. Letter after sigma |
| 23. A ball of yarn | 52. Incontinence |
| 24. A musical pause | 54. Breakdown |
| 25. Harvest | 56. An artist using watercol-
ors |
| 26. Two times two | 57. Chatter |
| 27. Legal wrong | 58. Thigh armor |
| 28. Sea eagle | 59. Church officer |
| 29. Ensign (abbrev.) | |
| 30. Frothy | |
| 31. Bunched together | |
| 34. Annoyed | |
| 36. Type of whiskey | |

CROSSWORD www.mirroreyes.com**DOWN**

- | | | | | |
|------------------------|--------------------------------|---|-------------------|----------------------|
| 1. Gauge | trator | 22. Dapple | soldier | 53. Ribonucleic acid |
| 2. High-spirited horse | 9. Barley bristle | 24. Chart showing
routes and streets | 38. Rouse | 55. Little bit |
| 3. Tavern | 10. Middle of the year
exam | 26. A bitter quarrel | 39. Coach | |
| 4. Not legs | 13. Spirited | 27. Foot digit | 40. Bicker | |
| 5. Not first | 14. At one time
(archaic) | 30. Fuss | 42. Covet | |
| 6. Dominate | 15. All excited | 32. Directed | 44. Chick's sound | |
| 7. Extend | 16. Draws | 33. Lofty nest | 45. Affirmatives | |
| 8. University adminis- | 19. Graphic symbols | 34. Large lizard | 48. Wagers | |
| | | 35. A recently enlisted | 49. Make do | |
| | | | 50. Throw | |



Answers on
page 9

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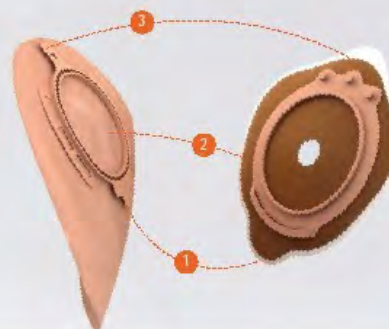
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SHARING EXPERTISE

(Continued from page 10)

9) Have you ever looked back and kicked yourself for not saying something?

It's better to speak up, than have regrets later, especially when it might be something as serious as your health and well-being. Your doctor has many other patients and concerns on his/her plate so don't run the risk that they will remember everything about you or what was discussed at your last visit together. You know your health history. You are the person experiencing the symptoms or whatever the issue is. It is absolutely your place to express your concerns.



10) Do you sometimes draw a blank or choke under pressure and miss out on speaking up?

Keep an ongoing list of your questions and concerns prior to meeting with your medical professional. Practice the conversation that you want to have by role-playing with a

family member or friend acting as your doctor or nurse. Practicing will help instill confidence in what you want to

say. You can also decrease stress by bringing your questions with you and reading them from your paper. That way you are sure that nothing is forgotten. "Asking for what you need, what you want, and what you're worth requires practice. So practice self-love and start asking."
~ AnneMarie Houghtailing

IF YOU CAN'T FIND YOUR VOICE; BE SURE TO GET AN ADVOCATE

We realize that having major surgery can be overwhelming. Be sure to find someone who can help you along the way. Sometimes you might "lose your voice" especially after surgery, from medications, or just being overwhelmed. Your advocate should be someone close to you, whom you can share your deepest fears and concerns with, and HAS A VOICE, and can speak up for you when you can't. Your advocate can ask questions for you or simply listen and take detailed notes so you can recall and understand later.

LAUGH FOR THE DAY

1. I bought some shoes from a drug dealer. I don't know what he laced them with, but I've been tripping all day.
2. I told my girlfriend she drew her eyebrows too high. She seemed surprised.
3. My wife told me I had to stop acting like a flamingo. So I had to put my foot down.
4. What's the difference between in-laws and outlaws? Outlaws are wanted.
5. What's the difference between a hippo and a zippo? One is really heavy, and the other is a little.
6. My friend says to me: "What rhymes with orange" I said: "no it doesn't"
7. How many opticians does it take to change a lightbulb? Is it one or two? One... or two?
8. What do you call a frenchman wearing sandals? Phillipe Phillope.



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