

## We Need Your Help

*Ostomy Lifestyle is becoming busier than ever. Our Careline currently helps between five and ten callers per day on a range of issues relating to stoma surgery, from diet and exercise to body image and relationships. We send Ostomy News and printed information to over 15,000 people and provide training to companies, patient support groups and carers.*

Demand is increasing and we urgently need your help to keep these services operating. We need funds to ensure we can keep providing these services; over the last year we resolved over 6000 issues over the phone.

### There are lots of ways you can support us:

Make a donation. This can be a one off contribution or a regular pledge that will help us plan effectively from month to month. This can be done by post or via our website [www.ostomylifestyle.org](http://www.ostomylifestyle.org).

Organise a fundraising event, and have some fun at the same time. There are loads of possible events; organise a jumble sale, fun day, fancy dress party or run a marathon; the possibilities are endless!

You may be able to get your company to sponsor us, collect money or organise an event. You

can also give automatically through your payroll, and many companies will match your fundraising, making your donation twice as valuable!

For more information about fundraising opportunities or donating give Laura a call on 0118 3240069 or email [laura.sterling@ostomylifestyle.org](mailto:laura.sterling@ostomylifestyle.org)

Ostomy Lifestyle urgently needs your support. Please donate today.

## Ostomy Lifestyle & AW Cycles team up

*Cycling team [awcycles.co.uk](http://awcycles.co.uk) has joined forces with Ostomy Lifestyle. The Reading-based shop team races in all cycling disciplines and competes in some of the biggest races on the UK calendar.*

Former international rower and Team Manager, Tim Bedingfield had just taken up road racing when he had ileostomy surgery five years ago.

Tim quickly got back to an active lifestyle and sporting career, and now wins road, time trials and track races all over the country.

“Dispelling some of the myths about stoma surgery is a big motivation behind my racing”, Tim says, “I want to take the opportunity to promote a clear message that although everyone faces different challenges, life can return to normal and indeed be much better.”

“I could see that the way that I view my stoma is absolutely the way Ostomy Lifestyle view life after surgery, and the reason behind the work they do.”

Ostomy Lifestyle is grateful to the all of the team and Andy Wilkins,



owner of AW Cycles, for their support helping promote a positive message across the country.

Visit [www.teamawcycles.co.uk](http://www.teamawcycles.co.uk) for information about the team and the riders.

## Another award for Laura!



*Ostomy Lifestyle's new fundraiser already has shelves full of awards, (she's won nine so far this year for voluntary projects) and has just added another trophy to her list of achievements.*

The Socially Responsible Student of the year award was awarded by Real World magazine and Price Water House Coopers. Laura won the award for the innovation and flair she showed in the area of community, charity and motivating others to get involved in volunteering.

*"I still cannot believe I won, there were over 200 entries from across the country!"*

Laura recently graduated from Birmingham University where she was heavily involved in various fundraising projects, and is full of enthusiasm to get fundraising events under way for Ostomy Lifestyle.

## Do you have Crohn's disease?

*Considerable genetic research has led to greater understanding of the causes of Crohn's disease. A ground breaking study is seeking smokers who are close relatives of patients with Crohn's disease, to better understand the causes of this condition and how it can be prevented.*

So if you have Crohn's, King's College London would like to hear from your parents, siblings or children if they fulfil all these criteria:

- Aged over 18
- Smoke 5 or more cigarettes a day
- Do not have Crohn's disease or ulcerative colitis
- Live in the UK or Republic of Ireland

The study is conducted entirely by telephone so taking part is easy, and relatives who take part will find out more about their risks of developing Crohn's disease and how they might reduce these.

For more information please contact Sophia Whitwell on 020 7188 9778 or email [Sophia.Whitwell@iop.kcl.ac.uk](mailto:Sophia.Whitwell@iop.kcl.ac.uk)

## National Launch

*After a year of research and preparation, we presented to dignitaries and representatives from charities, hospitals and companies at our National Launch Evening in Reading.*



Deputy Lord Lieutenant of Berkshire Dr Christina Hill (above) gave special recognition to Nigel Piercey (above) of CliniMed Ltd, who have supported Ostomy Lifestyle from the beginning, and Mayor of Reading Councillor Peter Beard made presentations of thanks to the many volunteers who help establish the charity.

In her speech Dr Hill said *"It is wonderful to have another national charity based in the Royal County of Berkshire. Ostomy Lifestyle is dealing with an important issue in a positive way"*.

## Volunteer's Voice



### Alex

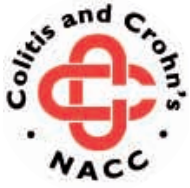
I wanted to help others in similar situations to my own, and have only been with the charity for a

few months but already feel part of a fantastic team that cares strongly about people affected by stoma surgery.

I was born with an imperforate anus and have had a colostomy from birth. I am now 22 years old and enjoy a very active lifestyle. I like swimming, tennis, football, fishing and outdoor pursuits such as walking and climbing.

My colostomy has never been a problem for me and I feel I can do whatever is thrown my way. My hope is that I can inspire others to feel the same way.

## Other Support Groups



# NACC - Improving life for people affected by Colitis and Crohn's Disease (IBD)

*The National Association for ulcerative colitis & Crohn's Disease (NACC) provides support and information for IBD patients & their families, and raises public and political awareness to achieve positive change for those affected by IBD. They also promote research into all aspects of IBD and strive to improve healthcare services & provision for IBD.*

NACC has 30,500 members, 70 local Groups and over 1,000 active volunteers. NACC's information and support services are available to anyone affected by IBD:

### Information Line:

Information Officers answer queries from anyone affected by Colitis or Crohn's Disease, giving information on topics such as employment and insurance as well as more complex medical information, including the symptoms of IBD, diet and drugs and their potential side-effects.

**Weekdays from 10am to 1pm.  
0845 130 2233**

### NACC-in-Contact:

A supportive listening service. Trained volunteers give people the chance to talk confidentially to someone with personal experience of

living with Crohn's or colitis.

**Weekdays from 1pm to 3.30pm  
and 6.30pm to 9.00pm.  
0845 130 3344**

### Parent to Parent:

Volunteers have children with Colitis or Crohn's Disease and are trained to offer other parents the chance to talk to someone who can really understand.

Available by telephone appointment to any parent with a child of school age or under the care of a paediatric gastroenterologist.

**Membership & Administration:  
01727 830038 [www.nacc.org.uk](http://www.nacc.org.uk)**

## Southampton PCT Tender – Update

*After this edition of Ostomy News went to print, we received an update from Southampton City Primary Care Trust (PCT). The original tender for the supply of stoma care products has been withdrawn, and a major review of this service is underway.*

By including stoma care within a wider strategy of 'enabling' patients in the region, the PCT will be able to provide better multi disciplinary support before and after stoma surgery. The plans include community nurse clinics and

a drop in information centre for advice and information, as well as links to other primary/secondary care services and support organisations.

Chris Webb, Specialist and Clinical Equipment Services Manager, said: "Southampton City PCT is committed to ensuring our clients receive the best possible care. We are re-evaluating how we provide services to people with a stoma, to provide an opportunity for focussing on a person's needs and concerns, rather than solely on which product should be supplied."

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Ostomy Lifestyle is pleased to see that Southampton City PCT is taking this opportunity to consult with stakeholders: "By taking a measured approach and reviewing services in this manner, there is an opportunity to improve services for everybody".

We will provide a further update in the next issue of Ostomy News.

# Be a model for Ostomy Lifestyle

Are you proud of your stoma surgery? Are you an example of Positive Living?

You could be a positive influence for others and make an impact by helping us to promote images of happy, healthy people who are confident and above all aren't afraid to talk about their stomas and show off their experiences to the world.

We want your positive images to include in leaflets, information sheets and our website, as well as finding candidates for more exciting projects, including our underwear and swimwear show!

If we invite you to take part in further projects you will also receive:

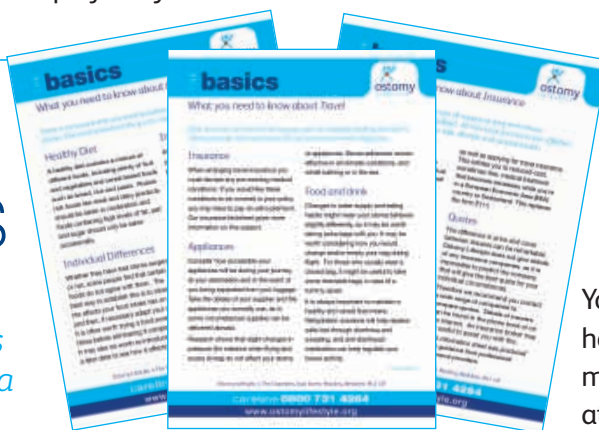
- Professional photo shoot
- Professional make up & hair styling
- Professional styling advice
- Lots of other goodies!

We're looking forward to hearing from you; send us some photos of yourself getting on with your life and state what sorts of modelling you would like to be considered for (e.g. sport, fashion, medical information, underwear etc) to [models@ostomylifestyle.org](mailto:models@ostomylifestyle.org)

## Resources

We produce an increasing range of information sheets on subjects relating to stoma surgery. These cover the basic facts on issues such as diet, travel, insurance and bag selection, so that you have all the essential information when you need it, and don't waste any time finding what you need.

If you're out and about or going overseas, our **Lifestyle Card** explains in several different languages that you have a stoma, and what that means in terms of toilets, travel and security searches, as well as some useful phrases.



Do you need more leaflets, newsletters or posters for your support group or department? See the resources page on the website to view leaflets and update your details to receive more copies.



### Events Diary

Do you have an ostomy event happening in your area? – let us know!

You can see the online diary of hospital open days, support group meetings, and information sessions at [www.ostomylifestyle.org](http://www.ostomylifestyle.org). If you know of an event or are organising one you can have it listed where everyone can see it – just fill out the form online.

### Training

Our education programme is becoming extremely successful. We now offer a one day course for anyone who provides support or services to anyone affected by stoma surgery, especially support group volunteers, company representatives, nurses and carers, and a shorter information session for groups. See the website for more information.

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