

CHit CHat

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



OUCH(uk)TM

Summer 2014

This issue has exciting news of our **London Conference**, set to be the largest gathering of cluster headache sufferers in Europe, with topline speakers, if you only attend one event this year, make it this one.

We're also paying tribute to and saying thank you to all our wonderful fundraisers, you'll see the unusual and blood tingling ideas and events that have taken place and are due to take place and we'll publish the final totals from them all in our next issue.

And a very poignant quote from a letter OUCH has received, illustrates just what this disease can do to sufferers lives and reinforces OUCH (UK)'S remit to raise awareness of this terrible condition.



Val Hobbs
Editor

CHAIRMAN'S REPORT TO APPG

In our last issue you may remember that Mike Pollock, our chairman, produced a report on how cost savings to the NHS treatments budget might be achieved by switching cluster headache patient oxygen users to ultra high flow demand valve oxygen and we asked you all to write to your MPs and send a copy of the report. We had replies from several MPs forwarded to us, including one from Lord Howe, Parliamentary Under Secretary of State for Health, who was interested in the reports findings.

We continue to press for this treatment to be formally trialled and accepted as a standard NHS treatment for CH, - thank you everyone who wrote to their MPs, we couldn't do it without you. Mike presented this report to the APPG on Headache disorders in June and that event was even reported in the International Daily Express in Australia, so the message is getting round the world now!



Julian takes to the skies for OUCH!

A FUNDRAISING SUMMER!

It's a fundraising summer for OUCH, which started with sufferer **Julian Yates** doing a wingwalk on May 31st at Rendcomb Airfield in Gloucestershire. He and his colleagues at NatWest West Somerset Business Team will be doing other fundraising events, such as a car wash, throughout the summer. OUCH is one of two charities chosen by the group to benefit from 50% of the funds they raise over the course of the summer. Very grateful thanks to Julian and everyone in the group.

Jayne Pomeroy's son is a sufferer and she wanted to raise funds for us and along with a group of friends arranged a Family Fun Day at Old Redcliffians Rugby Club in Brislington, Bristol on Sunday July 13th. There were stalls and bouncy castles, fancy dress, tombola, tug of war, airballing and all the fun of the fair and they raised over £1,000 for OUCH.

Also on the same day, **Sal O'Reilly** who is a sufferer and must be a very charming lady as she persuaded a group of eight friends, her husband and eleven year old son to do a sponsored zip wire ride on the longest and fastest zip wire in Europe at Zip World in Llechwedd in North Wales. The video's are wonderful, the shouts of joy from her son as he reached his Dad at the end of his run were heartwarming and we learnt some new swear words from his Dad on his run!

They have so far raised £1,000 and the money is still coming in.



Tug of War at the Family Fun Day.



Sal's family and friends getting ready to zip for OUCH.

If you can be braver than that, **Liam Dennis** might take the cake, Liam from Norfolk [up the Canaries!] is doing a tandem Skydive on Sept 28th. He has set up a Virgin Giving page here: www.virginmoneygiving.com/liamdennis.

Liam is a chronic sufferer, but has already done a bike ride for us in 2013 and spares no effort to help other sufferers. If he is brave enough to jump out of a plane knowing he might have an attack at any time, then as he puts it, 'its got to be worth a few pennies from you all.' Go Liam! Good luck on the 28th, don't forget to hang on!

Is there a hint of daredevil in a CH sufferer, do we dare because we know there's nothing worse than a CH attack??? Answers on a postcard please!

Katie Collier whose mum is a sufferer and her friends at Lever House School in Preston raised £73.78 for us by having a stall with OUCH merchandise at their school charity week. Thank you to everyone at Lever House and especially to Katie who organised the stall.



Katy Scrivener

And **Katy Scrivener** in Leighton Buzzard in Bedfordshire is having her dreadlocks shaved and is getting her family and friends to sponsor her! The headshave takes place at the Black Lion pub, Leighton Buzzard on Saturday 23rd August, you can sponsor Katy here: www.virginmoneygiving.com/KatyScrivenor.

Let's hear it for our fundraisers!
A huge thanks to all of you who have gone more than the extra mile for all CH sufferers.

WALKING TO CHRISTMAS

Huge and belated thanks to **Nadia Joseph** from London, who raised the magnificent sum of £687 by doing a sponsored walk last November.

Nadia was supported and sponsored by friends and family and to gather such a large sum in the run up to Christmas was quite an achievement. We're all geared towards the festive gifts and food and don't have much cash to spare at that

time of the year, so very well done and grateful thanks to Nadia and family. We hope you weren't too footsore after your magnificent effort.

As always every penny is gratefully received and enables us to maintain our helpline, our website and to produce printed information for sufferers, the medical profession and the public.



Daredevil Liam Dennis!

SHREWSBURY MEETING

Late spring saw the first meeting we have held in English/Welsh border country at Shrewsbury, birthplace of Charles Darwin.

As always the day commenced with a meet and greet session where newcomers to CH have a chance to speak to another sufferer. Our event feedback from previous events tells us that many newcomers value this part of the day and the chance to talk to another sufferer, sometimes for the very first time and they leave our events having made friendships with others who understand totally what they are going through.

Helpline volunteers Andrya Barnett and Sandra McDowell and Trustee Scott Bruce gave a presentation, 'Pain so Severe', talking about how to deal with CH and living with the condition, both as a sufferer and as a supporter and offered advice to newcomers to OUCH and CH.

Trustee Peter May brought us up to date with the Ultra High Flow Oxygen Diary Study that OUCH is conducting into UHF oxygen delivered via a demand valve. The results so far are very, very clear that this is a treatment that works and works fast to abort cluster headache attacks.

When the study is complete the results will be presented to relevant authorities such as NICE, MHRA and relevant departments in the NHS so that a full trial can be undertaken and this method of oxygen therapy be adopted as standard treatment for CH under the NHS. Not only is the treatment fast and effective, but it is also very cost effective [more on that elsewhere in this issue].

The first of the popular group workshop sessions followed on four subjects, Supporting a Sufferer; Treatments and getting them prescribed; Neurosupport and assistance with employment matters; and oxygen therapy. Each attendee had the chance to attend two workshops of their choice, one at this session and one at the session that followed after lunch.

The next speaker was very warmly welcomed as he had stepped into the breach at less than 24 hours notice; Dr Giorgio Lambru, consultant neurologist from St Thomas' Hospital, London. We were due to hear from Dr Brendan Davies, but unfortunately he had to withdraw at the last moment. Dr Lambru talked to us about the headache service at St Thomas' and the integrated multi-disciplinary approach they will be adopting at St Thomas for CH and severe headache sufferers.

After lunch, helpline volunteers Andrya Barnett and Sandra McDowell gave a short presentation on the work of the helpline – Sandra's husband Andy is a sufferer and is our helpline manager and Andrya is a sufferer herself. All our helpline volunteers are either sufferers or supporters of sufferers. Andrya and Sandra's presentation was followed by the second group workshop session.

Our final speaker was our patron Professor Peter Goadsby, now based at Kings College Hospital, London. With his usual humour and insight, he spoke to us on upcoming treatments for CH and what may be available in the future. Again our feedback tells us many left the meeting with a feeling of hope for the future, having heard the professor's presentation.

We closed the day with a question and answer session with the medical professionals and the next meeting is north of the border at Kirkcaldy on 20th July.



Group workshop at the Shrewsbury meeting.

OUCH SCOTLAND REGIONAL MEETING

In July, Scotland hosted 2 very significant events, after a 2 year absence an OUCH (UK) regional meeting at the Victoria Hospital, Kirkcaldy on July 20th, and some sports day! The OUCH event was well attended by sufferers and supporters alike who listened eagerly to the speakers who had given up their free time to come and speak to us.

First up was Scott Bruce, one of our Trustee's a local voice, who presented a layman's view of the condition. Next up was another of our Trustees, Peter May who gave an important update on the Charities continuing diary study on ultra high flow oxygen; this method of aborting Cluster Headaches continues to provide excellent results, which we hope will lead to a full clinical trial.

Our medical speakers for the day were, Dr Anish Bahra, of the National Neurological Hospital, London and Whipps Cross Hospital London; Dr Giorgio Lambru of St Thomas' Hospital, London and our keynote speaker was Dr Alok Tyagi, clinical lead of the headache group at the Southern General Hospital in Glasgow. Each speaker looked at a different aspect of Cluster Headaches; Dr Bahra taking on the causes and diagnosis, posing several questions about the causes of CH and its mechanisms.; Dr Lambru discussing many of the up and coming treatments for cluster headaches and in his presentation slides showed some

innovative abortive devices that are being considered for future treatment of CH.

Dr Tyagi was our keynote speaker of the day and his presentation was cluster headache and its treatment but with a Scottish flavour; for those sufferers who live south of Hadrian's Wall, sufferers in Scotland must be referred to a neurologist to obtain oxygen.

Another change of meeting format was started at Kirkcaldy, drop in sessions during refreshment and lunch breaks where sufferers and supporters could ask questions of trustees and officers on various subjects, the subjects on offer were benefits advice, supporters, Treatments (abortive and preventative) and Treatments Surgical and Trials all were well attended with everyone benefitting from the sessions. The more relaxed approach proved very popular.

Not all went to plan however, Scotland decided to throw an unusually warm July day that resulted in significant heat problems inside the venue. I dare say a few sufferers could out pace Mr Bolt in the 100m Sprint if an O2 bottle was at the finishing line. And we apologise for the discomfort we know many of you suffered that day. The day ended with a question and answer session with the medical professionals and the next OUCH meeting will be in London in the autumn, see elsewhere in this issue for details.

NEW DOWNLOADS ON THE OUCH WEBSITE

We've just added two new documents to the downloads section of the OUCH Resources page on the website; a document called 'New to CH' which outlines what to do when you have been diagnosed with CH and how to get treatment, what to ask for and who to ask for it. We'll be sending a copy to every new member too, in the membership pack.

The other new document is a tri-fold leaflet, 'Pain So Severe' which is useful to show to

potential sponsors for fundraising events, show to non-sufferer friends and family. It has a description of CH in layman's terms and all the contact details for OUCH. Useful too to put in display holders at events and also in doctors' surgeries and pharmacies.

You'll also find there the Part A H00F form for prescribing oxygen and the Fact sheet/note for colleagues, similar to the trifold leaflet described above.



OUCH CONFERENCE AT ST THOMAS' HOSPITAL, LONDON

SUNDAY OCTOBER 19th 2014

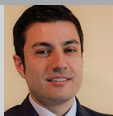
We are delighted to announce our next meeting will take place on October 19th 2014, in London in the Governors' Hall at the world renowned St Thomas' Hospital by kind permission of Guys & St Thomas Hospitals Trust, Dr Adnan Al-Kaisy Clinical lead and Consultant in Pain and Neuromodulation and Dr Giorgio Lambru, consultant neurologist of St Thomas' Hospital Headache Team. This will be a very special meeting as we have some topline speakers.

CONFIRMED SPEAKERS

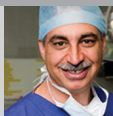
Prof. Peter Goadsby
OUCH patron and director of the
Welcome Trust Neuroscience research
facility at Kings College Hospital.



Dr. Giorgio Lambru
Consultant Neurologist and Lead of
the Headache Service at Guy's and St
Thomas' NHS Foundation Trust.



Dr. Adnan Al-Kaisy
Clinical Lead and Consultant in Pain
Medicine and Neuromodulation at Guy's
and St Thomas NHS Foundation Trust.



Dr. Anish Bahra
Consultant Neurologist, National Hospital
for Neurology and Neurosurgery and
Whipps Cross Hospital.



Prof. Lance McCracken
Lead Psychologist at INPUT Pain Management
Centre at Guy's and St Thomas' NHS Foundation
Trust and Professor of Behavioural Medicine at
King's College London.



OUCH Trustee Peter May



The conference will be focused on different aspects of cluster headache, including the clinical presentation and diagnostic challenges, the burden and disability related to cluster headache, the current medical and surgical treatments, besides the future of cluster headache management, including a new integrated approach to treating cluster headache sufferers. There will be drop in sessions where members can discuss issues with trustees and officers.

The day will start at 9.00am and the final event of the day will be a Question and Answer session with all the experts – your chance to ask a burning question of the best headache experts in the UK and indeed, even the world! The day will end around 5.00pm.

Because of the very high quality and number of speakers, tickets for this meeting will be limited to two per application, but if you have a higher ticket requirement, please contact info@ouchuk.org.

Tickets are £12.50 each - £6.00 children.
Ticket cost subsidised by OUCH (UK).

You can book at www.ouchuk.org or by post using the form on the next page. Don't forget to note any dietary requirements when you book and book now to be sure you don't miss an opportunity to hear the best of the best on cluster headache.

COMPUTER SECURITY

In recent months there have been several scares regarding computer virus' and compromising of open source software between users and servers.

We'd like to reassure members that our website and database remain secure and protected. However, we also need you to take steps to ensure that your data remains secure and we suggest the following:

- **Change your passwords at least once every 3 months.**
- **Never use the same password in more than one place.**
- **Keep your passwords secure and not easy to guess.**
- **Use a password database!**

Not many people know about or do this, but there are numerous, free applications available that will securely store all your passwords on your local PC, protected by a master password.

Check out **www.keepass.info** for a free application.

Be safe!



OUCH Conference 2014 | BOOKING FORM

Name (Ticket 1):	
Name (Ticket 2):	
Address: (Inc Postcode)	
Dietary Requirements:	
Special Assistance:	

Please return, with your cheque made out to OUCH (UK) for the appropriate sum to:
OUCH (UK) Meetings, P O Box 62, Tenby SA70 9AG

WHY OUCH WILL CONTINUE TO FIGHT FOR AWARENESS

Every so often we hear from family members that a sufferer has passed away, and recently we heard from a lady in Scotland whose partner of 21 years, who was a sufferer, passed away very suddenly while only in his fifties. We quote below part of her letter which was very moving and illustrates all too graphically just how much CH can affect a person's life; in fact in this case he really didn't have a life, read what his partner says:

I was partner to Peter for 21 years in a loving relationship which produced 2 children. Our son is only 8 years old.

Peter eventually conquered CH by finding the triggers. In doing so, he diagnosed himself with multiple chemical sensitivity. However, in doing so, he gradually isolated himself from the outside world. By June this year, Peter was stick thin because he avoided most foods and had very little company as mostly everyone wears perfume of some description nowadays, either through shower gels, perfumed washing powder or even fragranced candles in their homes adhering to their clothes. He often thought of writing to you to disclose his findings – his cure as he thought it. Sadly now, looking back, I can see that his fear of this horrible disease returning greatly reduced his quality of life. When he thought he had beaten the disease, it was clearly beating him.

Peter was well-built, charismatic and sociable when CH first struck him, but over the years, his obsession with beating it turned him into a virtual prisoner, a shadow of what he used to be.

I will sign off here, the memories are very painful. I hope, truly in my heart, that one day brings a real cure for this affliction.

Thank You

No-one should live a life like that, and this is why we need to raise awareness of the condition, to help not only sufferers, but also their families.

Contact Us

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