

Clyde Network

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MEDIA CAMPAIGN

BY EDMUND MURRAY

In April Crohn's & Colitis UK launched the next phase of their "Not Every Disability Is Visible" campaign and I was asked to be the campaign's spokesperson in Scotland, doing media interviews for organisations who wished to find out more. I was initially contacted by the Daily Record and a phone interview was arranged between myself and Vivienne Aitken, the paper's Health Editor. I was on holiday at the time so did my side of the interview on Plockton beach looking out over Loch Carron. A tough job but someone had to do it. I didn't get the chance to see if the article was published but if it was, then I hope it went some way to raise awareness of the campaign with their readers.

When I returned from holiday I was invited on to the Mornings show on BBC Radio Scotland. I was joined in the studio by Raven Lane, a young woman with

arthritis and fibromyalgia, and we both spoke about our experiences of being challenged in public for using accessible toilets. Both of us had been challenged quite angrily by members of the public for using accessible toilets so hopefully our stories highlighted to the listeners that not every disability or long-term condition is visible to others.

A couple of weeks later Radio Scotland phoned me again and asked if I would take part in another feature about the lack of public toilets available nowadays. I was all primed and ready to go for the next day as requested but that turned out to be the day Theresa May announced her resignation as Prime Minister so they didn't have the time to fit in that feature on the programme. However, these were interesting events to be involved in and just a small part of the overall UK-wide campaign.

CLYDE NETWORK FEEDBACK

We often receive feedback on the day from those members who kindly attend our meetings but rarely hear from those of you who can't manage along to Glasgow for members' meetings. In order to develop a spirit of inclusivity we would like to invite you to send in comments to our network email address.

We would welcome ideas and suggestions for the types of speakers or topics you might be interested in, or some information on what prevents you from attending meetings. Also welcome would be your general views on the network. All feedback will be collated and discussed by the OT.

The email address for your comments and/or suggestions is: clyde@networks.crohnsandcolitis.org.uk

MEET THE TEAM Jennifer Arthur



I'm a new member of the Clyde network volunteer team and am looking forward to some new challenges in my life.

I was diagnosed with ulcerative colitis about 8 years ago, after many years of gut issues that had been previously attributed to IBS. Unfortunately, I have been one of the few that did not respond to the treatments and now have an ileostomy with a wee stoma I call Bella. There have been many challenges along the way, but

I'm now hopefully on a better path for the future. I've had amazing care and support from my health care team and have joined Crohn's & Colitis UK as a Volunteer as I now want to give something back. I managed to volunteer at the Edinburgh Walk It event last year, met some lovely people and here I am now. This year, I signed up to complete the 5K... albeit pretty slowly! I really hope that I can help other people affected by IBD, raise awareness and help raise funds. I look forward to meeting more IBD family in due course.

CLYDE NETWORK ORGANISING TEAM

Following the recent AGM, our current Organising Team is nine-strong, including our two new members, Jennifer and Luke.

We are:

- Edmund Murray (Lead Volunteer)
- Connor Stuart (Treasurer)
- Janice Taylor (Newsletter Editor)
- Jennifer Arthur
- Amy Bednarz
- Luke Farrell
- Matthew Hilferty
- Rhi Humphrey
- Robert Mason

STOMA DAY IN STIRLING *by Jennifer Arthur (Volunteer with Clyde Network)*

I had the opportunity to attend an open day for ostomates in May. This event is held bi-annually and is organised by the stoma nurse team in Forth Valley Royal Hospital. Venues are chosen in both Falkirk and Stirling alternately.

All those with a new stoma (less than one year) are automatically invited to attend, by letter. You are asked to bring a stamped, addressed envelope on the day if you wish to be invited to the next event. I was only too happy to go along, as I'm still learning, and I think that many will relate to that feeling.

The day was held in a local hotel and hosted by one of the stoma nurses. The great thing about this was the informal opportunity to chat and discuss any concerns without a formal appointment.

Many of the large medical companies were there and the idea was that all attendees were freely able to chat to the reps, discuss any needs or problems and request samples

of pouches and other stoma accessories. Information was also available to take away on various topics such as skincare, leaks and odour control. There was further information on suitable exercise and rehabilitation guidelines, to help patients improve their recovery from surgery and regain core strength. All could be discussed with the stoma nurse too. Refreshments were provided and it was a good opportunity, for those who wanted to, to chat to other ostomates and share experiences.

Representatives from Colostomy UK were present. The local representative from the Ileostomy Association was unfortunately unable to attend on this occasion. The afternoon concluded with an informative talk from the stoma care team on resources available, both in the local area and generally. Information shared included:

- Local support groups
- Carer groups
- Fitness facilities and classes suitable post op and for those

with health considerations

- Transport discounts and help available
- Information relating to Crohn's & Colitis UK, Ileostomy Association, Colostomy UK
- Information on a healthy diet

Plenty of tea, coffee and tables were available to sit and chat to others, share experiences and just generally enjoy the day. I came away armed with information, samples and more to follow by post. All in all, this was a productive day which I found to be very useful.

I will definitely attend the next event. It is worth checking what is available in your local area; always good to see what new products are available, discuss issues with the stoma support team and meet others in a similar position.

