

THE NEWSLETTER OF THE WINNIPEG OSTOMY ASSOCIATION, Inc. (WOA)

FROM THE PRESIDENT'S DESK

I am feeling full of warm fuzzies and I'm sure you all will be too after reading this newsletter.

before we know it and some very special people. Emma & Jayden will be travelling to the **UOAC Ostomy Youth** camp in Alberta once again thanks to the sponsorship of the WOA. I direct your attention to the "We Get Mail" section for some very heartwarming letters. Riley, who is highlighted there as well, has attended camp for the last two years and

we wish him well in his exciting opportunity. Such wonderful coincidences happen when I put on my editor's hat. I Summer will be upon us had just found "Mabel's Story" in the newsletter summer means camp for from Seattle. That evening we had our chapter meeting. As it happens, we have two members who can remember what General meeting and it was like in those days. Evelyn Waldera, who had her surgery in 1946 and George Moodie who had his surgery in 1954, were asked to tell their stories. While they didn't toil in the fields, both Evelyn & George spoke of living without ostomy supplies, the

search for something that would work, the steel flanges, leather bags, heavy straps and numerous surgeries to get to where they are today. It was a well spoken, emotional presentation and we thank them both for sharing. April is our Annual you will find a lot of information within these pages. We try to run our AGMs efficiently and we hope that you will join us, be part of the process and become informed. The WOA has an excellent history of

having great members

(Cont'd on Page 9)

Happy Easter!





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MAY WIND-UP

WED. MAY 22, 2013

7:00 PM TO 9:30 PM

Catered by IRA'S DELI TICKETS: \$10.00 per person

Tickets must be purchased in advance at the March & April chapter meetings or by contacting Jan Dowswell @ 204-254-3735

Inside this issue:	
Notice of AGM By-law Proposals	3
How to Use Paste Recognition for the Spouse	4
We've Got Mail	5
Stats and more Stats Thank You	6
We've Got Mail (cont'd from Page 5) Arthritis & the Intestines	7
Mabel's Story	8
Mabel's Story (Cont'd from Page 8) Pres. Letter (Cont'd from Page 1)	9

UOA OF CANADA MISSION STATEMENT

The United Ostomy Association of Canada Inc. is a volunteer-based organization dedicated to assisting all persons facing life with gastrointestinal or urinary diversions by providing emotional support, experienced and practical help, instructional and informational services through its membership, to the family unit, associated care givers and the general public.

WHO WE ARE

The Winnipeg Ostomy Association, Inc. (WOA), is affiliated with the United Ostomy Association of Canada, Inc. (UOAC), a volunteer-based organization dedicated to assisting all persons facing life with gastrointestinal or urinary diversions by providing emotional support, experienced and practical help, instructional and informational services through its membership, to the family unit, associated care givers and the general public.

Members receive the UOAC's magazine, <u>Ostomy Canada</u>, the Chapter Newsletter, <u>Inside Out</u>, and the benefits of meeting fellow persons with ostomies at our regular meetings.

The WOA is a not-for-profit registered charity and welcomes bequests and donations.

VISITING SERVICE

Upon the request of a patient, the WOA will provide a visitor for ostomy patients. The visits can be pre or post operative or both. The visitor will have special training and will be chosen according to the patient's age, gender, and type of surgery. A visit may be arranged by calling the Visiting Coordinator or by asking your Doctor or Enterostomal Therapist (ET). There is no charge for this service.

WOA visitors do not give medical advice.

MEETINGS

All persons with ostomies, spouses, family members, interested members of the medical profession and the general public are welcome to attend our meetings and social functions.

Chapter meetings are held from September through May, except December, in <u>Room 203 of the SMD Building</u>, 825 <u>Sherbrook Street</u>, <u>Winnipeg</u>, <u>MB</u>, beginning at <u>7:30pm on the 4th Wednesday</u>, of the month. There are no scheduled chapter meetings in June, July or August. A Christmas party is held in December. <u>Free Parking</u> is in the SMD parking lot to the south of the building. You must enter the lot off McDermott Ave.

DISCLAIMER

Articles and submissions printed in this newsletter are not necessarily endorsed by the Winnipeg Ostomy
Association, Inc., and may not apply to everyone. It is wise to consult your Enterostomal Therapist or Doctor before using any information from this newsletter.

