

CHit CHat

Official newsletter
of OUCH UK - The
Organisation for the
Understanding of
Cluster Headaches.



OUCH(uk)TM

Spring 2016

www.ouchuk.org

NEW EDITOR



Chloe Bailey

OUCH(UK) is delighted to announce we have a new editor of CHit CHat, trustee and member, Chloe Bailey. Chloe, a chronic sufferer, joined OUCH(UK) in 2012 and was recently appointed a trustee. She and her husband Fraser are enthusiastic fundraisers for OUCH(UK) and Chloe has previously worked with Fixers, an organisation that helps young people make positive changes to their lives based on their life experiences. She has appeared in press items, been the subject of a video, and done her utmost to raise awareness of Cluster Headache. We welcome her as our new editor and if you have items for CHit CHat, please e-mail submissions@ouchuk.org.

EUROPEAN CLUSTER HEADACHE AWARENESS DAY

OUCH(UK) are pleased to announce, in conjunction with The European Headache Federation and European Headache Alliance, we will be promoting the first ever Cluster Headache Awareness Day. This will be held on **21st March 2016**.

We welcome fundraising efforts by our members for this day, and we can provide you with Cluster Headache Awareness Day posters to put up in your workplace, local GPs, and in your community, as well as sponsorship forms and information leaflets. If you are planning to promote Cluster Headache Awareness Day in your local area, please email info@ouchuk.org.

OUCH(UK) will be participating in the Under The Hat campaign as part of the European Headache Alliance, to build interest and awareness for Cluster Headache Awareness Day. We will provide OUCH(UK) members a platform to share their story of Cluster Headache, and the impact it has on their lives. We aim to inspire public compassion for Cluster Headache, making the invisible visible, and giving this condition the priority it deserves. We want to show that this disorder can affect anyone, and for patients to feel empowered by sharing their story.

We ask our members to submit your photo and story of Cluster Headache to submissions@ouchuk.org, but there is a twist! We want you to take a photo of yourself wearing a hat – this hat can be a simple beanie or baseball cap, or you can get creative with fancy dress! You could even make your own; it's completely up to you!

Your submitted photos and stories will then be uploaded to the OUCH(UK) website and Facebook page on Cluster Headache Awareness Day (21st March). We will be

encouraging members to use their released photo across social media platforms, as well as sharing the album of photos and stories, to increase the awareness of the Under The Hat campaign. We will be promoting the hashtag #UnderTheHat for this campaign. We hope you will all get involved in this campaign, and help OUCH(UK) promote the first Cluster Headache Awareness Day!



OUCH(UK) NEWS

Scotland Conference 2016 – 3rd April

OUCH(UK) are pleased to announce a return to Scotland, with our first ever meeting in Aberdeen at Scotland's Rural College [SRUC] Craibstone Campus. We have scheduled a full programme of events specifically aimed at cluster headache sufferers and supporters.

As usual the event will be a mixture of presentations from the UK's top neurologists, information sessions and opportunities to meet and talk with other Cluster Headache sufferers and share experiences.

Our medical speakers will give us an overview of Cluster Headache and other primary headache disorders, the current treatments available for Cluster Headache, which treatment trials are in progress, and what the future holds for Cluster Headache both in treatment and management.

- **Dr Alok Tyagi** Consultant Neurologist (Southern General Hospital, Glasgow)
- **Dr David Watson** General Practitioner (based in Aberdeen, special interest in headache disorders)
- **Dr Giorgio Lambru** Consultant Neurologist (Guy's and St Thomas' Hospital, London)
- **Dr Anish Bahra** Consultant Neurologist (Whipps Cross Hospital, London)
- **Jason Clark** Specialist Volunteer (employment), Officer of OUCH(UK)
- **Fraser Bailey** Supporter, Trustee of OUCH(UK)
- **Carolyn Matheson** Sufferer, Officer OUCH(UK)

Tickets can be purchased through the OUCH(UK) website, and we are delighted to inform you that OUCH(UK) members receive 20% discount off conference tickets. Accommodation is available on-site, and can be booked via Gwen Bruce at www.sruc.ac.uk/info/120214/aberdeen_holiday_lets



Scotland's Rural College, Aberdeen

LONDON MEETING NOVEMBER 2015

OUCH(UK) were invited by Guy's and St Thomas' Hospital in London to host an event at Guy's Campus. This to OUCH(UK) is significant as it is recognition that what we do is on the correct path regarding information days.

Guy's Campus was different for a multitude of reasons; over two years the trustees and officers have slowly embarked on changing the way in which we present our conferences and meetings, away from long lectures (which too many felt repetitive), to a more structured and yet informal day. So on a foggy day in the shadow of the Shard, the team prepared to put on one of their biggest and boldest events.

Our Neurologists are always a great draw at these events, and Dr Giorgio Lambru and Professor Peter Goadsby's talked summed up perfectly the optimism that is felt about the upcoming treatments for Cluster Headache. A whole raft of new treatments are being trialled: a range of stimulators for Cluster Headache are currently being trialled ranging from surgical options where electrodes are implanted along the spine; a device implanted below the cheek bone and stimulated externally; the continuing study of the non-invasive Gamma core device. Other trials in focus were the ongoing CGRP antibody studies. Professor Goadsby is also taking forward brain mapping as a study, and is looking for willing volunteers. (He also gently reminded us to gift him our brains... once we are done with them, of course)

A welcome and always fascinating talk was provided by Dr Alex Nesbitt, often referred to as the Sleep Doctor! Dr Nesbitt's continuing study into the role of sleep in Cluster Headache and the body's circadian rhythm, as well as how the seasons impact on Cluster Headache. Key points from his lecture confirm that the Spring Equinox sees a huge spike in Cluster Headache activity (No surprise for many of us) and one of the reasons that March 21st is now named Cluster Headache Awareness Day.

Jason Clark, one of OUCH(UK)'s Officers, made his public speaking debut in London. His work for OUCH(UK) is becoming more diverse since his introduction just a few short months ago. Jason did a presentation on Cluster Headache and Employment Law. A complex subject, but hopefully with Jason's advice many of you in work can gain some assistance. Jason can be contacted via rights@ouchuk.org.

One of the things we introduced to meetings some time back was our workshops. These are small groups where attendees can ask the OUCH(UK) team questions, or indeed each other, on a variety of topics. Our most popular workshop is usually on Medications, followed hard on the heels by our Supporters Space. OUCH(UK) believe it is very important that the supporters are supported too. This is so important to us that we have a dedicated supporter on our helpline, and another representing on the Board of Trustees.

Overall the day was a huge success! Those who attended from the pharmaceutical industry and the Demand Valve manufacturers went home significantly more informed about Cluster Headache. Sufferers and Supporters alike left with more hope that we are understanding Cluster Headache better, and that it is a subject neurologists are studying and are interested in.

WALES CONFERENCE 2016

OUCH(UK) are busy planning a conference for Autumn 2016 in South Wales. More information to follow, and keep an eye on www.ouchuk.org for details of where, when and how to book!

GIVE AS YOU LIVE AND EVERYCLICK

Give As You Live is a shopping and price comparison website, which is completely free to use. Simply register on www.giveasyoulive.com and choose OUCH(UK) as your chosen charity. Every time you purchase something through Give As You Live, OUCH(UK) get a percentage back as a donation. There is also a handy app/toolbar to remind you when you are online shopping.

Everyclick is a search engine which raising money while you search! If you are registered with Give As You Live, you can log in on <http://www.everyclick.com> and help OUCH(UK) raise money while simply browsing the internet.

OUCH(UK) has received close to £200 in donations from these fundraising platforms since signing up. Every penny counts!

N.I.C.E. GUIDELINES

We know many sufferers experience difficulties getting the right treatment prescribed by GPs and even getting a referral to a headache neurologist. In response to this in 2014 we produced a document called 'The Basics' which detailed how to get a referral to a neurologist, and how to get the correct treatment for your diagnosed condition. However, some GPs are still resistant to prescribing the right drugs in the right quantities and even referring a sufferer to a headache neurologist. At last, official guidance and help is at hand from NICE [National Institute for Healthcare and Clinical Excellence] with the publication in November 2015 of their Management of Headache Pathways including a section devoted to Cluster Headache.

You can find this document in two ways, go to <http://pathways.nice.org.uk/pathways/headaches> and then click on 'Management of Headaches' and select 'Cluster Headaches', or find the link to the pathways site on the Resources page of the OUCH(UK) website. Acute treatment recommendations include the Imigran injections/nasal sprays and high flow oxygen. It also details what NOT to prescribe, ie: opioids and NSAIDs. Preventive treatment includes Verapamil, and it goes on to detail interventional procedures too, such as the new SPG implant and DBS. We suggest you download this information from the NICE website and take it with you to your GP.

YOUR DATA

It has recently been in the news that some charities are outsourcing their fundraising to firms, who use high pressured telephone techniques to convince people to donate. OUCH(UK) would like to make it very clear that we do **NOT** share membership data with any other organisation, and will not be using these outsourced firms to raise money.

DRUG TRIAL UPDATES AND REMINDERS

CGRP TRIAL

The trial into CGRP [calcitonin gene related peptides] in the treatment of Cluster Headache is still ongoing, but now includes chronic sufferers as well as episodic. If you are recently diagnosed, but not yet on a preventive medication, you could be a great candidate for the trial. If you would like to take part, please e-mail your contact details including your phone number, your status (ie: chronic or episodic) to info@ouchuk.org. Your application will be forwarded and a member of the research team will contact you direct. This trial is taking place at Kings College Hospital in London, and will require several trips to London over a period of eighteen months.

FUNDRAISING ENDEAVOURS

THANK YOU to all these wonderful heroes, raising awareness and vital funds for OUCH(UK)! We are so grateful for your support.

Karen Garrett's young son Tom nominated OUCH(UK) to be his school's, Aylesbury Grammar School, Charity of the Year. He gave a presentation on Cluster Headache and the work we do. OUCH(UK) won the nomination and £368 was raised! What a smashing lad and a brilliant supporter of the cause on behalf of his mum.

Kevin Crook, who runs a paranormal events team, organised a charity event in Drakelow Tunnels, Kidderminster, in October 2015. The event raised £150 for OUCH(UK)!

In November 2015, Cedars Upper School in Leighton Buzzard ran their annual Help Week, a week dedicated to raising money for charity. This year, the school council elected to donate £1500 of the final £7000 raised to OUCH(UK).

Tracy Wakefield has recently completed the Great South Run for us, raising over £500, and her manager has added £100. She has already secured a place in the Great North Run 2016 for OUCH(UK).

Phil Smith, an episodic CH sufferer chose two charities for the Scunthorpe and District provincial grand lodge of RAOB to raise money during his year as PSP charity's fundraiser. He chose OUCH(UK) and St. Andrews Children's Hospice Grimsby. They raised £1175 for each charity by holding two Motown nights in Scunthorpe, and a fun day at Grove House Harrogate.

Telephone Technology in Long Eaton, Nottinghamshire, nominated us as a recipient for a charitable donation of £100.

And legal firm, Smith Williamson LLP also nominated us recipients for a Christmas donation of £200. Sufferer Simon Moore's wife is an employee of Smith Williamson, hence our nomination.

FUTURE FUNDRAISING EVENTS

GOOD LUCK to all our members who have signed up to raise money for OUCH(UK)! Jo Johnson has signed up to complete the Plymouth half marathon in April.

Carolyn Arnold is running the Sheffield half marathon in April, in memory of her friend, Crispian.

Chris Booth is running the Great Manchester Run for OUCH(UK) in May.

Liam Dennis and a team from Debenhams Norwich have chosen OUCH(UK) as one of two charities they will fundraise for this year. The team started off with a quiz night which raised £250. The team will be climbing Mt. Snowdon in June. Various other activities throughout the year will take place in-store with further outdoor events, to try and exceed their £2000 target. To sponsor the team, please visit Virgin Money Giving and search 'Dennis Dennis.'

Brian Munro is embarking on an epic sailing adventure around Britain this year, with his partner Lisa, a cluster headache sufferer, joining him on some of the journey's legs. You can track Brian's progress on his blog sailingaroundbritain.co.uk, and help him smash his £5000 fundraising target by sponsoring him via the OUCH (UK) website, under 'Events'. You could even join Brian on a leg of his adventure!

FUNDRAISING FOR OUCH(UK)

We always appreciate the efforts our members go to fundraising for OUCH(UK)! If you are planning an event, or promoting OUCH(UK) in the media, please let us know via email to info@ouchuk.org so we can thank you in future editions of CHit CHat!



Andi Barnett, OUCH(UK) Officer, accepting a cheque from Phil Smith, PSP charity fundraiser.



Tracy Wakefield at the Great South Run



Brian Munro and partner Lisa

CHATTER AND CHART

CHit Chat will now feature a Members Page, where we invite you to show off your creative talents. If you would like your artwork, poetry, or short stories to be featured in future editions of CHit CHat, please email submissions@ouchuk.org

You Couldn't Make It Up!

Long story, but may make you smile. Today for the first time I had to pick my son up off the supermarket floor. He was hysterical! Whilst I was having an attack in Aisle 2, stamping and banging my head on his shoulder, a very caring lady who works there came over and asked to help. My son announced, 'She's fine, she has clusters!' The lady ran off, which is not unusual when I'm in public, however she returned, running down the aisle, clasping a box of crunchy cluster cereal in her hands! "They were in Aisle 5" she announced! My son went to pieces rolling about laughing on the floor, with me still unable to explain. I handed her my OUCH(UK) card which she looked at and said, 'Sorry love, can't read without my glasses and I have a banging headache! You would not believe how much pain I'm in!' She made my day!

Submitted by Anonymous



'Me and My CH' by David Griffiths

'My Daughter Chrissy' by Ann Harper

*My daughter Chrissy is a real smarty,
She beats up her monster,
Because she's a black belt in karate.
She can sing and dance and makes us all laugh,
And when she's around it's beautiful to see!
She is so good looking,
With her long blonde hair,
And what people think of her,
She just doesn't care.
But there is just one problem with our Chrissy,
She has chronic pain that she lives with and it
drives her insane!*

*Her monster is waiting for her in the grooves of her staircase,
Which no one can see.
It's big I think, with red eyes and pointy teeth and it just sits there
waiting for her!
We don't know why it's there,
People just don't believe that it's there.
But I know it's trapping her waiting at the top of them stairs.
The other day it nearly caught her, she was trapped, frozen with fright,
But her little boy came in and scared it away,
By giving her love and hugs,
And then he said 'Mummy don't be silly I am here but I shall keep that
monster away so we can go outside and play again!'*

'Eugene the Monster in My Head' by Kevin Crook

*I think of you, I haven't slept,
I think I do but I forget,
My body moves, I can't keep still,
It never goes, it's always there,
First my ear starts a-ringing,
I know I'm going to get a beating,
So my eye starts to water and just goes red,
As you stick your poker in my head,
Then as quickly as you come, you finished having fun,*

*You just leave me feeling numb,
Wondering will this ever end,
And you're always in my head,
You're always in my head!
Just wishing this nightmare would end,
And one day you will be gone,
Just as quick as you come.
But until then the fight goes on and on.*

Contact Us

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OFFICIAL NEWSLETTER OF OUCH (UK)
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