NB: The next event will be held on Thursday, November 21st between 1pm and 3.30pm in the Leapark Hotel in Grangemouth. Clyde Network will have an information stall at this event.

CLYDE NETWORK AGM 25TH MAY TISSUE SOLUTIONS

Our talk at this year's AGM was from Morag McFarlane, PhD, from Tissue Solutions, which she described as a 'Virtual Biobank'. Morag set up Tissue Solutions in 2007 and has 22 staff members at its Glasgow HQ. They facilitate the transfer of human tissue, such as blood, urine, faeces, saliva, skin and tissue from biopsies to help biobanks access tissue for studies, acting as a facilitator between hospitals and scientists working in research and development.

The process of developing new drugs can take 10-15 years, going through different stages. Tissue Solutions become involved during the basic research, prototype design and pre-clinical development stage to ensure that tissues are used ethically for the correct purpose in the development and testing of drugs. Tissue Solutions ensures that the right material is used for the right experiment, that the materials used are of good quality, that donors consent to their tissues being used and that they are delivered in a timely fashion. Aspects such as the temperature of samples, effective packaging, customs

clearance and delivery times are taken into consideration. The disease areas where the company's work is utilised include oncology, brain disorders, inflammatory conditions, autoimmune conditions, cardiovascular disease, blood disorders, infectious diseases and metabolic diseases such as diabetes.

Morag ended her talk by showing some examples of studies where Tissue Solutions were involved, including a Crohn's Disease study and an Alzheimers study.

A short Q&A followed with one member asking what 'identification of stratogenic markers' meant. Morag replied by explaining that some people respond to some treatments better than others.

Further discussion revolved around the issue of patient consent and one contributor stated that, when his colon was removed during surgery, he was asked for his consent to his tissue being used in future.

Edmund Murray led the meeting in thanking Morag for her talk.

RESEARCH OPPORTUNITIES

Many of us like to feel that, despite the impact our illnesses can have, we can make a difference to others who are affected by them. Some of us do this through volunteering; raising money for research and activities or hosting information stalls and meetings to reach Crohn's and Colitis patients as well as the wider public.

But there is another way in which many of us can help others affected by Crohn's or Colitis; by becoming involved in research.

In this newsletter we have shown you how one Glasgow-based company does work to aid research into different diseases. Crohn's & Colitis UK also plays a huge part in funding research and in providing opportunities for patients to get involved.

People affected by Crohn's or Colitis can join Crohn's & Colitis UK's **Research Community**. If you are interested in doing this the charity will help to connect you to the latest research news and the types of opportunities that may be relevant to you.

It is very easy to help our research work. Go to the website crohnsandcolitis.org.uk, click on the heading 'Research' and follow the left-hand page links to 'Research Involvement Opportunities' to see how you can take part in research which may be very relevant to your own future.



Clyde Network AGM

DATES FOR YOUR DIARY

CLYDE NETWORK EDUCATIONAL MEETING

21 September, 1:30pm
Adelaide's, Bath Street, Glasgow

Nancy Greig from Crohn's & Colitis UK and the Alliance will give a talk about the charity's Self-Management Project.

STOMA INFORMATION DAY

Thursday 21 November 1:00-3:30pm
Leapark Hotel, Grangemouth

Clyde Network will host a stall at the Forth Valley Hospital Stoma Information Day, where there will be nurses on hand to answer questions about living with a stoma, preparing for life with a stoma, exercise, diet and other related factors.

POUCH INFORMATION DAY

23 November
Jury's Inn, Jamaica Street, Glasgow

Pouch Information Day; a joint meeting with West and Central Scotland Ileostomy Association.

CLYDE NETWORK EDUCATIONAL MEETING AND CHRISTMAS LUNCH

7 December 1:30pm
Adelaide's, Bath Street, Glasgow

Sarah Sleet, the new CEO of Crohn's & Colitis UK, will give an update on the working of the charity.

Sharon Tait will talk on Neuro-Linguistic Programming and Hypnosis.

As always, we are on the lookout for raffle prizes and ask members who attend to bring a contribution if possible.

If you have received this newsletter by post and would be happy to receive future editions by email please provide your name, membership number and email address to networks@crohnsandcolitis.org.uk.

This will save the network valuable funds which can be used to benefit all those affected by Inflammatory Bowel Disease.

The Clyde Network has made every reasonable effort to ensure the content of this newsletter is accurate, but accepts no responsibility for any errors or omission. The views of the contributors do not necessarily reflect the views or policies of Crohn's & Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.

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HELPLINE

Our helpline is a confidential service providing information and support to anyone affected by Crohn's Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease (IBD).

Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide information to help you to live well with your condition
- help you understand and access disability benefits
- be there to listen if you need someone to talk to
- put you in touch with a trained support volunteer who has a personal experience of IBD

CONTACT US BY:

Telephone: 0300 222 5700*

Monday, Tuesday, Wednesday and Friday - 9 am to 5 pm

Thursday - 9 am to 1 pm

Email: info@crohnsandcolitis.org.uk

Web Chat (Live Online): see our website for details

**Calls to this number are charged at a standard landline rate or may be free if you have an inclusive minutes' package. Calls may be recorded for monitoring and evaluation purposes.*

NEWSLETTER

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