UPCOMING EVENTS

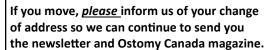


March 27, 2013—Chapter Meeting—Rap Sessions with the ETs

April 24—Chapter Meeting—AGM

May 22, 2013—May Wind-Up, catered—tickets required

ARE YOU MOVING?





Send your change of address to: WOA 1108 - 88 Eric St. Winnipeg, MB. R2M 4A7

LETTERS TO THE EDITOR

The Editor, Inside Out 1101—80 Snow Street Winnipeg, MB R3T 0P8 woainfo@mts.net

All submissions are welcome, may be edited and are not guaranteed to be printed.

<u>Deadline for Next Issue:</u> Friday, July 5, 2013

WORLD WIDE WEB

Visit the Winnipeg Ostomy Association Web Pages: http://www.ostomy-winnipeg.ca

CONSTITUTION

Copies of our constitution are available at our Chapter Meetings, on our website, or can be obtained by mail by contacting a member of the Executive Committee.



NOTICE of ANNUAL GENERAL MEETING

Notice is hereby given that the Annual General Meeting of the *Winnipeg Ostomy Association* will be held

on Wednesday, April 24, 2013 beginning at 7:30 pm

Rms 202 & 203, 825 Sherbrook St., Winnipeg, MB.

The purpose of the meeting is to elect officers for a one-year term beginning September 1, 2013; to receive annual reports; and to conduct any other business deemed necessary.

Nominations Chair:

John Kelemen **Tel:** 204-338-3763

Email: jkelemen1@shaw.ca

Please contact John if you are interested in one of these positions or if you would like a copy of the Executive members' duties.

All Executive positions (President, 1st & 2nd Vice-Presidents, Secretary, Treasurer, & Visitor Coordinator) are open for a one year term. Nominations will be accepted from the floor at the meeting.

The Board of the WOA wishes to present a by-law amendment (below), that if passed prior to the elections, would then allow two more positions to be up for elections.

BY-LAW AMENDMENT TO BE VOTED ON AT THE ANNUAL GENERAL MEETING PRIOR TO ELECTIONS OF OFFICERS

ARTICLE No. 6: (CURRENT) OFFICERS:

The officers of this association shall be President, Vice-Presidents (maximum 2), Secretary, Treasurer, Visitation Co-ordinator, and the immediate Past President.

Proposed change:

ARTICLE No. 6: OFFICERS:

The officers of this association shall be President, Vice-Presidents (maximum 2), Secretary, Treasurer, Visitation Co-ordinator, the immediate Past President, and two "members-at-large".

RATIONALE:

- Members may often be reluctant to take a position on the Board without some prior experience.
- At this time, there are only "Executive Officer" positions available.
- Taking on the role of "member-at-large" would give potential members a chance to feel comfortable in the running of the Executive before stepping into the role of an Executive officer.
- As "members-at-large" they can take on tasks as they arise and as determined by the Executive that they would feel comfortable doing.
- This would allow the officers to focus their attention to the duties they are assigned without overloading them with other tasks.
- This would allow "members-at-large" field of expertise to develop.

ARTICLE No. 7: (CURRENT)

<u>**DUTIES OF OFFICERS:**</u> Lists duties of current officers.

Proposed Addition:

The duties of the "Member-at-large" shall be such as assigned by the Executive.

For information purposes the following has been developed.

<u>A "MEMBER-AT-LARGE' CANDIDATE</u> SHOULD BE SOMEONE WHO:

- Aspires to get involved in the work of the WOA
- and who, upon invitation, accepts the challenge to get involved in the work of the WOA.

AND who could be asked to.....

• Pick up some of the extraneous duties handled by the rest of the Board members.

(Cont'd on Page 4)

BY-LAWS (Cont'd from Page 3)

- Fill in when other Board members are away on vacation or personal leave.
- Assist with the trade shows and education seminars (eg: transporting display materials; setting up; taking down; scheduling volunteers)
- Find volunteers for chapter meetings: (eg. hospitality, social convenors, meeting set up, and takedown, equipment use (podium & video), etc.)
- Possibly manage the WOA message line
- Learn and appreciate the work that is done by the officers of this organization on behalf of its members.



HOW TO USE PASTE

Skin barrier pastes are used as "caulking" to fill in the space between the stoma and the opening in the skin barrier. Skin barrier pastes are not "glue", and should not be used to keep the pouch on the abdomen. Think of this product more as a caulking material rather than an adhesive. Paste fills in gaps or uneven areas, protects the skin around the stoma, and can increase weartime. Generally, this is the procedure you should follow if using skin barrier paste.

- 1. Remove the soiled wafer and gently clean the skin around your stoma in the usual way. Pat the skin dry.
- 2. Apply a thin line of skin barrier paste around the barrier opening on the body side (sticky side).
- 3. Let the paste air dry for about one minute. You can use a hair dryer set on 'cool' to speed this up.
- 4. Gently apply the wafer over the stoma and on to the skin. Hold in place for a few minutes, allowing the warmth of your hand to mold it to your abdomen
- 5. If using a two piece system, now attach your pouch.

Source: Vancouver Ostomy HighLife, Jan/Feb 2012, via Regina Ostomy News, Mar/Apr 2013.

OSTOMY—THE NEW NORMAL: Recognition for the Spouse

By K. Karvounis via Chicago "The New Outlook"

There are few times when a genuine and real recognition is given to the spouse of a person with an ostomy. The spouse deserves more credit than anyone can possibly bestow on him/her. Try for one moment, if you can, to imagine that the shoe is on the other foot...that is, that your spouse has the ostomy and you do not. Now you find yourself waiting to use the bathroom, waiting for your mate to get through irrigating or replacing the pouching system. When you go out of town or make a visit and your spouse has an accident, you have to cut short your outing and go home so the person with the ostomy may clean up, not to mention that all the way home there may be an odour.

Of course, we should add that most of these challenges happen so rarely and with such minor intensity that they should hardly be mentioned at all. The quality of life of people with ostomies is being studied vigorously right now. The results of every study demonstrate that the quality of life after ostomy surgery is remarkably better than before the surgery for people with inflammatory bowel disease. One of the goals of our local ostomy association is to witness to this amazing fact.

Nevertheless, the spouse of the person with an ostomy should be given a great big orchid, and we should all thank God that we have a person like our spouse in our midst. That goes for families as well. Even though we may have a new opportunity for life given to us by our ostomy surgery, there is still a natural period of mourning the loss of an important bodily organ. Our spouse and our family can be the most supportive while we mourn our loss.

For most of us, our spouse is very happy to have us alive. Ostomy surgery gave us a new life, and our life partner may be more thankful than we are to have us with them. For those of us with Crohn's (Cont'd on Page 7)



WE'VE GOT MAIL!

Hi Lorrie, (via email Feb. 11, 2013)

Hope this finds you well and that 2013 is turning out to be a fantastic year for you and the WOA.

It's that time of year again when Emma starts to think about Summer Camp. We've contacted the National office and they are going to send out her application form to us in March. Would the WOA again generously consider sponsoring her registration and airfare?

She turns 14 this week. Grade 8 is turning out to be an awesome year for her. She is very active in all of the intra-mural sports. Currently basketball is occupying her after school time in addition to playing the trumpet in jazz and concert band. She shines academically and takes a great deal of pride in getting excellent marks. Her other personal goal is to be taller than her mom (5'8") and she's almost there! Emma did have some surgery in December. Her stoma has been leaking intermittently and randomly. Dr. Psooy tried to correct this by re-positioning her mitrofanoff but Emma doesn't feel the procedure was successful. Not sure what we are going to do next. She has a new procedure in May (scope to see inside the bladder?) that may give some insight. Otherwise she is in excellent general health. So that's a brief sneak peek into a day in the life of Emma. Feel free to share this with other members of WOA if you like.

Regards,

Bonnie Radcliffe (Emma's mother).

Dear Winnipeg Ostomy Association,

(via email Feb. 21, 2013)

My name is Emma Church. You have been sending me to Ostomy camp for 4 years. I was born with female epispadias and I have a mitrofanoff. I absolutely love going to camp every year. It means the world to me. I have made so many friends at camp. I look forward to camp all year. I feel like the only people that understand what I am going through are the people I meet at camp. The week that I'm at camp is the best week in the whole year. I care about people at camp like they are my brothers and sisters. I want to say a big huge thank you to everyone that has helped in sending me to camp. I can not express how much camp



means to me. Thank you so much. I am so lucky that there are nice people in the world that would help someone else. Thank You!

