

CHit CHat

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



OUCH(uk)TM

Autumn 2015

www.ouchuk.org

MIKE POLLOCK – Obituary



Mike Pollock

On Saturday June 20th, our much loved and respected Chairman, Mike Pollock passed peacefully away surrounded by his family at his home. He had been suffering from cancer for some months, but typically he kept his health problems to himself and put everyone else first. He fought this final battle with great courage, dignity and humour. Every CH sufferer in the UK has benefited in one way or another from Mike's unceasing hard work tracking down treatments, approaching government departments, working with the NHS to raise the profile of CH and to gain OUCH a reputation as an expert patient group.

A sufferer since childhood, Mike joined OUCH in 2002 and became a Trustee in 2003. He served as treasurer for a couple of years and in 2011 he was unanimously elected chairman. During the 12 years he was a member, Mike also volunteered on the helpline and hundreds of sufferers have had his valuable advice, guidance and support, sometimes to the point of him driving round to see them and take oxygen for them to try. He also attended employment tribunals and benefits hearings, assisting sufferers in the battle for fair treatment from employers and applying for benefits for this literally disabling condition. Right up until a few days before he passed away he was still involving himself in OUCH business. We will probably never know the full extent of the tireless work that Mike did for and on behalf of sufferers, not just in the UK, but all over the world.

Mike was a gentleman – a gentle man – totally selfless, generous, warm-hearted and loving. Through Mike's efforts and hard work, awareness of cluster headache has progressed to the level that OUCH is recognised as an expert patient group by the NHS – they contacted Mike to ask for our details to put on the NHS Direct website. Mike pioneered the occipital nerve stimulator implant procedure as the first recipient in the UK. Hundreds of us have had this procedure and it has changed our lives for the better. Mike discovered by trial and error that a triptan tablet taken at night could give a sufferer a night's painfree sleep, much needed when you are in a severe bout or if you are a chronic sufferer, as Mike was. He discovered the half life properties of another tablet which enables sufferers to get through 24 hours without an attack. Again giving a respite to severe sufferers and ensuring that sufferers don't miss a family celebration, can give presentations, attend interviews, in fact any situation where you really do not need an CH attack. After a trip to the United States where he tried ultra high flow oxygen, he was instrumental in setting up the diary study which OUCH is conducting and which has brought relief to many severe sufferers.

Just eighteen months ago Mike authored a report on treatment costs to the NHS for CH sufferers and he found that if oxygen was properly and appropriately prescribed, there would be a saving of millions of pounds a year to the NHS. Mike followed up anything and everything that might help CH sufferers, because as a chronic sufferer he well understood what living with CH was like.

In the four years of his chairmanship he has forged links with consultants, headache clinics, headache nurses, support groups, pharmaceutical companies, the Department of Health and the NHS. He has spoken at parliamentary receptions for the All Party Parliamentary Group on Headache Disorders and taken up every interview opportunity in all media.

Mike's funeral took place at Golders Green Crematorium on 24th June. His brother Philip gave the family eulogy, filled with humour and warmth and Professor Goadsby gave a very moving eulogy on behalf of OUCH, honouring Mike for all he had done to promote awareness of CH, its treatment and diagnosis. There were no flowers at Mike's specific request, but instead donations to OUCH (UK).

OUCH owes so very much to this truly unique and wonderful man – the foregoing only scratches the surface of Mike's achievements in raising awareness of CH, actively supporting sufferers, and constantly trying to find treatments that will help; and, as ever, working towards that wonderful day when there is a cure.

Our heartfelt sympathies are extended to Mike's lovely wife Jane, his son Luke and partner Diana, as well as his wider family.

Messages of condolence may be sent by e-mail to: val@ouchuk.org, or by post to: **OUCH (UK), P O Box 62, Tenby, Pembrokeshire. SA70 9AG**

APPOINTMENT OF NEW TRUSTEES

Following the sad death of our chairman Mike Pollock, at an extraordinary general meeting on 24th June, Professor Peter Goadsby – our patron- already a member of the board, was nominated as chairman and was unanimously elected. Mike's tenure as chairman will be a hard act to follow and the Board felt that Professor Goadsby was equal to the task. Colin Allen was unanimously elected vice-chairman, and Peter Wynne Davies becomes company secretary, also unanimously elected. Fraser Bailey, husband of member and sufferer Chloe Bailey, was again unanimously elected a trustee. Also at an earlier Board meeting, Elizabeth Kelly, one of our helpline volunteers and an OUCH officer was appointed a trustee with responsibility as Helpline Manager. Welcome all of you to your new roles in OUCH.



Peter Goadsby
Chairman



Colin Allen
Vice-Chairman



Peter Wynne Davies
Company Secretary



Fraser Bailey
Trustee



Elizabeth Kelly
Trustee & Helpline Manager

STUDY INTO CGRPs

Study into CGRPs in the Treatment of Episodic Cluster Headache

Professor Goadsby is conducting a trial of calcitonin gene related peptides [CGRPs] in the treatment of episodic cluster headache and the team at Kings College are looking for volunteers. You will need to be just starting your cycle or at least expect to start before the end of September, be an episodic sufferer on no preventive or at least not started your usual preventive. Please contact info@ouchuk.org with your name, contact details and date of birth. These will then be forwarded to the team at Kings who will call you direct to assess your suitability for the trial. This is a fantastic opportunity for sufferers to be at the forefront of medical research, which may go on to benefit hundreds of other sufferers.

SUN GENERIC SUMATRIPTAN INJECTIONS



Sadly, the Sun sumatriptan injections are no longer being manufactured, following a close-down of their production premises. There are still some available stocks in the UK, but eventually these will cease. Our advice to sufferers is that if they have been using the Sun injections, that you ask your GP to put on your prescription either, 'Imigran subcutaneous sumatriptan,' or 'subcutaneous sumatriptan'. This will assist the pharmacist so that you can be switched to Imigran injections. If anyone is still having difficulties sourcing the injections or indeed any form of sumatriptan please call the helpline; 01646 651979, leave your name and number and a short message and one of our volunteers will get back to you.

FUNDRAISERS

Way back in November of 2014, OUCH was nominated by Nathalie Staakman, whose partner is a sufferer, to benefit from a dress down day at her workplace, Zolfo Cooper in Manchester. Huge thanks to all her colleagues and to Nathalie for raising £113 for us.

OUCH members seem to have a penchant for jumping out of aeroplanes, sufferers Kevin Sutherland and Colin Simpson both did tandem skydives for us in May and Colin has raised over £1,000 in sponsorship and monies still coming in, and the same from Kevin. We are in awe of your bravery!

Trustee Dorothy Chapman's sons David, Colin and Tony, plus Tony's wife Sara, with two band mates who make up Four Worried Men did a gig for us and raised £600. Hooray for the Chapmans, and the FWM, lets hope we don't worry them too much!

FUNDRAISERS

Another concert, this time in memory of sufferer Crispian Baker and Crispian's family asked for donations in lieu of flowers at his funeral and raised over £1,000 in all. Thank you for remembering us at such a sad time.

NORMADS – The North Harrow Methodist amateur dramatic society amateur sent us £100 from the proceeds of their production of – 'Robin Hood'. Seems the Sheriff of Nottingham has been very good for a change! Thank you to the NORMADS.

CJ Conrad had his head shaved and raised over £700 – some friends must have been desperate for him to get rid of all that hair!

Chloe Bailey, OUCH officer, has been successful in getting 'Fixers' to work with her to raise awareness of the CH – she has already participated in a film being made of her having a CH attack and of how it affects her life. Bravery above and beyond Chloe, thank you!

Gary Ebdy did the Great Scottish Swim at Loch Lomond on August 29th, he did the two mile swim in 63 minutes and has raised over £1,000 and counting! Sponsor him here: uk.virginmoneygiving.com/fundraiser-web/fundraiser/showFundraiserProfilePage.action?userUrl=GaryEbdy.



NORMADS Robin Hood'

UP AND COMING FUNDRAISING EVENTS

The 46th Isle of Mull Car Rally has nominated OUCH as a beneficiary of charity funds raised from their rally on 9th -11th October – no doubt Sandra and Andy McDowell who are resident on the Isle of Mull [NB NOT the Mull of Kintyre!] will be cheering the participants on – and if motorsport is your thing and you need a holiday – well, the Isle of Mull sounds like the place for you! You can donate on the OUCH website, click on the link on the front page.

And a prize competition for OUCH members – see the website and have a go at winning a remote control rally car!

On October 25th supporter Tracy Wakefield is doing the Great South Run for OUCH, and you can sponsor her at: <http://uk.virginmoneygiving.com/fundraiser-web/fundraiser/showFundraiserPage.action?userUrl=TracyWakefield&fald=550216&isTeam=false>

What a wonderful mixture of events, something for everyone. Our very grateful thanks to all of you for every penny raised.



OUCH CONFERENCE AT ST THOMAS' HOSPITAL, LONDON

SUNDAY OCTOBER 19th 2014

This was something of a record-breaker of a meeting – the largest ever gathering of cluster headache sufferers in the world! Over 200 of us gathered in the historic surroundings of the Governor's Hall of St Thomas' Hospital, London, right beside Westminster Bridge and opposite the Houses of Parliament.

The day opened with the usual coffee and meet and greet session where newcomers can meet other sufferers and talk and ask questions and not have to explain! There was the OUCH pop up shop, selling t-shirts, wrist bands, pens etc, all proceeds to OUCH. There were also information tables, a chance to talk to helpliners and try out the Gammacore device at the Electrocore stand.

Val Hobbs welcomed everyone on behalf of the Trustees and gave a brief overview of OUCH fundraising activities in the preceding year, including the Ice Bucket Challenge!

The first speaker was Trustee Peter May, who gave an overview of the diary study he is conducting into ultra high flow oxygen therapy, delivered via a demand valve. He outlined how the UHF oxygen works and showed the results from the first tranche of volunteers. (NB The diary study has now been suspended for the time being.)

Dr Anish Bahra, a great supporter of OUCH and who has done much to help sufferers in the last few years, spoke to us on the diagnosis and pathophysiological aspects of CH. She was kind enough to compliment OUCH on the work that they do with sufferers on the helpline and on the website. Her presentation was clear and concise and in terms that the layman could understand.

Our next speaker should have been Professor Lance McCracken, Professor of Behavioural Medicine at King's College Hospital, but unfortunately he had been taken ill the day before the meeting and was at the time an inpatient at St Thomas'. We wish him well. Dr Richard Doherty, a clinical psychologist who is part of the Headache and Facial Pain service team at St Thomas', stepped into the breach at short notice and spoke to us of the behavioural aspects involved in pain conditions and the use of cognitive behavioural therapy in assisting sufferers to cope with their condition.

After lunch and drop-in sessions, Dr Giorgio Lambru, clinical lead of the Headache and Facial Pain service team, presented the medical management of CH and the approach used at St Thomas regarding treating not just the symptoms of CH, but the patient as a whole. His presentation began with a hard-hitting video clip of sufferers experiencing attacks, very often sufferers are reticent to talk about their attacks as their reaction to the pain can be very extreme; we are too well mannered, we don't like to upset people.

Dr Adnan Al Kaisy, co-clinical lead of the HFPS team followed on with the various injections procedures available to treat refractory CH and peripheral neurostimulation techniques

being pioneered at St Thomas', including sphenopalatine ganglion stimulation – as Dr Al Kaisy put it, 'real 21st century stuff'. Both presentations were lively and informative and gave us all great hope for the future.

After a coffee break and drop-in session, our patron Professor Peter Goadsby gave his presentation on ongoing trials and future management strategies for CH. The Professor asked us all to 'Stand up for Cluster Headache' and got us all to stand and wave our hands in the air. He tweeted his picture at the end of his presentation, with the hope it would go viral! Based now at Kings College the Professor is undertaking a trial of a drug known as calcitonin gene related peptides [CGRPs] as a preventive, firstly in episodic cluster headache [see elsewhere in this issue for details of the trial]. The Professor's presentation was informative and humorous as always and his positivity regarding the future was infectious.

The Professor also played back a special video message from a world famous figure who is a sufferer. Nobel Laureate, F W de Klerk, who was awarded the peace prize jointly with Nelson Mandela for freeing South Africa. Mr de Klerk has been a lifelong CH sufferer and just the fact that it was such a successful figure giving us that message, means that if you suffer CH you can achieve great things in life in spite of suffering this disease.

Following a question and answer session the meeting, the speakers were thanked for giving up their free time to come and speak to us and the meeting was then closed.



OUCH CONFERENCE AT LIVERPOOL MEDICAL INSTITUTION

SUNDAY 7th JUNE 2015

After a three year break OUCH returned to the north-west for a regional get together, this time at the magnificent Liverpool Medical Institution, in Mount Pleasant, Liverpool. The Institution is a magnificent Georgian style portico'd building, immediately opposite Metropolitan Cathedral of Christ [known to all Scousers as Paddy's Wigwam]. 80 sufferers and supporters attended and in beautiful June weather met for coffee and chat before settling down to listen to the presentations.

The speakers were Dr Anita Krishnan, consultant neurologist at the Walton Neurological Centre; Dr Anish Bahra, Headache Group, National Hospital for Neurology and Neurosurgery and Whipps Cross Hospital; Dr Nick Silver, Clinical lead, Headache Clinic, Walton Neurological Hospital and our patron, Professor Peter Goadsby. Their topics covered diagnosis and treatment, upcoming trials, coping strategies and how to get the most from your treatment.

There was also a presentation from CH supporter Fraser Bailey, who supports his wife Chloe who suffers with CH. He outlined what it is to be a supporter and presented constructive information on how best to help if you are supporter.

Yet again a lively and well attended meeting and we look forward to returning to the north-west in two years time.

OUCH HELPLINE – SOME CHANGES

Earlier in this edition you will have seen that Elizabeth [Liz] Kelly has been appointed a trustee and Helpline Manager. She takes over from Colin Allen who is now OUCH vice-chairman. Colin did a magnificent job and he and his team have helped thousands with timely advice and suggestions. Liz has been a helpline volunteer since 2006 and her experiences have prepared her for the task of overseeing the running of the helpline, welcome aboard Liz!

ULTRA HIGH FLOW OXYGEN (DEMAND VALVE)

The diary study that OUCH was conducting has been suspended for the time-being. However, if you wish to purchase a demand valve, please contact info@ouchuk.org who can put you in touch with Oxylitre to purchase your own demand valve direct.

If you have a Demand Valve on Loan that you have not returned, please contact info@ouchuk.org or phone our Helpline 01646 651979, so we can help other sufferers who are waiting.

CHRISTMAS CARDS

Our Christmas Card Competition is now closed. The winning entry is now for sale. Please contact Chloe Bailey at chloe@ouchuk.org for details. The Christmas Cards will be on sale at our Conference in London on 1st November 2015.

Contact Us

HELPLINE | 01646 651979
INFORMATION | info@ouchuk.org
MEMBERSHIP | membership@ouchuk.org
CHIT CHAT | chitchat@ouchuk.org

OFFICIAL NEWSLETTER OF OUCH (UK)
The Organisation for the Understanding of Cluster Headache

www.ouchuk.org

CORRESPONDENCE ADDRESS
OUCH (UK) Admin, PO BOX 62, TENBY SA70 9AG

REGISTERED OFFICE ADDRESS
Pyramid House, 956 High Road, London | N12 9RX
Charity Reg No. 1091919 | Reg No. 4339368

PATRON
Professor Peter Goadsby
BMedSc MB BS MD PhD DSc FRACP FRCP