

## Herefordshire Group

### THE YEAR SO FAR...

Catch up with what the team has been doing over the last few months and what is planned for this year!

By Jan Stevenson

#### FUNDRAISING

At the end of 2015 the Herefordshire Group of Crohn's & Colitis UK sent an amazing £5,000 through to the Head Office central fundraising to support research and development to improve treatments, or even a cure, for IBD. This was a fabulous amount to have raised by a small group of volunteers, putting on events and fundraising activities over just a couple of years. However, a huge thank you to everyone else who supported these activities and donated money - it could not have been done without you.

Even more exciting now is that we are getting other people who are affected by Crohn's or Colitis offering to do their own fundraising events. The first of these are Kate Thomas and her daughter who raised a stomping £710 from a fundraising at the local rugby club. They came along to our Education Evening in March and said that they would like to do some fundraising for us - and then a few months later a cheque arrived! It was amazing and so encouraging for our group to get this boost. Many many thanks to Kate and her mother Shan.



Kate Thomas and her son

In addition, last year, a Herefordshire man with Crohn's Disease ran a marathon and raised £3,000; and a 22 year old is doing a bingo night and charity nail-paint at work to support Crohn's & Colitis UK research.

We would be TRULY delighted if more people might like to join our fundraising effort - and in the process raise awareness of IBD and its two main diseases, Crohn's & Colitis. We are happy to give you any advice, support or literature, etc that might help. Ideas could be a coffee morning, open garden, car boot stall, supper party, school charity nomination, or a sponsored event - or anything you can think of, however small or local...

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**INCREDIBLE  
BRAVE  
DETERMINED**

CROHN'S &  
COLITIS UK

#### CALLING NEW VOLUNTEERS!!

We are always looking for new organising team members, or even someone who could help out at one of our events.

Even a few times a year. Please get in touch with us at the Herefordshire group and we will welcome you with open arms ☺

For more information, visit:  
[www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

## EDUCATION EVENING

### Latest Medical Developments:

The 2016 Herefordshire Crohn's & Colitis Education Evening got off to a great start with a Dr Milestone whistle-stop tour of the latest medical developments. These covered new biologics for both Crohn's and Colitis - some still in development, but a range now approved for NHS use. He also explained about much improved testing techniques to help diagnosis of IBD and also to measure the efficacy of the drugs prescribed - or to tell if people are taking their drugs correctly!

It was a fast-paced and informative talk which gives hope to all IBD patients: showing how this is an area where research and funding is currently focused and is delivering a range of new drugs/ products, greater understanding and potential for longer term relief from symptoms.

### MAP Bacteria and Vaccine for Crohn's:

The second speaker of the evening was Professor John Hermon-Taylor of Kings College London. His talk illustrated the journey his research had taken to find the roots of Crohn's Disease, based on research into a very similar disease in cattle, called Johnes Disease, which is well known to farmers. Johnes was first noted in Germany early in the 20<sup>th</sup> century and spread as cattle started being moved abroad. Growth rates of the disease were particularly notable in Iceland which was a "closed" island economy but mirrored the import rates of cattle. He then went on to identify and isolate a bacteria, *Mycobacterium avium* subspecies

paratuberculosis (MAP), which comes from the same family as Tuberculosis and Leprosy and was found in all the diseased animals (cows, sheep, goats, rabbits, etc). However, the MAP bacteria is very difficult to see even under huge magnification and has the ability to "hide" or change. The recent breakthrough has been the creation of antibodies marked with dye that attach to the MAP bacteria and can then be scanned to see and measure the distribution of MAP. We were shown photographs of MAP from infected cattle guts; and from people with Crohn's disease - both looking identical. From this, Professor Hermon-Taylor has developed potential vaccines which can disable MAP bacteria - both stopping its activity on the immune system and preventing re-occurrence. These vaccines are now coming to the final stages of testing, the most critical and expensive ones, that of testing on humans. Firstly this is done with "healthy" people, and then on people with Crohn's. The MAP vaccine team are inundated with people offering to be "Crohn's" guinea pigs for the testing - but would be delighted to hear from any healthy volunteers aged 18-45 who could get to Oxford and want to help (see: Jenner Institute volunteers).

Thanks to all our speakers for their time and commitment. We are planning to have another education evening next year.



L - R. Professor John Hermon-Taylor, Dr Andy Milestone, Jan Stevenson and Clinical Nurse Specialist, Gastroenterology Elaine Horne

## IBD and Sport

The final talk of the evening was with the return of Jon Clarke who talked about his personal experiences of living with Ulcerative Colitis. With a love of sports and now working as a sports scientist, Jon explained about both the mental and physical benefits of doing exercise, getting started, and feeling positive about doing something that can be social, enjoyable and helpful to IBD. His light-hearted, enthusiastic personal approach made for a relaxed end to the evening.



Jon Clarke - Author of "Shituation"

# DATES FOR YOUR DIARY

## SOCIAL MEETINGS

**Wednesday Coffee Mornings -**  
**September 28th, December 7th**  
**(10.30am-11.30am, All Saint's Café)**

**Saturday Get-togethers - September 3<sup>rd</sup>**  
**at The Imperial - Hereford 10.30am-**

### SAVE THE DATE

**Hereford Town Centre Walk – Sunday 7<sup>th</sup>**  
 August walk – 10 for 10.30am start.  
 Families and walkers £3 each or £5 per family. Imperial pub in Hereford will be our base.

**Ladies Night - Wednesday 28<sup>th</sup>**  
**September.** £10 a ticket at Debenhams Hereford 7pm.  
 You will receive Bubbley and Canapes on arrival! There will be a Fashion Show and Beauty Demonstrations. Also Live Music and a Raffle. You will also receive a Goody Bag, with some great gifts.  
 Debenhams are also offering 20% discount on any clothing purchased on the night.

Tickets available from Eventbrite, Phase Eight Hereford or our Facebook page. Click [here](#) to buy a ticket

**Quiz Night - Merton Hotel Friday 11<sup>th</sup>**  
 November - MAX 6 per team £5 per person. 7.30pm for 7.45pm start. Contact our facebook page or a member of the team to take part

*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 [groups@crohnsandcolitis.org.uk](mailto:groups@crohnsandcolitis.org.uk).*

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

*The Herefordshire Group 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 and Colitis UK and no reference in this newsletter to any product or service is intended as a recommendation.*

## CONTACT US



### HEREFORDSHIRE GROUP

Chairperson: Jan Stevenson  
 Group telephone: 0845 130 6824  
 Website: [www.crohnsandcolitis.org.uk/herefordshire](http://www.crohnsandcolitis.org.uk/herefordshire)  
 Email: [herefordshire@groups.crohnsandcolitis.org.uk](mailto:herefordshire@groups.crohnsandcolitis.org.uk)



[Crohns and Colitis UK](#)  
[Hereford Group](#)



[@CCUKHereford](#)

### Crohn's and Colitis UK

45 Grosvenor Road, St Albans AL1 3AW

[enquiries@crohnsandcolitis.org.uk](mailto:enquiries@crohnsandcolitis.org.uk)  
[www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

Charity registered in England Number 1117148  
 Charity registered in Scotland Number SC038632  
 A company limited by guarantee in England:  
 company number 5973370

### INFORMATION SERVICE

Trained Crohn's and Colitis UK Information Officers answer questions on IBD  
**0300 222 5700**  
 Mon-Wed & Fri 9am-5pm, Thu 9am-1pm (except English bank holidays)  
 Answer phone service outside these hours

### CROHN'S AND COLITIS SUPPORT

Confidential support from trained Crohn's and Colitis UK volunteers who have personal experience of living with Ulcerative Colitis or Crohn's Disease,  
**0121 737 9931**  
 Monday-Friday, 1pm-3.30pm & 6.30pm-9pm

### DISABILITY BENEFITS

Call the Information Service on 01727 734 470 to arrange a telephone appointment with a trained volunteer for help with Disability Living Allowance or Personal Independence Payment (PIP)

### PARENT TO PARENT

Call the Information Service on 01727 734 470 to arrange a telephone appointment to talk to another parent who has a child with IBD.

*Calls to all our 0845 numbers cost 7p per minute plus your phone company's access charge.*