Editor's Note: These are very simplistic definitions of epispadias & mitrofanoff for your information.

Epispadias is a rare congenital defect located at the tween the skin surface and the uriopening of the urethra. In this condition, the uretha does not develop into a full tube and the urine exits the body from an abnormal location. Epispadias occurs in 1 in 117,000 newborn boys and 1 in 484,000 girls. The condition is usually diagnosed at the skin to form a stoma. birth or shortly thereafter.

Mitrofanoff: This is a surgical procedure in which the appendix is used to create a conduit benary bladder. The surgeon sepa-

rates the appendix from its attachment to the cecum. One end is connected by surgical sutures to the urinary bladder, and the other is connected to

WE'VE GOT MAIL (Cont'd on Page 7)

A warm welcome to new chapter members:

> **Jeff Mason Bob Kirk** Amber Weiss Joan Macooh



If you jumped off the bridge in Paris, you'd be in Seine



We're all smiles *because* you are so generous!

Stan Eagleton

Camp Fund Carole Osborne

Your donations are greatly appreciated.



Time flies like an arrow. Fruit flies like a banana.



WOA VISITING REPORT-**FEBRUARY 2013**

COLOSTOMY 3 **ILEOSTOMY**

UROSTOMY

Requests came from:

HSC:

ST. BON: PRE-OP

A SPECIAL THANK YOU **GOES OUT TO:**

Ion Parrish, Audrey Graham, Hope Lawson, John Kelemen, Laurette Godard. Helmut Friesen, Joanne Maxwell,

Report submitted by:

Joanne Maxwell Visiting Coordinator.



INCLEMENT WEATHER ON A MEETING NIGHT

Should the weather be so bad that we need to cancel our meeting—

- here are the steps to follow:
- 1. WAIT until after 12:00 Noon
- 2. CALL 237-2022, # found on back page.
- 3. MEETING Cancelled—IF there is a "CANCELLATION MESSAGE" on the machine

WOA STATS

Total Membership as of March 12, 2013 **248** 108

September renewals mailed: September renewals outstanding: 13

March renewals mailed: 103 78 March renewals outstanding:

Report submitted by: Jan Dowswell—1st Vice-Pres./Membership Chair

WE'VE GOT MAIL

(Cont'd from Page 5)

Hi Lorrie, (via email March 10, 2013)

I just wanted to let you know that Riley was hired on as a councillor at Camp Horizon this summer! He will be leaving in May and working through to the end of August and is very excited for this new adventure.

Please share at the next meeting.

Allison Wall (Riley's mother)

And.... (via email March 11, 2013)

I am a little sad about him being away for so long but we are already planning a weekend trip to see him

I just wanted you and the group to know since you played such a big part in helping this happen.

I will keep you posted! Thank you,

Allison

Editor's Note: Donations to help send a child to the UOAC Ostomy Youth Camp are gratefully accepted.

Please make out cheques to:
Winnipeg Ostomy Association
and mark "Youth Camp" in the Memo space.

Official receipts for tax purposes are issued for all donations.

(Cont'd from Page 5)

Crohn's Disease or ulcerative colitis, our lives are better than ever. Our mates may once again have us all to themselves, without sharing us with a disease. It is nice being married. It is nice being healthy.

Source: Green Bay Area Ostomy Support Group—Nov/Dec

ARTHRITIS and the INTESTINES

Arthritis is the most common non-intestinal condition associated with the Crohn's Disease and Ulcerative Colitis. Although most people with these diseases do not develop arthritis, three primary kinds may develop, mainly:

- 1. rheumatoid –like arthritis,
- 2. Ankylosing spondylitis and
- 3. Large joint arthritis.

The first form of arthritis mimics rheumatoid arthritis in many ways. It usually involves the wrists and fingers and may improve or worsen without regard to the course of the bowel disease. Sometimes people with this form of arthritis have an antibody in the blood called rheumatoid factor which is found in persons who have rheumatoid arthritis. Not all people with the rheumatoid-like arthritis have this antibody, however. Ankylosing Spondylitis is a condition that involves the lower part of the spine and adjacent joints. In addition to pain, it may cause stiffening of the spine, hips, neck, jaw and rib cage. Its course is independent of the course of the underlying bowel disease. As time goes on, the condition may get better or worsen and on occasion, it may develop even after the bowel has been removed or has improved. The disease usually commences before age 30. Large Joint Arthritis usually affects the knees, ankles, hips and occasionally the elbows and shoulders. The small joints of the hands and feet and the spine are not usually involved. Unlike other kinds of arthritis, this form often worsens as the bowel disease worsens, and improves as the disease improves. It sometimes worsens before the bowel activates. This kind of arthritis does not leave permanent joint deformities. We do not know what causes these three forms of arthritis that develop with either Crohn's Disease or Ulcerative Colitis. Many physicians have attributed the arthritis to some immunological process which may accompany the intestinal disease, but convincing evidence for this is still lacking.

Source: Its In The Bag. Niagara Ostomy Assoc. via Ostomy Halifax News Nov/Dec. 2012

LIFE AS AN OSTOMATE IN 1938 (MABEL'S STORY)

Paul Riome is a Canadian Ostomate who recently posted this article on his blog. It has been published in the American Ostomy magazine and in the Greater Seattle (WA) Ostomy Association Newsletter "The Ostomist"—March 2013.

My Grandma Mabel had ostomy surgery in 1938, and was sent home with no ostomy equipment. How did she cope? How did she live with her ostomy? I have tried to recreate her experience.

Let us imagine living with an ostomy in 1938. This was before the internet, before cell-phones, before microwaves, before TV, before plastics. The stock market had crashed in 1929, followed by a decade named the Great Depression. In parallel, there was a decade of drought and crop-failure in the entire Mid-West of North America, aptly named the Dirty 30s. This was before the Second World War!

It was a challenging time to live. This was also before Elenges and Pouches and any other Ostomy.

It was a challenging time to live. This was also before Flanges and Pouches and any other Ostomy gear was invented. Ostomy patients were sent home after surgery, with no collection device.

No collection device!?!!

How did Mabel live with an ostomy without ostomy equipment? Mabel lived on the prairies in Western Canada, where summer temperatures rose to +40 degrees Celsius (104 Farenheit) and winter temperatures dropped to -40 degrees Celsius. The only heat in the house was the stove, which burned coal when they had money, wood when they could scrounge, and buffalo-chips (dried cow manure) when there was nothing else.

There was no cold running water. Water was pumped from a well—winter and summer. There was no hot running water. They heated water in a large pot on the stove. There was no shower. There was no bath-tub.

There was no bathroom in the house. There was just an outhouse—a seat perched over a pit in a small building fifty yards from the house. This outhouse experience, in the winter when it was minus 40 degrees, was the origination of the expression "so cold it would freeze your backside off!" With no collection device supplied, available, or even invented yet, Mabel made do with rags and towels (try to imagine her angst). Mabel's husband Walter was a practical

and inventive man, and soon devised a tin-can with a belt-strap, to contain the stool. This was leaky and stinky, but a big improvement over the very messy rags.

Personal ostomy clean-up was in the outhouse, probably with a pail of cold water—summer and winter.

The tin-can had to be strapped tightly around her waist to reduce the leakage (not prevent leakage—just reduce leakage). The edge of the tin-can bit harshly into Mabel's skin and left a nasty red compression ring on her skin. Walter was a horseman who made his own horse-harnesses, so he built a leather collar to cover the tin-can edging. This was certainly more comfortable and leaked less. But it was difficult to clean the leather collar and the devise was still stinky.

Mabel considered a glass container which would be easier to clean than the tin-can. But adding a leather collar and attaching a belt would be difficult and the risk of glass breakage and serious cuts to her stoma would be a big concern. The tin-can with leather collar, strapped around her waist, Mabel's best-and-only ostomy equipment.

The four inch circle around her stoma was constantly covered with stool, and I expect she had many rashes, breakdowns, infections, and damages to her skin. The salves use for harness-burns on horses would have been Mabel's only relief from these skin problems.

There was no real ostomy equipment for Mabel. There was no 'support group' for Mabel.

Mabel never talked about her ostomy. My father, who lived at home for the first six years of Mabel's ostomy, was never told about her ostomy, never saw anything that would indicate an ostomy, never saw a bulge on her dress. While her husband designed and built her ostomy-gear, that would be the last time he participated and the last time they would talk about it. It just wasn't ever discussed.

For 15 years, Mabel lived silently with the inconveniences of an ostomy without ostomy-gear and with no-one to talk to.

Mabel was the sole steward of a one-acre vegetable garden. She dug the entire garden with a shovel, planted seeds and hoed weeds.

(Cont'd on Page 9)

Mabel's Story (Cont'd from Page 8)

In the fall, she dug out the potatoes and carrots, harvested and preserved corn, peas and beans for each cold winter ahead. For fifteen years, from age 52 to age 67, she worked that garden, and she lived with an ostomy. And she lived without ostomy equipment as we know it today.

How did Mabel keep herself physically clean, mentally content, and spiritually thankful, with such crude ostomy equipment and under such harsh conditions?

Mabel was British, Victorian, stoic, and content...never complained. She was so thankful that her ostomy gifted her 15 years of good living.

There have been days I have complained about my colostomy. Imagining reliving Mabel's ostomy experience, I will not complain again. **Ever.**

Paul Riome recently embarked on a climbing venture in Nepal—check out further stories on www.livingbiggerwithcolostomy.com

No matter how much you push the envelope, it'll still be

CONGRATULATIONS STOMA MEMBERS on your SPECIAL ANNIVERSARY

stationery.

Stan Sparkes 1991 22 years Florence Olsen 2010 2 years

17 members, including the above, have donated a total of \$1474 towards our audio & video equipment to date.

Our sincerest thanks to you all

President's Desk (Cont'd from Page 1)

who have answered the call to keep the chapter running by taking their turn on the Board. There is a lot that goes on behind the scenes that is not evident at our regular meetings, so please consider putting your name forward. We will be presenting a by-law change that will allow us to increase the size of the board. Again, I believe it is well explained earlier on in the newsletter.

Take note of our rap sessions with the ETs this month and our Wind-up in May. Have a Happy Easter everyone! Was I right about the

warm fuzzies?

Lorrie

ARE YOU MOVING?

Please inform us of your change of address so we can continue to send you the newsletter and Ostomy Canada magazine. Send your change of address to:

WOA 1108 - 88 Eric St. Winnipeg, MB. R2M 4A7

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The anniversary date of my stoma is and to celebrate my second chance for healthy living, I am sending the sum of \$ per year since I had my ostomy surgery.
NAME:
AMT. ENCLOSED:
Official receipts for tax purposes are issued for all donations, regardless of the amount.
My name and the number of years may be printed in the "INSIDE/OUT" newsletter. YES NO
Clip or copy this coupon and return with your donation to: Winnipeg Ostomy Association 204-825 Sherbrook Street
Winnipeg, MB R3A 1M5
Proceeds from the Stoma Anniversary Club will continue to go towards the purchase of audio & video equipment to

promote the Winnipeg Ostomy Association and its pro-



INSIDE/OUT Page 10 **MARCH 2013**



THE WINNIPEG OSTOMY ASSOCIATION, INC. (WOA)

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Past President		

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Helen Rankin, BN, ET Brande	on, R.H.C.	204-578-4205

PHYSICIANS

Dr. D.J. Gillespie: Dr. H.P. Krahn: Dr. R. MacMahon: Dr. C. Yaffe

COMMITTEES

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Vacant

RECEPTION/HOSPITALITY:

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FOW SUPPLIES

PICK UP Helmut Firesen 204-888-4014

OSTOMY SUPPLIES HSC MATERIALS HANDLING 59 Pearl St., Winnipeg, MB.

ORDERS: 204-926.6080 or 1.877.477.4773 E-mail: ossupplies@wrha.mb.ca Monday to Friday 8:00am to 4:00pm PICK-UP: Monday to Friday 8:00am to 11:00pm

WINNIPEG OSTOMY ASSOCIATION MEMBERSHIP APPLICATION

Current Members—PLEASE WAIT for your green membership renewal form to arrive in the mail. Your renewal date is printed on your membership card.

New Members: Please use this form

Please enroll me as a new member of the Winning Ostomy Association. I am enclosing the annual membership fee of \$40.00.

NAME:	PHONE:
ADDDEGG	
ADDRESS:	E-MAIL:
CITY:PROVINCE:	POSTAL CODE:
I have a: Colostomy: Ileostomy: Urostomy: Ilea	al Conduit:
Cont. Diversion:: Pelvic Pouch: Other:	YEAR OF BIRTH: