

CHit CHat

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



OUCHTM
UK

Organisation for the Understanding of Cluster Headaches

Spring/Summer 2017

www.ouchuk.org

EDITOR'S NOTE

Welcome to the Spring/Summer edition of CHit CHat 2017!

We've got lots to cover since our last edition. We had another successful Cluster Headache awareness day with two events, one in Liverpool and the other in Parliament, radio interviews, and magazine interviews. We are grateful to everyone who got involved. OUCH(UK) have some incredible members who have pushed themselves above and beyond for this charity. In this edition, we'll be giving our thanks to those who have run, kayaked, shaved, and climbed mountains for cluster headache sufferers all over the UK! If anyone would like to submit an article, poem, artwork, or idea for future CHit CHat editions, please contact me at submissions@ouchuk.org

NEW TREASURER ON BOARD



Andrya Barnett

OUCH(UK) welcomed Andrya Barnett to the Board of Trustees as our treasurer last year. When asked about her role, Andrya said the following:

I wanted to give something back to the charity that saved my life on more than one occasion, so when I was asked to be a helpline officer, I jumped at the chance and I have been doing that for many years. I was asked last year to join the board as treasurer, due to my professional background, and again I jumped at the chance to give back to the charity.

A bit about my background: I have worked for HMRC (Inland Revenue) for 21 years, during which time I have worked in Self Assessment, Corporation Tax and Employer Duties. I loved my time as a technical inspector, but due to declining health I decided it was time to move into management.

CLUSTER HEADACHE ON THE BBC

On 5th May, Trustee Scott Bruce was featured in a piece on current cluster headache research which was shown on BBC Breakfast on BBC1! This was followed by a radio interview with Chairman Professor Goadsby, and OUCH(UK) member and superstar, Carolyn Matheson on BBC 5 Live. OUCH(UK) member Rob Chapman also took part in a phone interview for Radio Solent. These awareness pieces increased our reach on social media platforms Facebook and Twitter. One post on Facebook reached over 25,000 people, and the BBC Breakfast clip had over 1.6 million views in less than 24 hours! On 6th May, Officer Val Hobbs and cluster headache hero Dr. Silver of The Walton Centre spoke on BBC 5 Live about the impact of cluster headache and current research. Due to the increased exposure of cluster headache, OUCH(UK) received emails, Facebook posts, Tweets and phone calls to the helpline! This type of awareness is fantastic, and we are very proud to have spread the word on cluster headache to more and more people.

THE MIKE POLLOCK AWARD

We have pleasure in announcing a new annual award in honour of our late, much loved Chairman, Mike Pollock. Nothing was ever too much bother for Mike and he always went the extra mile to help cluster headache sufferers. To say he did a great deal of good for OUCH(UK), and its members, is putting it mildly and we wanted to do something special in his name. The award winner will be chosen from nominations submitted by you, the sufferers, about your own cluster headache hero and in keeping with Mike's well known qualities. If you know someone who has gone that extra mile to help either yourself or cluster headache sufferers in general, we'd like to know about them. We think Mike would be happy with a tribute to his memory which, even though in a small way, enables him to keep on giving.

The winner will be chosen by our membership from nominations submitted by the cluster headache community in the UK. We want to hear your stories about your own CH hero - anyone who has gone that extra mile to help either yourself personally, or cluster headache sufferers in general.

STOP PRESS: It's an absolute pleasure to announce that the very first winner of the Mike Pollock Award is Mr Darren Hamilton! He will receive his award at our London conference on July 16th, and there will be a piece on our winner in the next edition of CHit CHat! Well done, Darren!

TRIAL INFORMATION

The Walton Centre is a major neurology hospital located in Liverpool. There is continuous research at the centre, trialling new treatments for both cluster headache and migraine. If you would like more information on current research, or you are interested in taking part in trials based at The Walton Centre, please contact Patricia by emailing clusterresearch@thewaltoncentre.nhs.uk or migraineresearch@thewaltoncentre.nhs.uk

Professor Goadsby at **King's College Hospital**, London is seeking volunteers for a series of important studies testing several new CGRP [calcitonin gene related peptides] treatments for episodic and chronic cluster headache sufferers. The criteria for participants for the CGRP trials have been amended:

- **The participant needs to be an episodic or chronic sufferer of cluster headache**
- **Aged 18-65**
- **Willing and able to attend trial appointments in London approximately once a month**
- **If you are not currently in cycle, but would be willing to take part, please apply giving an approximate date for your next cycle commencement.**

Please contact info@ouchuk.org if you wish to receive more information and potentially apply, giving your contact details, telephone number and date of birth.

Cluster Headache Imaging Study - Brain Activation during Cluster Headache - **BANG-CH**.

OUCH (UK) is delighted to continue to support the study that is being undertaken at Kings College Hospital in London and we are inviting you to take part. If you really want to do something to help your fellow sufferers, then here is an opportunity for you to do just that.

- **Do you have cluster headache?**
- **Are you 18-60 years old?**
- **Would you like to help us understand how cluster headache is generated using a new brain scanning technique?**

If you are interested in taking part or would like additional information please contact Dr Diana Wei at clusterheadache-research@kcl.ac.uk

FIGHTING SHADOWS DOCUMENTARY

In October 2016, a group of students from Southampton Solent University, studying BA (Hons) Film, chose cluster headache as the subject of their short documentary assignment. Students Dominic McCafferty, Kane Le-Petit, Danie Millar, Bradley Hilton and Jordan Burton released the short film titled 'Fighting Shadows – Short Documentary' in February this year. Here is what Dominic McCafferty had to say about the project:

When brainstorming ideas, I remembered my brother, a fourth year medical student, telling me about a man he had met who had cluster headache. I was shocked by how extreme it sounded, and when I searched the condition online, I was baffled that there weren't already many documentaries on the subject. As well as being an interesting topic that very few people at the University had heard of, we also felt we should take advantage of our position as filmmakers, to tell the personal struggle of cluster headache sufferers in order to create a greater sense of awareness for the condition.

When we first did our research for the film, knowing very little information on the condition, we were shocked by how extreme and serious it really was. However, after meeting Jade, the main focus of the film, the group and I were deeply moved by her courage and resilience, despite being a chronic sufferer, as well as trying to successfully get through University.

We have received very positive feedback from cluster headache sufferers from all over the world, which we were not at all expecting when we first set out to make Fighting Shadows. Even people who had never heard of the condition have told me that they were inspired by Jade's story. All I hope now is that the film can bring some attention to cluster headache and hopefully bring some courage to people who endure this terrible condition or anyone else who is going through difficult times in their life.

OUCH(UK) want to thank the group for producing such a respectful and powerful short documentary and for choosing cluster headache as their subject. The film can be found on YouTube (username **LeKanePetit**).

CHRISTMAS CARD COMPETITION 2016



Congratulations to Paul Isemonger who won our design competition with a beautiful scene named 'Cotswold Church'. We still have the design in stock, and Christmas cards in packs of 10 will be for sale at our London conference, and again next winter.

CHANGES TO PRESCRIBING OXYGEN

These changes apply to new patients requiring oxygen. Along with the Home Oxygen Order Form (HOOF), the GP or health professional prescribing has to complete a form called an Individual Home Oxygen Risk Management and Home Oxygen Consent Form. The GP has to fill in a form, asking you questions and drawing conclusions from your answers. He will need to know, amongst other things, if you smoke or anyone in the house smokes, and questions about your home, environment and your overall health. A copy of the IHORM can be found on the OUCH(UK) website **www.ouchuk.org/resources** under Downloads. The file is named 'IHORM and HOCF form'.



When the GP has completed these initial forms, they then need to complete the HOOF, and must indicate on this form that the IHORM assessment has been completed. This must then be signed. If the HOOF is received by the oxygen company without this confirmation and signature, it will be rejected.

We know from members' experiences that some medical professionals are reluctant to prescribe oxygen, and this extra form may make it more problematic for new patients to obtain oxygen. We will be making representations to the Department of Health and the NHS regarding the nature of the IHORM and we will keep members updated.

For the correct HOOF forms, go to the OUCH(UK) website **www.ouchuk.org/resources** under Downloads and from the HOOF Forms section select the appropriate form, either 'Demand Valve Oxygen' or the 'HOOF form'.

Questions and queries to **info@ouchuk.org** or by post to our P.O. Box address in Tenby.

CLUSTER WARRIOR T-SHIRTS

A small clothing company The Silver Lining Clothing Co. have designed an OUCH(UK)-specific t-shirt for all 'cluster warriors', sufferers and their supporters. 100% of the profits from each 'Cluster Warrior' t-shirt goes to OUCH(UK). These can be purchased online (email **info@silverliningsclothing.co.uk**) and will also be available at our London Conference in July.



PADDLING EVEREST WITH A BEAVER!

Every sport has its pinnacle, and in the sport of canoeing, it's a race from Devizes Wharf to Westminster Bridge, 125 miles non-stop, held every Easter since 1948. Any canoeist who has completed it gains instant respect from their peers. The race is the oldest and longest canoe race in the world, and known as 'The Canoeists Everest'. A quarter of those who start will fail to finish, with most succumbing to fatigue and injury. The race is so brutal, the Royal Marines and British Special Forces use it as a test for their members. It is not undertaken lightly.



Neil and Tim before setting off

Neil Boast, a BOC 'Oxygen Man' who is based in Ipswich, and his friend Tim Beaver, trained for 7 months to prepare themselves for the race. Neil had one previous finish and Tim was going for his 11th! Neil wanted to raise money to support OUCH(UK) as he has witnessed the effects of cluster headache. "I'd never heard of 'clusters' until I started at BOC. One of my first jobs was dealing with a new cluster headache patient suffering an attack and it was very upsetting for me." Neil said, "Luckily I had my police experience to call upon" (Neil was a Sergeant and retired from the police in 2010. He was awarded an MBE for Services to Policing) "I have made sure I keep abreast of all cluster headache developments and try to educate people... especially health professionals".

Neil and Tim had an eventful race. Despite both being 54 years of age, they were expected to do well in the race and predicted a top 20 finish, out of the 168 starting crews. All was going well until Tim hit his head on a low river bridge causing a nasty cut (6 stitches) and concussion! The boys then suffered leg cramps and sciatica, but paddled on. At 108 miles in, the race moves onto the tidal Thames and this is considered the most dangerous part of the race. The boys managed to paddle the final 17 miles to the finish, opposite the Houses of Parliament, where they were presented with their coveted medals and emotional hugs from their wives. Both vowed never to do it again, claiming, "we are too old".



Neil and Tim on the River Thames

They finished in 24 hours and 50 minutes. 138 crews finished and they came 59th. At one point they were on for a 20hr 45 minute time and 14th place, but circumstances transpired against them. Nearly two weeks on and both are talking about doing it again! "It's an addiction. My wife says it's divorce if I commit to it again" said Neil, "but she'll come round". Both men have found the event has forged a real bond of friendship. They quote Churchill who said 'When you're going through Hell, keep going'.

We wish to send a huge thank you to both Neil and Tim for taking on this challenge in the name of OUCH(UK) and cluster headaches. Your commitment to helping cluster headache patients is truly inspiring.

LIAM DENNIS – RECIPIENT OF THE LES CHARLTON AWARD 2016

Liam Dennis won our Les Charlton Award for his outstanding commitment to fundraising and raising awareness for cluster headache. We spoke to Liam about winning the award, and he said:

Winning the Les Charlton Award 2016 meant so much to me, to be recognised for my efforts, doing various charity events to raise money and awareness for OUCH(UK), it just shows how kind, thoughtful and appreciative OUCH(UK) are as a charity. For me, personally, they are life savers. This award, although means a lot, does not match how OUCH(UK) also deserves awards and more for everything they do, day-in, day-out. My reason behind skydiving, mountain walking, triathlons and more was to try and give something back to OUCH(UK).

Back in 2012, I was in desperate need for help: in a suicidal state and my mum would not leave my home that day for fear. I somehow came across OUCH(UK)'s helpline number and managed to speak to a chap called Andy. The words he said, and the advice he gave, gave me hope. I soon started to fight back and so I'll never forget his calm Scottish voice. This inspired me to want to give back, so I did just that and starting a series of events to raise funds and awareness for OUCH(UK). I have been shouting out loud and proud of how OUCH(UK) saved my life since that phone call. Since then, with the constant help, I've become stronger, fighting the fear and dealing with cluster headaches, as I am now chronic. Yet, I've learnt to live a life with cluster headache and not cluster headache taking over my life.

Moving forward, the trustees have decided to introduce a new award, in honour of our dearly departed Chairman, Mike Pollock. Details of this award are discussed in OUCH(UK) News section.

The Les Charlton award will now be aimed at healthcare professionals who have excelled in promoting better treatments and diagnosis, who have been involved in trials and research, and/or have helped OUCH(UK) in increasing awareness of this condition.



BEATSON'S MULL RALLY 14-16TH OCTOBER 2016

I was delighted to join Team OUCH(UK) in Tobermory on the beautiful island of Mull in October for the 47th Mull Rally. OUCH(UK) was chosen again this year to raise funds at the Rally after last year's event was cut tragically short. After being involved in the terrible crash in which his close friend and co-driver Andy Mort lost his life, John MacCrone and co-driver Stuart Loudon claimed a very emotional win.



Winners John & Stuart

Congratulations to winners John MacCrone and Stuart Loudon! What a fitting end to the Rally.

MULL RALLY BIGGEST HEADACHE AWARD



This year, OUCH(UK) presented a trophy – a prize for the biggest headache! The “headache” is the struggle that crews and engineers have to endure to get the car to the finish line, a nod to the struggle that clusterheads have to get to the end of their day. The winning pair were Jonathan Mounsey/Richard Wardle – Mitsubishi Lancer. The prize certainly went to a deserving team who battled to stay in the race. First, they overcame car problems when their transfer box burst. They offered to buy a Mitsubishi Lancer Evo on Facebook from anyone on the island, give them a car to use over the weekend and use the box to get the rally started! After all that, they then had to contend with Richard taking ill and becoming so poorly they had to retire from the race. Although they didn't reach the finish, it was felt they had endured the biggest headache in the attempt and were awarded the trophy.

Once again, huge thanks to the drivers, crew members and all of the wonderful spectators who made our fundraising a resounding success. It was a real pleasure to have been part of it and an experience I won't ever forget – Dorothy Chapman (Trustee).



OUCH(UK) CONFERENCE



OUCH(UK) are pleased to return to London for our annual conference in 2017. The event is aimed specifically at cluster headache patients and their supporters. We welcome anyone with an interest in headache disorders to the conference too.

As usual, the conference will host some of the UK's top neurologists who will give talks on a range of related topics, and attendees will have the opportunity to join our information sessions. OUCH(UK) conferences are a fantastic chance to meet and talk with other cluster headache sufferers to share experiences, and meet new friends. Our medical speakers will take you on a journey through cluster headache, and other primary headache disorders, discuss current treatments available, and inform you of current research studies and trials and how to enrol if interested.

Confirmed speakers at this year's London conference include Dr. Anish Bahra, Consultant Neurologist St Bartholomew's Hospital, and Professor Peter Goadsby, Professor of Neurology King's College London and Chairman of OUCH(UK). Trustee, Fraser Bailey will be at the event to help the Supporters attending, and Jack Holland from King's College London will be informing us of current trials. The Brain Charity will be in attendance, with information and advice on benefits, employment, etc, and OUCH(UK)'s employment officer Jason Clark will also be on hand to offer advice. The Guy's and St. Thomas' neurological team will be attending, as well as companies ElectroCore, Oxylitre, BPR Medical, The Silver Linings Clothing Co. and OUCH(UK)'s mini shop.

The conference will be held at **Robin Brook Centre, Queen Mary University of London Barts Hospital, EC1A 7BE on Sunday 16th July 2017, 10am-4:30pm.** Tickets can be purchased online from our website **www.ouchuk.org** and OUCH(UK) members can receive 20% off conference ticket prices. If you have any questions regarding the conference, please contact Scott Bruce via email, **scott@ouchuk.org**. We are looking forward to seeing you there!

AN INTERVIEW WITH THE CHAIRMAN OF OUCH(UK)

Professor Peter Goadsby, Professor of Neurology King's College London



Professor Peter Goadsby

In summer 2015, Professor Peter Goadsby took over the role of OUCH(UK) Chairman after the devastating loss of our Chairman, Mike Pollock. CHit CHat editor and trustee, Chloe Bailey asked you to send in your questions on our social media platforms, to help you get to know our Chairman a little better!

Thank you, Professor Goadsby for accepting the role of Chairman for OUCH(UK). Can you tell us why you decided to get more involved with our charity?

I became more involved when Mike Pollock, the previous chairman, became ill. We had always had a very good working relationship and I admired what he and everyone at OUCH(UK) had done to further the cause of patients with cluster headache. It was a traumatic time for OUCH(UK) as his illness became known. He asked me, on his deathbed, to be more involved. So I am.

A neurologist with knowledge of cluster headache is vital for patients receiving the correct medical care. Was there any reason why you decided to specialise in headache disorders and cluster headache in particular?

I became interested in headache disorders because my neurological mentor, Professor James Lance in Sydney, was very interested in headache disorders and certainly, in cluster headache. He introduced me to the challenges and to patients with the problem. Headache disorders struck me as very burdensome and ill understood, I found them so interesting. When I began to study cluster headache in the late 1980's I began to meet more patients with the problem. As I saw them in attacks I understood how dreadful the attacks were and how important it was to study the problem.

Many of our members have difficulty receiving informed care from their GPs, specifically in attaining a diagnosis, suitable amounts of sumatriptan injections and accessing home oxygen. How would you advise an individual talk to their GP if they suspect they have cluster headache? Do you have any suggestions how OUCH(UK) and our members can help educate GPs and more healthcare professionals?

I would advise members to prepare on several levels. They should recall that most GPs would have one or two patients with cluster headache at most, so they may not have it sharply focused on their radar.

Preparing a diary that sets out the time of day and length of attacks is helpful. It may be helpful to bring along a medical paper that describes the problem, such as one I wrote in the British Medical Journal (Nesbitt AD, Goadsby PJ. Cluster Headache. British Medical Journal. 2012;344:e2407.). One could politely suggest you may have the same problem, leave it with them and make an appointment to talk about it again.

Chronic conditions can often affect an individual's physical, psychological, financial and social situations, as well as their family and friends. Do you have any general advice on how cluster headache patients can best manage the burdens of this condition?

Yes, that is true; the sufferer's entire life is blighted by the condition. I have no magic here. Establishing a good relationship with a physician who is trained to deal with the problem so your treatment is optimal is crucial. It is probably easier to be sure that those you live with know what you have and what might happen. Many sufferers find their partner can be a crucial part of their management as they know what to expect and how to help.

Cluster headache often lives side by side with depression and anxiety conditions. Do you have an opinion on how to manage the psychological effects of a chronic pain condition such as cluster headache?

Understandably, cluster headache can provoke very significant anxiety and significant depression. These should be treated on their own merits. If they are very troublesome they should be addressed by your GP in concert with the physician primarily managing the cluster headache. This may involve medicine or simply talking therapy. They certainly should not be ignored.

Finally, is there anything you'd like to say to any cluster headache patients reading this, who may have lost hope in being out of pain and/or finding successful treatments?

There is always hope since research in this area is very active. We are studying two totally new treatment approaches and even ways to use the new approaches. We are developing a new surgical approach for chronic cluster headache that is much less invasive than what has been used. Lastly, we are very active in pursuing and understanding the problem using brain imaging and genetic approaches to refine treatments and ultimately devise a cure.

Thank you, Professor for taking the time to answer our members' questions. Remember, Professor Peter Goadsby will be at our London conference on 16th July 2017! You can get your tickets on our website www.ouchuk.org

CLUSTER HEADACHE AWARENESS DAY 2017

Cluster Headache Awareness Day was launched last year as an initiative of the European Headache Alliance (EHA), an organisation of European Headache Charities which gears its work to ensuring headache conditions are talked about at European level. This year we hoped to make the day even bigger and better than the first.



European Parliament

A meeting dedicated to cluster headache in the European Parliament, along with a sister organisation the European Federation of Neurological Associations, was organised, with almost every cluster headache related charity in Europe represented. Sabine Verheyen MEP spoke about creating a common set of guidelines covering cluster headache across Europe. Professor Paulo Martelletti talked to the delegates about equal access to treatments for the condition across Europe as some countries still don't offer abortive treatments. Ms Kalina Tyminski, President of ACFAVF (France), told her story of cluster headache and surgery, and the impact the condition has had on her life.

Finally, Miguel Angel Pascual (AEPAC Spain) spoke to delegates about living with cluster headache in his country. OUCH(UK)'s efforts for Cluster Headache Awareness Day were recognised at the meeting, and our awareness day slogan 'Stronger Together' was used by the EHA.

The next event took place in Westminster, with a collaboration between OUCH(UK) and Guy's and St Thomas' NHS Foundation Trust. Trustee Liz Kelly attended the Parliament event, and had this to say:



Parliament Speakers

This is just a flavour of Awareness Day in Parliament. Just going into such a significant building complex is awe inspiring as history oozes from its walls, and we were privileged to be using a room dedicated to Churchill, decorated in a classic style with a hint of luxury and huge pictures on the walls of Churchill's time there. This was a free ticketed event and all tickets were allocated very quickly, so the room was filled to capacity.

Jim Fitzpatrick MP started the meeting with a warm welcome and introduced each speaker. Carolyn Matheson spoke first giving a wonderful description of cluster headache, and how it affected not just her life, but the impact it had on her family too.

This gave me the perfect platform to follow her with my speech telling everyone about OUCH(UK) and what we do! This was followed by Professor Paolo Martelletti (President of European Headache Federation), and Dr Giorgio Lambru who is passionate about getting the right treatment to patients who are in crisis as quick as possible, hence the "Rapid Access Clinic" and his determination to help cluster headache sufferers in general. Then Dr Anna Andreou (Director of Headache Research at GSTT Headache Centre & Kings College London) talked about her cluster headache related research.

After the speeches we had time to talk to a mixture of people who attended, including consultants, nurses, sufferers, and their families. It was uplifting to see so many people dedicated to supporting sufferers and a way forward with this terrible disease.

The day finished in Liverpool, with an evening arranged at The Walton Centre. Dr. Nick Silver hosted the event, and started the evening with a presentation about cluster headache and other related headache conditions. He covered information on The Walton Centre and Vanguard, and discussed the causes of headache conditions, how to diagnose, and relevant symptoms. Trustee and treasurer, Andrya Barnett then addressed the attendees on the history of OUCH(UK), the benefits of our forum and helpline, and the assistance we can give to cluster headache patients and their family and friends. We had a short break, during which attendees could speak to Kate and Patricia, two research nurses from The Walton Centre's Neuroscience Research Centre, on the current and upcoming research trials running at the centre. Visitors were encouraged to sign up for further information (if any of our readers would like further information too, contact details can be found in OUCH(UK) News, under Research). The group once again gathered in the lecture room, and Dr. Nick Silver covered current and future treatments for cluster headache, and then opened the floor to questions. We thank Dr. Silver for his time in organising and hosting the event – especially as the Q&A session ran 45 minutes over(!), and also for his commitment to both OUCH(UK) and cluster headache patients. OUCH(UK) would also like to thank ElectroCore Medical for their generous assistance, without which this event would not have taken place.

We are thrilled at the success of the 2nd Cluster Headache Awareness Day, and the number of people the cluster headache community reached during the day! It is wonderful to see how powerful the community can be, we truly are 'Stronger Together'. Founder of Notjustaheadache, Katie Clarke-Day spoke with Dr. Giorgio Lambru on BBC Radio Nottingham, about the severity of cluster headache and its impact on individuals' lives, while member Kevin Crook spoke on The Milk Bar (episode 403), on his experiences with cluster headache. A number of our members contacted media outlets, asking for them to cover a story on cluster headaches. We are grateful for every one of you who puts yourself out there, and shares your story with the world – you are helping to foster better understanding for cluster headache patients across the UK and beyond. OUCH(UK) and sister organisations in Europe are already discussing the next Cluster Headache Awareness campaign. If you have any ideas on how to make the 3rd awareness day even better than the 1st and 2nd, we welcome emails to info@ouchuk.org or speak to us on our forum!

FUNDRAISING

Here at OUCH(UK), we are overwhelmed with the determination and generosity of our members! We are so inspired by your commitment to this charity, and for taking part in such a wide range of events to raise money for OUCH(UK)! If any of our readers would like to raise money for OUCH(UK) or would like to run an event for our charity, please contact us at info@ouchuk.org



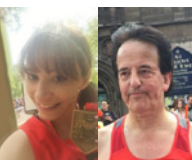
THE DYNAMIC DOBSON FAMILY

Natalie Dobson, mother of four young children, began the year with a resolution to complete a series of challenges throughout 2017. She set herself a target to clock up 500 miles of running, walking and cycling, to raise funds for OUCH(UK) in support of husband, Gareth. Gareth was diagnosed with cluster headaches in 2013, and had found support from being a member of our charity. The Dobsons are not a family to dwell on the negatives in life and decided to turn their challenges into positives. Not wanting to be left out, their two eldest children, Leon (9) and Rhianna (6), set their own targets of 200 miles each for OUCH(UK)! Gareth was so inspired by them that he began to join in with the activities – he now has his sights set on a half marathon in September. To date, Natalie and the children are well past their half-way marks; Natalie has logged up a whopping 384.75 miles, Leon has achieved 158.23 miles and Rhianna 141.49 so far. I think you'll agree that this is a family of OUCH(UK) champions!



NORTH WALES CARDIAC TEAM

Helen Tagaris and her team, Hannah, Joe and Kat, will be running in the Chester Half Marathon to raise funds for OUCH(UK). This event is the first of two half marathons they plan to do this year! Helen's brother in law is a chronic sufferer and Hannah's husband is episodic. Joe and Kat decided they wanted to join in and help the cause. OUCH(UK) thanks the team for their dedication to our charity!



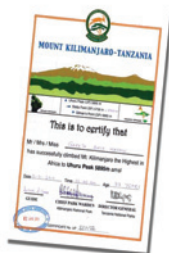
JADE AND GEOFF RAN THE LONDON MARATHON

Jade Lambrick and her dad Geoff, ran the London Marathon in aid of two charities, Macmillan Cancer Support and OUCH(UK). Thank you for choosing OUCH(UK) as one of your charities, and congratulations on running the Marathon!



KILIMANJARO CLIMB

Huge well done to KMF employee Gareth Birch-Machin, for climbing Kilimanjaro over Christmas 2016! In doing so, Gareth raised £2,183 for OUCH(UK). Thank you to everyone who donated, and huge respect to Gareth for his efforts despite having cluster headache for the last 10 years!

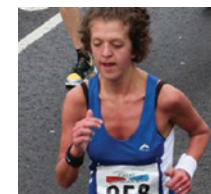


COFFEE EVENING FOR OUCH(UK)

Dedicated OUCH(UK) members Andy and Sandra McDowell, hosted a coffee evening at Glen Isal in April. They ran a raffle at the event too, and we are very grateful for the money raised for OUCH(UK)!

EMMA'S RUNSTREAK FOR OUCH(UK)

Emma Backhouse suffers from cluster headaches and has been so inspired by reading stories from other sufferers that she decided to put her running shoes on for the cause. Emma will start her year of running on 1st April, doing some set runs as part of it - including the Manchester Half Marathon in October. We will be following Emma's runstreak on our social media pages – thank you Emma!



DRAGONS' DEN PROJECT AT MORCHARD BISHOP PRIMARY SCHOOL

A group of 10 year old pupils at Morchard Bishop Primary School in Crediton took part in a Dragons' Den style challenge, in which they sold handmade copper necklaces and peppermint creams! They presented their business plan to a local supermarket manager and farmer. Congratulations to the group for being the most successful fundraisers, and donating their earnings to OUCH(UK)!



BOXING DAY DIP IN SEABURN

Six pals from Sunderland joined the mad rush into the sea at Seaburn on Boxing Day for OUCH(UK). The lads, Parnell, Adam, Grant, Jack, Anthony, and David got together to do something for the charity as Anthony's grandmother has suffered from episodic cluster headache for 50 years. We send a big thank you, and commend the boys on their bravery!



GOING BALD FOR OUCH(UK)

A big thank you to Kevin McArdle who shaved off all his hair for OUCH(UK)! We are very impressed by your efforts!



DOUGHNUTS FOR DOUGH!

Chichester School Business Studies department made and sold doughnuts, and operated a car wash service to raise money for OUCH(UK). Thank you for raising money for us!

RANCHERO'S LINE DANCERS

Tracey Unsworth is the 'caller' for the Ranchero's Line Dancers group, and unfortunately also a cluster headache sufferer. We want to thank the group for raising money for OUCH(UK) at one of their events.

DONATIONS

OUCH(UK) would like to say a massive thank you to the following for their kind donations:

- Chichester School Business Studies department
- iPSL Financial Services of Camberley
- St Francis Hand Bell Ringers
- The Cecil Rosen Foundation

CHATTER AND CHART

Our members are incredibly talented, and we love to feature your creative gifts on our Members Page. If you have any artwork, poetry, short stories, or anything else you feel would fit within this section, please email me at submissions@ouchuk.org and it may be featured in a future edition of CHit CHat.



A' Level artwork by
Christopher Elliot
'Clarity and Distortion' and
'Destruction'.



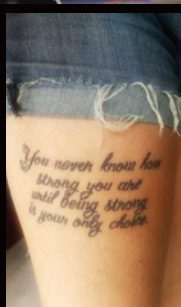
The Torturer by John Harris

The torturer walks down the Hall
Each foot closer as it falls
Unlocks the door
Then steps inside
And says
"You have nowhere to hide"
He sharpens his knives
And warms his poker
I just pray
It'll soon be over
Sometimes quick
And sometimes slow
Sometimes does nothing
I never know
I do get away though
Sometimes I'm free
But how can I escape him
When the torturer is me



In the next edition of CHit CHat, we will be celebrating our furry cluster companions who help us through our attacks. Jayne has shared a lovely photo of cat Daisy, helping

her recover from an attack. If you would like your pet to feature in the next edition, please email your photos and stories to submissions@ouchuk.org



Tattoo piece -
Sal O'Reilly

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

www.ouchuk.org

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