

Spring 2017 Issue 2



STOMA SUPPORT GROUP WORKING WITH ST. MARK'S AND NORTHWICK PARK HOSPITAL

Incorporated with St. Mark's Hospital Foundation Charity Registration No: 1140930

Hello Friends

by **Tanuja Patel - Editor**

My name is Tanuja Patel, born and brought up in Britain! I am a 44 year old lady with Spina Bifida Hydrocephalus since birth. I am paralysed from my waist down. I use an electric wheelchair to get around everywhere. I live with my disabled husband and family.

I am educated to GCSE Level, have completed courses such as BTEC Level I & II in Business Technology Applications and BTEC Business Administration Level II in college. I was volunteering at a Day Centre twice a week for a few years after my education.

My Interests are going to the cinema, theatre, visiting museums, going to the park, concerts, library, gym, dining out and swimming. Unfortunately, I have not been able to go swimming for several years now as in 2009 I developed a diabetic foot ulcer under my right foot. Since this has occurred, it keeps healing and breaking down and does not allow me to go swimming as I am not supposed to get it wet.

I have a urostomy that has been a part of my life since the age of 3 and it is accompanied by a colostomy since the age of 25 years.

I have been with the group for 14 months now and have great pleasure in announcing that I am the new Editor for the "Inside Out" Newsletters.

ENJOY READING!

IOSSG a Brief History and *Thank You*

by Andy Coogan

Some 22 years ago (circa 1995) a small number of ostomists got together with St. Mark's stoma department and decided to form a post-op self-help group. It started with around 7 to 10 people, quickly grew to 20, then 50 and today we number approximately 100.

The original members were Bob Azevedo-Gilbert, Barry Kindred, Jean Burke (who was Secretary and Treasurer), Caroline and the stoma nurse Clare Bossom. We were joined shortly after by Diane Owen who has carried out the job of Secretary, Postmaster General and keeping us all in order at committee meetings and AGMs for the past 22 years.

Please forgive me if I have left anyone out, although very long in the tooth I am a 'new boy' acquiring my stoma just five years ago.

To those we extend not only our thanks but our lifelong gratitude for their help, advice and information given to help us to come to terms and enable us to cope with and manage our stomas and get back to carrying on with our lives.

The person who has stood out by not only keeping the group going but organising just about everything to do with the IOSSG is Bob. He is always available to advise what to do and whom to see in order to alleviate any problem. From an ostomists point of view his encouragement and advice has been exemplary and many hundreds of us have benefited from his advice over the years.

To Bob "**A very Big Thank You**" from all of us and please get better soon.

Committee Contacts

Chair

Barry Caplan - Email: chair@iossg.org.uk

Vice Chairman/Secretary

Diane Owen - Email: diane_owen@hotmail.co.uk

Joint Treasurers

Kathy Higginson and Janice Fitton

Editor

Tanuja Patel - Email: Tanuja247@gmail.com

Dear Friends

by Bob Lopes de Azevedo-Gilbert

I am overwhelmed by your gift and I thank you from the bottom of my heart. It was privilege and an honour to have been a part of such fantastic group of fellow ostomists determined to regain control of their bodies. To be empowered to regain a quality of life, not to be afraid to ask searching questions so that you have a better understanding and not be fobbed off with answers that you did not understand, as your consultant or stoma care nurse use language aimed at the medical profession.

I am proud of you all, you have taught me to be more caring, understanding and patient with everyone. Some of us go through life without a problem and there are others that have everything that the book can throw at them, but we still come out smiling and that is the greatest thing of all. A little humour goes a long way, to see the funny side of things helps us to get on with life.

A while back, I read a very interesting book that compared life to a train ride or of several train rides.

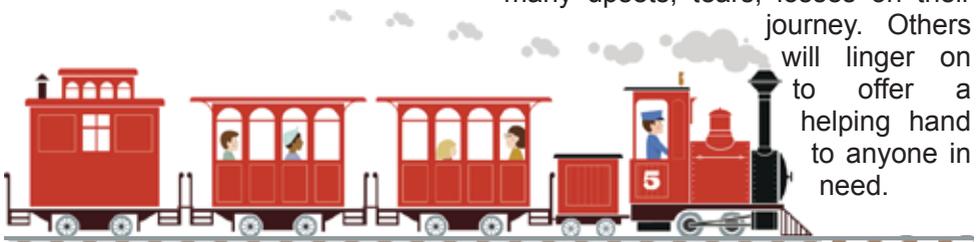
'Life is like a train ride' it read, 'we get on, we ride, we get off, we get back on and ride some more. There are accidents and there are delays. At certain stops there are surprises, some of these will translate into great moments of joy, some will result on profound sorrow'.

When we are born and we first board the train, we meet people whom we think will be with us for the entire journey, these are our parents! Sadly, this is far from the truth. Our parents are with us for as long as we absolutely need them.

They too have journeys they must complete. We live on with the memories of their love, friendship, affection, guidance and their ever presence.

There are others who board the train and who eventually become very important to us. These people are our brothers, sisters, friends and acquaintances, whom we learn to love and cherish.

Some people consider their journey like a jaunty tour. They will just go merely along, others will encounter many upsets, tears, losses on their journey. Others will linger on to offer a helping hand to anyone in need.



cont pg 4...

Dear Friends

by Bob Lopes de Azevedo-Gilbert *cont...*

Some people on the train will leave an everlasting impression when they get off. Some will get on and get off the train so quickly, they will scarcely leave a sign that they ever travelled along with you or ever crossed your path.

We will sometimes be upset that some passengers whom we love will chose to sit in another compartment and leave us to travel on our own. Then again, there is nothing to say we cannot seek them out anyway. Nevertheless, once sought out and found, we may not be able to sit next to them because that seat is already taken. That's okay, everyone's journey will be filled with hopes, dreams, challenges, setbacks and goodbyes.

We must constantly strive to understand our travel companions and look for the best in everyone. Remember that at any moment during our journey, any one of our travel companions can have a weak moment and be in need of our help. We may vacillate, hesitate or even trip, hopefully we can count on someone being there to be supportive and understanding.

The bigger mystery off our journey is that we do not know when our last stop will come. Neither do we know when our travel companions will make their last stop. Not even those sitting in the next seat to us.

Personally, I know I will be sad to make my final stop... I am sure of it. My separation from all those friends and acquaintances I made during the train ride will be painful. Leaving all those I am close to will be a sad thing.

But then again, I am certain that one day I will get to the main station only to meet up with everyone else. They will all be carrying their baggage, most of which they did not have when they first got on this train.

I will be glad to see them again. I will also be glad to have contributed to their baggage and to have enriched their lives, just as much as they will have contributed to my baggage and enriched my life.

We are all on this train ride together. Above all, we should all strive to make the ride as pleasant and memorable as we can, right up until we can make the final stop and leave the train for the last time.



Inside Out Stoma Support Group Committee

Diane Owen, - Vice Chairman/Secretary - 4th April 2017

After many discussions at committee meetings held at The Windsock Club and the St. Mark's coffee mornings, it is with pleasure we can announce that IOSSG is to continue.

I would like to take this opportunity to thank those who have served on the committee over the past 22 years. Our debt to you is immeasurable. Thank you from all the members past and present for your valuable time and support over the years.

Those present for the first meeting of the new committee on 4th April 2017 were:

- Barry Caplan (Acting Chairman)
- Diane Owen (Vice Chairman/ Secretary)
- Janice Fitton
- Kathy Higginson
- Andy Coogan
- Ian & Liz McLuckie
- Tanuja Patel
- Cliff Mansi

Janice and Kathy were nominated as treasurers. They agreed.

Our balance today stands at £2,693.83.

Discussion about the annual Masonic fete that is held at the Royal Masonic School. Cliff says that as members of IOSSG are all getting older he has asked younger people to help out this year. He is asking for donations for the stall; any money made goes to St. Mark's Foundation.

Date of the fete is **Saturday 22nd July** not Sunday 23rd July (not as it was given at the meeting).

Tanuja will be the contact for future newsletters with Fittleworth. The next newsletter will be A5 as it will fit into the patients discharge pack that is given when patients are discharged.

Dates for your diary...



- **Saturday 20th May 2017**
Patient Open Day at St. Mark's
- Date of the next coffee morning:
Wednesday 5th July 2017
at 11.00am

Tomorrow's Doctor Finals March 2017

by **Andy Coogan**

Around 22 members of IOSSG volunteered as patients for Tomorrow's Doctor Finals at St. Mark's Hospital. It was an early start 8:00am (though not the very early 7:00am start as in previous years)

Our group were approximately one quarter of all the patients present. It was very enlightening and encouraging to see the very high standard of the candidates, who are the future of our country's health. It is a credit to the university staff at St. Mark's for the excellence shown by the candidates.

It was very pleasing to see the camaraderie and friendliness of the IOSSG group between themselves and with other patients who were on their own.

A big thank you to Anup, Briti and their crew for organising the event, with special thanks to the caterers for the lovely food prepared and served throughout the day.

Useful Contacts

Stoma Care (answerphone):

T: 0208 235 4110

Pouch Care (answerphone):

T: 0208 235 4126

Fredrick Salmon Ward (South):

T: 0208 235 4191 or T: 0208 235 4190

Fredrick Salmon Ward (North):

T: 0208 235 4022 or T: 0208 235 2387

Stoma Care Email:

E: Inwh-tr.stomacare@nhs.net

Pouch Care Email:

E: Inwh-tr.internalpouchcare@hns.net

Hello everyone my name is Barry Caplan

by Barry Caplan

'Who is Barry Caplan?' I hear you say and why should you know who I am? Let me give you a brief history about me. I will be 73 in the next few weeks. My ileostomy and I have been together come this October for 60 years.

At the age of 12 I became unwell and by the age of 13 I had my operation. I really didn't know what happened to me at first as nobody explained what type of surgery I was going to have, you just knuckle down and accept what you've been given. The main thing I remember was there was no pain after the surgery had settled down.

My adolescence was somewhat difficult as I still had to have several small operations. Meeting and making friends with girls was a big problem, I got hurt many times by girls who could not accept me and the bag.

Eventually, I met the right person and we have just celebrated our Golden Wedding Anniversary. We have two lovely sons and four fabulous grandchildren. When the family were young we had great fun camping, climbing Snowdon and had many holidays in Spain visiting my parents.

Bob in his wisdom has put me forward to take his place, which I am very honoured to accept. I have been associated with Bob and the charity for many years, before the name of "Inside Out" was thought of. You haven't seen me much over the last few years as I have been busy earning a living driving a London taxi. Having now retired I can attend more of our coffee mornings.

Those of you who have just assisted in the Tomorrow's Doctor Finals must agree that we all enjoyed ourselves and had a laugh. That's what life is about, enjoyment and laughter. Let's face it we have all been given a second chance of a pain-free life.

I wish you all well and look forward to seeing you at our coffee mornings. Please come along and meet everyone, we might be able to help you if you have a problem or you may be able to help someone else.

Don't forget the patients Open Day we are having on Saturday 20th May 2017, it should be fun.

Keep well everyone.

My name is Kathy Higginson, I have been with the Inside Out group for a year now. I thought I would let you know about a trip I had recently to Norway to see the Northern Lights. It was a Cruise of 12 Days.

The Northern Lights on P&O ship Oriana - 6th March 2017

Day 1

Left Southampton at 17:00 hours. We had a Life Boat drill in case we had to abandon the ship for any reason. We dined with two other couples. The cabin was very small not what we were used to.

Day 2

We were in the North Sea and the electrics all went off. We were motionless for at least an hour. It was funny not moving at all. We sat through a lecture about Astrology from Professor Alan Smith. It was formal night to night, everyone dressed up.

Day 3

Still at sea, coming into Aldasnes in Norway. We docked at approximately 10:00 hours. People were in the swimming pool and the Jacuzzi even though it was minus 6° but the water was warm. It was casual dress at dinner.

Day 4

Went into town, it was 3°, snowing in the wind on our way to the Antarctic.

DAY 5

On our way to Tromso should see the Northern Lights if we're lucky.

Day 6

On board again, another formal night. Next stop was Tromso minus 2°. Had a white out at 4am. The Filipino staff had never seen snow before and were dancing in it. They also made three snowmen.



The Northern Lights on P&O ship Oriana *cont ...*



Day 7

Today we saw huskies coming back from a 36 hour race. There were ice sculptures of all shapes and sizes and houses made out of ice.

Day 8

We are at sea again and it's cutting a bit rough now.

Day 9

I ended up in bed with sea sickness. The North Sea was very rough.

Day 10

Had something to eat for the first time today. I feel a bit better now, not so poorly.

Day 11

Had dinner with our friends. We shall be eating with them at breakfast in the morning.

Day 12

We arrived back in Southampton at 06:30 hours. Had breakfast then had to go and find all our luggage.

We were picked up by a family friend who took us home.

This trip was an experience. I did not see the Northern Lights, but my husband did.



Want to join our Support Group?

If you have a colostomy, ileostomy or urostomy and you would like more information, please complete the section below and send to: Diane Owen, Vice Chairman/Secretary, 170 Malvern Avenue, Harrow, Middlesex HA2 9HD



Name:

Address:

.....

..... Postcode:

Telephone:

Email Address:

Newsletter:

Please confirm below how you would prefer to receive the Inside Out newsletter.

Electronically via the email address above

By post to the address above

I do not wish to receive a newsletter

Welcome to the Inside Out Stoma Support Group

Important information:

**Annual membership subscription: £5.00, please make cheques payable to:
St. Mark's Foundation.**

Send to: Diane Owen, Vice Chairman/Secretary, 170 Malvern Avenue, Harrow,
Middlesex HA2 9HD

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IOSSG Coffee Mornings

10:00am to 12:00 Noon

Day/Date:	Venue:	Supplier:
Thursday 4th May	Post Grad 5th Floor	RESPOND
Friday 19th May	Medaware 6th Floor	CLINIMED*
Monday 5th June	TBA 6th Floor	OAKMED*
Tuesday 20th June	SeminarRoom5-6thFloor	CW ATOS
Wednesday 5th July	Post Grad 5th Floor	HOLLISTER**
Thursday 20th July	Post Grad 5th Floor	FITTLEWORTH
SUMMER HOLIDAY - ENJOY YOURSELVES - SEE YOU IN SEPTEMBER		
	Venue:	Supplier:
Monday 4th September	Medaware 6th Floor	DANSAC
Tuesday 19th September	Post Grad 5th Floor	SALTS
Wednesday 4th October	Medaware 6th Floor	RESPOND
Thursday 19th October	SeminarRoom4-6thFloor	AMI MEDICAL/SUPORTX
Friday 3rd November	SeminarRoom4-6thFloor	CUI
Monday 13th November	Post Grad 5th Floor	BRAUN
Tuesday 28th November	SeminarRoom1-6thFloor	PELICAN
Wednesday 13th December	Post Grad 5th Floor	CHRISTMAS PARTY
Note 1: *Venue may change ALWAYS check the signs		
Note 2: ** Please note different time - 09:30am to 11:00am		

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