

## **NEWS**LETTER

Autumn 2016

Issue 35

### Family Network England

#### FAMILY DAYS, CHRISTMAS AND 2017

Family Network England aims to run even more activity days in new areas around the country.

This year we held an event in Kingswood near Doncaster, Longridge near Marlow and will be holding our Christmas event in Milton Keynes (find out more on page 2 of this newsletter). Reaching more areas and more new families than before!

#### **NEXT YEAR**

Right now we are actively planning our events for next year. We're planning to hold four events around the country in 2017, so look out for info on the website and in our next newsletter. To give you an idea of what is to come, we are looking at potentially running events in Merseyside, Oxfordshire, the Midlands, and on the South Coast.

#### **CCUK FAMILY DAYS**

From the feedback forms at our events we are aware that many of you are interested in attending medical talks.

CCUK have two Family Days which involve exactly that coming up in the next couple of months in Leeds and North London. Where Gastroenterologists and IBD Specialist Nurses will be giving talks and answering your questions.

For more information about these days, you can read about them on page 2 of this newsletter or call 01727 734472. If you're interested, be sure to register through the Family Days page of the CCUK website!



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# A PARENT'S GUIDE

CCUK has a series of over 40 publications, available to download for free online, about all aspects of IBD to help aid understanding of the condition.

One new booklet is 'IBD in Children - A Parent's Guide', which is written specifically to help parents understand the condition itself, tests that may be needed and the treatments available.

As well as aiding understanding, it also looks at some of the more general questions and challenges that parents may face, giving tips and suggestions based on the experiences of other parents with a child with IBD.

For more information, visit: www.crohnsandcolitis.org.uk

# OUR FUTURE EVENTS

Christmas is coming and what better way to get in the festive spirit than snow-based activities, crafts and games!

On the 3<sup>rd</sup> December, come to Milton-Keynes' Xscape for a Christmas event that's bigger and better than ever. Not only will our usual crafts and games be available but now we'll be spending even more time on the slope.

#### **ACTIVITIES**

- Sledging
- Crafts & Games

#### AND

Skiing Lesson

#### OR

Snowboarding Lesson

For a suggested donation of just £10 per person with the child with IBD going FREE, this event is a steal and even includes catering for the day.

The deadline for registering has been extended to the 15<sup>th</sup> of November. But to make sure you don't miss out, make sure you book now to avoid disappointment! Just fill in and send us the form attached at the end of this newsletter.

And as always, don't forget to bring a raffle prize along!





#### OTHER EVENTS

#### **CCUK's Family Days!**

The Leeds and District Group, in partnership with the NHS, is running a great family day at Headingley Carnegie Stadium on the 29<sup>th</sup> of October.

Whilst on the 13<sup>th</sup> of November a North London family day is being held at White Hart Lane, home of Tottenham Hotspur Football!

These days will include:

- Entry to an iconic stadium
- Activities for children aged 5 and over
- Medical Talks by Gastroenterologists and IBD Nurse Specialists
- Free Lunch

These days are another great opportunity to meet other families with IBD, but also talk with medical professionals and ask any questions you may have.

To register for these events go to the Family Days page of the CCUK website!

# NOT EVERY DISBABILITY IS VISIBLE CAMPIAGN

Asda has recently rolled out new disabled toilet signs in 421 stores reminding customers and staff that not all disabilities are visible and to make those with invisible disabilities more comfortable in using disabled toilets.

You can help support our campaign to see that other supermarkets do the same by sending our campaign email on the CCUK website under Campaigning.

For a limited time new CCUK members who join via direct debit or debit/credit cards, can also receive a free RADAR key, which gives access to locked disabled toilets under the National Key Scheme. You can also buy a RADAR key from



#### **PAST EVENTS**

Stacking, Splashing and Shooting at Longridge.

On the 3<sup>rd</sup> of September we enjoyed a long day packed with activities in Longridge, in association with the Berkshire Local Group!

The day started with some icebreaker activities and games, from trying (and failing) to learn everyone's names in a game of catch to trying to grab a cone before your opponent and become the champion of the cone.

The rest of the day was filled with four of a huge range of activities.

Some headed out together onto the water in a dragonboat, working together to race down the Thames, whilst others jumped into kayaks to race each other, playing a variety of games. One such game involved throwing a ball at the other boats to claim them to be on your team until only one team remained.

The water zorb activity was hilarious to watch and great fun to do, as you struggled to stand inside an inflatable hamster ball and tried to stay upright or take more than just a few steps before inevitably falling over!

Laser Combat was an extremely popular activity, and for good reason, as teams





fought each other in the outdoor arena and defended their base. Avoiding getting shot was very difficult and so there was a lot of running back to the respawn point to reenter the fray.

Many took on Longridge's huge 13m climbing wall, racing to get to the top or challenging themselves in trying out more difficult routes.

Close by were those taking on the challenge of crate stacking. Three people stood atop the increasingly wobbly structure as they continued to build it entirely out of crates, until they fell and swung around suspended in mid-air.

At the end of the day, everyone came back together for the raffle, which raised £182!

Overall the day was a great success. The event was entirely free, thanks to the funding given to us by the Waitrose 'green coin' collection and the money raised by the Dinton Walkers.

#### HOLIDAYS AND IBD

Planning a trip during the holidays can be hard enough without the additional problems IBD can cause.

This is why CCUK has produced Information Sheets such as 'Travel and IBD' and 'Insurance and IBD' to help guide you through the planning process and to see that you make the most of your holiday. Covering everything from Insurance to Medication and Medical Documents.

Whilst many of you may know that 'Can't Wait' cards (a discreet and useful card to help explain urgent toilet use) are available to members, did you know that you can get them in different languages for your trips abroad? So if you're going abroad, be sure to contact the Information Line to find out more about this!



PLEASE HELP -

The holder of this card has Inflammatory Bowel Disease and needs to use your toilet facilities urgently.

I hank you

CROHN'S& COLITISUK Registered charity numbers 1117148 (England and Wales) SC038632 (Scotland)

#### DATES FOR YOUR DIARY

#### MILTON KEYNES EVENT

Date: 3<sup>rd</sup> December 2016 Venue: Milton Keynes - Xscape

Book now using the form at the end of this

newsletter!

#### OTHER CCUK EVENTS

Date: 29th October 2016

**Venue: Headingley Carnegie Stadium**Book now through the Family Days page on

the CCUK website!

Date: 13<sup>th</sup> November 2016 Venue: White Hart Lane

Book now through the Family Days page on

the CCUK website!

#### **OUR THANKS**

We'd like to thank Brian Oatway from the Berkshire Local Group for his help at our Longridge event.

And give another big thanks to the Waitrose 'green coin' collection and money raised by the Dinton Walkers which made making Longridge free for all families attending possible.

#### **CONTACT US**

## CROHN'S & COLITIS UK

Family Network England

Chairperson: Andrew Collis Treasurer: David Pearson Newsletter Editor: Emma Collis

Website: crohnsandcolitis.org.uk/support/support-for-

families/family-network

Email: fne@groups.crohnsandcolitis.org.uk

Crohn's and Colitis UK

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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.

Family Network England 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.

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.

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

# CROHN'S &

# Family Activity Day – XScape, Milton Keynes Saturday 3<sup>rd</sup> December 2016

NAMES OF ALL PEOPLE ATTENDING	18 OR UNDER &	RELATIONSHIP TO CHILD WITH	CHILD DATE	We are offering Sledging p Tick the relev	ng Siedging plus a choice of a Skiing or a Snowboan Tick the relevant box or if you'd rather watch put 'W'	We are offering Sledging plus a choice of a Skiing or a Snowboarding Lesson. Tick the relevant box or if you'd rather watch put 'W'
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Dietary Requirements: (Please give name and details)	ind details)		αI	REMINDER: Personal Kit - Please wear suitable and appropriate clothing for the activity.	se wear suitable and appro	priate clothing for the activity.
			21	IS THIS YOUR FIRST EVENT?:	Yes/No	
Home Address:			គាគាខា	Telephone No.: Email Address. Crohn's and Colitis UK Membership No.:		
Suggested Donation Free for Child(ren) with IBD + a suggested donation of £10 per person for rest of family (Please make cheque payable to "Crohn's & Colitis UK (NACC)")	donation o	(NACC)7)	for rest of fami	ly £ endosed		
Photographs During Family Network England events, photographs may be taken for use or editorials for promotional purposes.	nay be taken f	or use in Crohn's and	Collis UK/Family	In Crohn's and Colitis UK/Family Network publications and/or web site, as well as online and in published newspaper and magazine features	as well as online and in published	d newspaper and magazine features
I give permission for any photographs taken of my family to be used for such purposes.	of my family	to be used for su	ch purposes.	Signed.		
Signature Town RETURN THIS FORM TO CROHIN'S & COLITIS UK, C/O SUPPORT SERVICES TEAM, 45 GROSVENOR ROAD, ST. ALBANS AL1 3AW  BY TUESDAY 15th NOVEMBER 2018	Print Name	ROHIVS & COLIT	TIS UK, C/O S	OLITIS UK, C/O SUPPORT SERVICES TEAM, 45 GROSVENOR ROAD, ST. ALBANS BY TUESDAY 15th NOVEMBER 2018	nd would like details of futu 5 GROSVENOR ROAD, S	ire events: