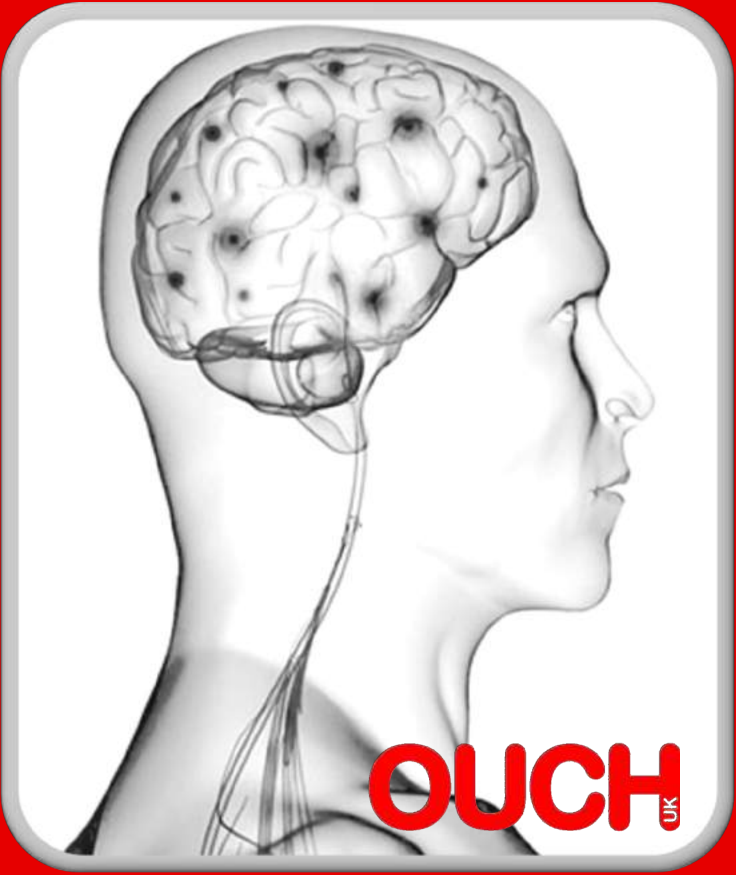
CHit CHat

The Official Newsletter of OUCH (UK)

The Organisation for the Understanding of Cluster Headache



See inside for details of our conferences including our summer conference in St Thomas' Hospital London

SUMMER 2019

WWW.OUCHUK.ORG

MAKING OUR PAIN INVISIBLE

NEW EDITOR FOR CHitCHat

I would like to introduce myself, from 1st March I took on the task of Editor and I am looking forward to giving something back to OUCH for the benefits that I have personally gained since discovering the Charity. I only became aware of OUCH a few days prior to the Conference held in Newcastle and thankfully, with my wife Sylvia, decided to attend the conference. I had been a CH sufferer for two years prior to that with no clear diagnosis. Since that time I have benefited from a correct diagnosis and a helpful treatment plan.
Thanks OUCH.

I am obviously new to OUCH, and CHitChat, but would like to work towards making it a regular, say twice a year issue, keeping all members up to date with available information. To make this possible I need you to send me your stories, pictures and information to share with all members. I can be contacted by email at chitchat@ouchuk.org

I hope you enjoy reading this issue of CHitCHat, please let me have your suggestions for future issues.

John, with my supporter, Sylvia

Evaluating the Treatment of Cluster Headache with Oxygen:

A population-based study

(ETCHO-1)

OUCH (UK) is pleased to be collaborating with the headache research team at King's College London on a new study of cluster headache sufferers who receive home oxygen.

This is a questionnaire study with a telephone interview follow up.

We are hoping this study will help us begin to explore who are the cluster headache sufferers who find oxygen a useful treatment.

Oxygen users in the South Central home oxygen region should look out for a letter asking if they would like to find out more about this study and if they want to be involved.

OUCH(UK) SUMMER CONFERENCE - LONDON

Sunday, 30th June 2019, Shepherd Hall, St Thomas' Hospital, London

We are pleased to be able to return to London to present a packed event specifically for cluster headache sufferers and supporters.

As usual the event will be a mixture of Europe's best Neurologists, information sessions and an opportunity to meet and talk with other cluster headache sufferers to share experiences and make and meet new friends.

Confirmed speakers for the event:

Professor Gianluca Coppola, Headache Researcher Rome, Italy

Dr Anna Andreou, Director of Headache Research at Guys and St Thomas' Hospital London

Professor Mads Barloese, Cluster Headache Researcher, Copenhagan

Dr Giorgio Lambru, Consultant Neurologist Guys and St Thomas', London

OUCH (UK) Trustees and Officers

Throughout the day there will be plenty of opportunities to chat to our speakers, our trustees and officers as well as other sufferers and supporters.

A day not to be missed!

Tickets available securely online via our website www.ouchuk.org or if you prefer, ring our helpline with your details and we can send out a postal application form.

We are able to offer our membership a fantastic 40% off the price of each ticket when logged in to the website. This discount is AUTOMATICALLY applied when you book your ticket.

At OUCH (UK) we completely understand how devastating CH can be on a family.

Thanks to generous sponsors and fundraisers we always make a number of seats available to sufferers who cannot afford the ticket price but who would benefit greatly from attending the conference.

If you and a loved one would like to attend the meeting, but are unable to afford the tickets please email scott@ouchuk.org in complete confidence.

We hope to see you there.

CONFERENCE REVIEWS

OUCH(UK) NORTH EAST & CUMBRIA CONFERENCE
Held at the
ROYAL VICTORIA INFIRMARY (RVI) NEWCASTLE

On 18TH MARCH 2018, we held our first conference in the North East, at the RVI in Newcastle. We had the whole of the New Education Centre at our disposal for the day and the event was a grand success.

The day turned out to be a freezing cold one, with snow closing some roads and we feared not many would turn up as weather conditions continued to worsen. However, our CH friends, old and new, began to arrive in a steady stream and the lecture theatre began to fill up.

Dr Paul Dorman gave an informative talk about the work that the RVI team do for cluster headache patients.

Dr Dorman's Clinical Nurse Specialist, Susan Hurst, was a great support before and during the conference. When Dr Jitka Vanderpol was prevented from travelling due to road conditions in Cumbria, Susan stepped in at the last minute and did Dr Vanderpol's presentation as well as her own.

Another local neurologist, Dr Gina Kennedy, from Sunderland Royal Hospital, was also keen to speak to us and to show her support for cluster headache patients and their charity.

Our esteemed guests and speakers included:

Professor Peter Goadsby, Professor of Neurology, Kings College London, Patron and Chairman of OUCH(UK),

Dr Giorgio Lambru, Consultant Neurologist, Guy's and St Thomas' Hospital, London,

Dr Paul Dorman, Consultant Neurologist, Royal Victoria Infirmary, Newcastle,

Dr Gina Kennedy Consultant Neurologist, Sunderland Royal Hospital,

Susan Hurst, Clinical Specialist Headache Nurse, RVI, Newcastle,

Jason Clark, Ouch Officer HR and Employment Law.

We were very grateful to all of our speakers for coming and sharing with us a wealth of knowledge and information.

Trustee speakers: Scott Bruce spoke about how supporters of sufferers can help and Dorothy Chapman gave a short history of her life with CH from age 19 to 70.

There were group discussions in the afternoon with advice available on current treatments, use of oxygen, supporter advice and employment issues.

CONFERENCE REVIEW Continued

As always, throughout the day, there was the welcome opportunity for sufferers to mingle and get to know one another or catch up with old friends. There was also time to chat with trustees and our medical experts. There was a quiet room provided with oxygen on hand to use with a demand valve, in case that all too familiar and uninvited guest turned up...

At the end of the day, our speakers assembled on the stage so that the audience could participate in a question and answer session.

Many thanks to all who helped to make the event a success.

Special thanks to our speakers for giving us their valuable time. Their dedication gives us all hope for the future.

HOLIDAY HINTS

Going on holiday with CH?
If you go into the OUCH(UK) website menu:
get support, then downloads, you'll find holiday hints.

You could find some of the suggestions very helpful.

CGRP study at Kings College Hospital

Dr Jack Holland who is conducting a trial at Kings into the use of CGRP's in cluster headache is urgently seeking volunteers for this study: details and criteria are below.

If you've ever said you wanted to do something to help sufferers and you are a sufferer yourself, well here is your opportunity!

Trials of new treatments for Episodic and Chronic Cluster Headache sufferers.

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 jack.holland@kcl.ac.uk if you wish to receive more information and potentially apply, giving your contact details, telephone number and date of birth.

Thank you. Trustees of OUCH (UK)

CONFERENCE REVIEW Continued

OUCH (UK) Conference South West (Plymouth)

On 4th November 2018, trustees Scott Bruce and Anne Turner travelled to Plymouth for our OUCH(UK) conference to cover the South West of England at the Post Graduate Medical Centre, Derriford Hospital, Plymouth.

Scott did a sterling job of leading the conference and covering not only his own, but the presentations of speakers who were unable to attend due to unforeseen circumstances. He was ably assisted by Anne, who gave a warm welcome to all attendees and handled the display and sales of our awareness merchandise.

The event was attended by Patrick Little, President of the European Migraine and Headache Alliance.

Also present were representatives of two companies: BPR Medical Ltd, who supply home oxygen products, including the highly effective Ultraflow oxygen demand valve; and electroCore Inc., who supply the gammaCore device, a non-drug and non-invasive stimulation therapy. Both were available to talk to attendees and explain their products, generating a lot of interest.

The esteemed speakers were Dr Giorgio Lambru, Consultant Neurologist, Guy's and St Thomas', who kept everyone informed of the latest treatments and current trials/studies available and Dr Anish Bahra, Consultant Neurologist, St Bartholomew's, Whipps Cross Hospital, joined in by Skype from London.

Specialist Headache Nurse, Rebecca Stuckey, Plymouth, was on hand to speak about the treatments available in the hospital.
As always, this was a wonderful opportunity for sufferers to mingle with the experts, meet fellow sufferers and make new friends.
The meeting finished with our popular Medical Panel Question and Answer Session held towards the end of the afternoon.

We wish to extend our sincere thanks to all at Derriford Hospital, our fabulous speakers and all of our attendees whose presence ensured that the meeting was a great success!

LES CHARLTON AWARD

LES CHARLTON AWARD PRESENTATION – SUSAN HURST

This award was created in memory of Les Charlton, chairman of OUCH (UK) who did so much for the charity. Les passed on in 2011 but is remembered with much affection, not only by OUCH but by all who knew him. The award honours Les and the recipient is chosen each year by the board of trustees. It goes to a health professional who has gone to extra lenghts to support cluster headache patients.

In autumn 2018, the trustees chose Susan Hurst, Clinical Specialist Headache Nurse at the Royal Victoria Infirmary, Newcastle, to receive the award. Susan's dedication to supporting cluster headache patients and raising awareness of the condition is outstanding. When I was invited to attend the 15th UK Annual Headache Nurse Meeting on the 2nd May in Newcastle to speak about my experience of being a patient with cluster headaches, this also turned out to be an excellent opportunity for Susan to receive her award in the presence of her peers. Susan was surprised and overwhelmed by receiving the award and it was my absolute pleasure to present it to her.

Dorothy Chapman (Trustee)

NEW OUCH(UK) ONLINE SHOP

We were very pleased with ourselves when we managed to open our online shop in good time to sell out all our 2018 Christmas cards well before Christmas.

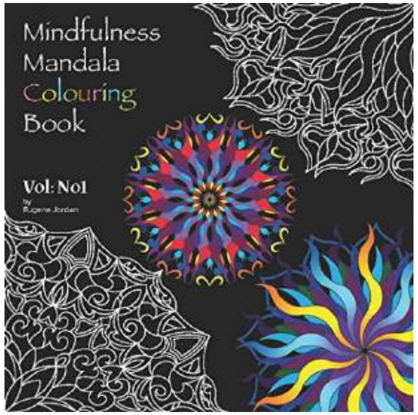
We've been selling some Cluster Headache awareness products at OUCH meetings for a long time, but the online shop has taken sales to a new level. We've added some new stock ranges and purchases can now be made online at any time of day or night for delivery right to your door.

If you haven't visited the shop yet, just click **Shop** at the top of our website to see our full range of items with their eye-catching OUCH logo. These include, among other things:

- colourful red tee-shirts and running vests, especially good for promotions at fundraising events
- smart white polo shirts
- several designs of badges and lapel pins
- wristbands in attractive colours
- our popular CH information cards, which can be shown during an attack to explain to other people what's going on

Payments can be made through PayPal and by debit/credit card in the usual way. Postage charges are tiered, with free delivery for sales over £50. The shop only accepts orders for delivery within the UK, but it is possible to request a delivery outside the UK by emailing **shop@ouchuk.org**

All sales help the charity to support sufferers. If you have any good ideas about further products you would like us to sell, please contact **shop@ouchuk.org** and let us know.



FIRSTLY THANK YOU FOR YOUR CONCERN I suffer from a rare neurological condition known as CLUSTER HEADACHE This condition causes me excruciating pain to one side of my head

THERE IS NO NEED TO CALL AN AMBULANCE

This attack can last anything between 45 minutes and up to 3 hours. Please don't be alarmed. I don't mean to be rude but please don't ask me any questions, as I am unable to think clearly during an attack.

My extreme agitation is a symptom of the attack

There is little you can currently do for me and I am best left alone until my medication takes effect and my pain is under control.

FOR FURTHER INFORMATION, PLEASE SEE OVER

NEW OUCH(UK) ONLINE SHOP

OUCH (UK) is proud to have such wonderful support from our fantastic fundraisers. Over the years, our brave members have faithfully thrown themselves out of aeroplanes, climbed mountains, trudged and crawled through mud, pounded the roads, zip wired across rivers, rowed endlessly, ignored pain and injury, worn out their shoes, backs, knees and feet! These people not only help to keep our helpline going but also help us to keep our website up to date, produce awareness booklets/leaflets and put on conferences all over the UK where members can meet the top experts for cluster headache and other headache conditions. We are very grateful to each and every one of them. Here are our fundraising champions from 2018. A huge thank you from us all. We must also thank our amazingly generous donors who help this charity to keep going!

KARYN'S 2018 CHALLENGE

KARYN FORD did a series of various challenges during 2018 in memory of her mum, Tania, a cluster headache sufferer for 15 years, who sadly passed away in 2017. Karyn raised funds for two charities who helped Tania, one being OUCH (UK).

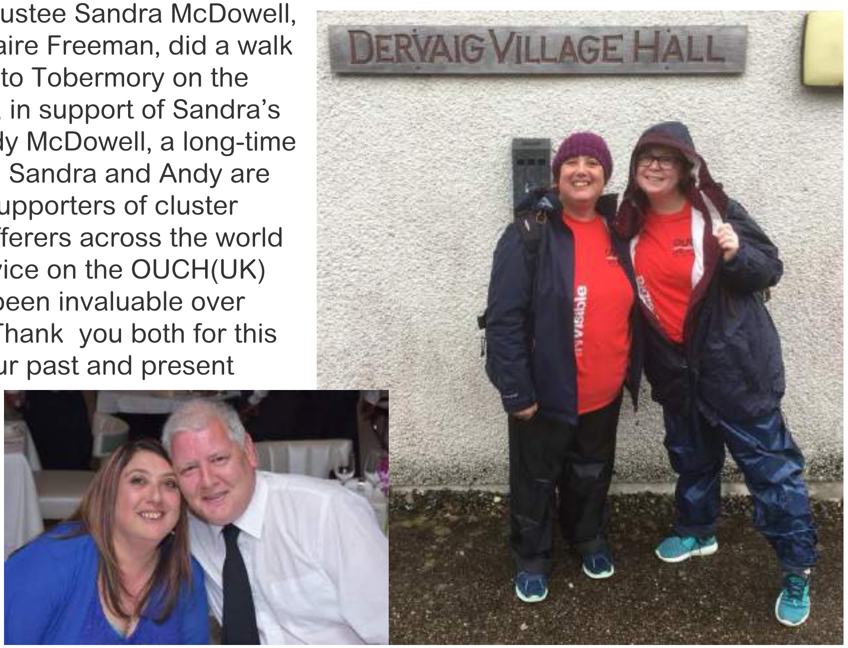
PRUDENTIAL RIDE LONDON-SURREY 100

Chronic cluster headache sufferer and OUCH member, Graeme Brightmore with a team of friends, James, Lucy, Chris and Steve, took on the challenging Ride London 100 mile cycling event.

SNOWDON CLIMB THE JOLLY BOYS OF CREWE

This jolly bunch of guys, Carl and Gary Shaw, James Dennis, Rob Wild, Michael Lloyd-Lawlor and step-son Sean Lawlor, did the Snowdon challenge in fancy dress in support of Michael's wife Gerardine who has a very rare case of post-traumatic CCH and has been a sufferer for 18 years.

OUCH(UK) trustee Sandra McDowell, and friend Claire Freeman, did a walk from Dervaig to Tobermory on the island of Mull, in support of Sandra's husband, Andy McDowell, a long-time CCH sufferer. Sandra and Andy are both strong supporters of cluster headache sufferers across the world and their service on the OUCH(UK) helpline has been invaluable over many years. Thank you both for this and for all your past and present service.



YORKSHIRE 3 PEAKS CHALLENGE

Mckenzie Bee suffers from cluster headaches and her mum took on the 3 Peaks challenge with friends and family helping and joining her on her hike. Unfortunately, due to the cruel nature of CH, Mckenzie was unable to join them.

Mouth watering or what?
OUCH cake from Kirsty Bob Jones, fundraiser.

ANGELA GEERING GREAT NORTH RUN

Here we had another super entrant wearing an OUCH tee shirt for the 2018 GNR (see also Tracy Wakefield below). Angela was supporting her dad who is a CH sufferer.

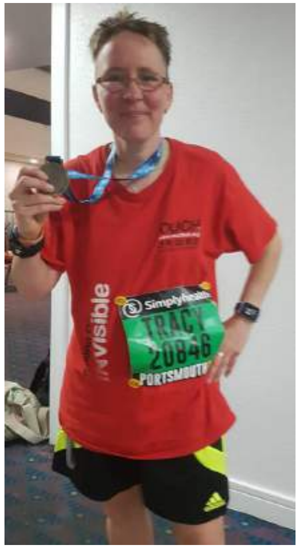
TRACY WAKEFIELD 2018 - 3 EVENT CHALLENGE

Many congratulations to TRACY WAKEFIELD who was chosen as the winner of the Mike Pollock Award 2018! She was a worthy winner and was chosen by OUCH(UK) members who voted for her after seeing regular posts and photos of her while she relentlessly pounded the roads three years in a row raising funds for us, each year completing the Great South Run and Great North Run, then last year running the Brighton Marathon, the Great North Run and the Great South Run, completing her 3 Event Challenge.

What makes Tracy extra special is that she does not suffer CH nor is she a supporter of a sufferer but has chosen to help us because once she became aware of the condition, she took our cause to her heart and we can't thank her enough for this. Mike would very much approve of this award in his name going to this absolute star to show how much she is appreciated by the membership and board of OUCH (UK). Tracy has not yet been presented with her award but photos of her presentation will be in the next issue of Chit Chat.

Brighton Marathon

Great North Run



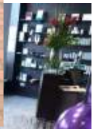
Great South Run

CHARITY WALK LONDON BRIDGES

CH sufferer MEERA LUMB and her team of 30+ Mortgage Consultant group for Nationwide Building Society put on this exciting 11 mile event for us, starting at Nationwide Victoria branch and ending up at Nationwide Aldgate branch visiting 7 other branches and crossing 8 bridges to make it more challenging!

CAROLS AND MULLED WINE EVENT AT THE ELMS RETIREMENT PARK

In early December a Carols with Mulled Wine event was held for the residents of The Elms Retirement Park, Lincolnshire, The funds raised were split between the Lincolnshire First Responders and **OUCH(UK)**. Our now Editor, John is a CH sufferer and his supporting wife, Sylvia, have lived at the Park for 8 years and are both very much involved in various voluntary activities there. The singers are from a local coral group.



EMMY FARNHAM held a FUNDRAISER at her hairdressing salon last March for CH Awareness Day.

SYLVIA POORE made these pocket tissue holders plus other handcrafted items to raise awareness and funds for OUCH, her husband John is a chronic CH sufferer.

ART SHOW AWARENESS EVENT

23rd/24th March, 2019

Member Clare Tucker had an art showing at Gosfield Shopping Village in Essex where she had her own stand to coincide with CH Awareness Day. All of her art work has been inspired by her cluster headaches - she didn't paint prior to that. On her stand, Clare had her display of paintings, plus OUCH booklets and leaflets as she wanted to explain why she was painting. If Clare sells any of her paintings she intends to donate some of the money to OUCH and will probably use a little of it to buy new materials to paint more and repeat the process.

Thanks go to Clare and also a big thank you to her employers, FR Shadbolt & Sons, who have done everything possible to help Clare to keep on working for them from home. The company intend to fundraise for **OUCH** throughout the year and have already made a generous donation.

BRIGHTON MARATHON

THANK YOU MORAD NADIMI for completing the Brighton Marathon to raise funds for OUCH(UK)! Morad's close friend suffers from cluster headaches and he has seen how debilitating it is. This is his way of showing support for his friend and we are grateful for every penny he raises. Well done Morad, good friends are invaluable.

Many thanks to anyone who donated to this event:

https://uk.virginmoneygiving.com/MoradNadimi

LONDON MARATHON 28th April, 2019 - Corin Ridout

Corin is raising funds for OUCH (UK) and has added to his London Marathon event to include three events - London Marathon, Ride London 100 mile and Swim Serpentine 2 mile; collectively they make up the London Classics challenge.

Thank you, Corin - you smashed the London Marathon and good luck with your remaining events!

LONDON MARATHON 28th April, 2019 - Alisdair Williams

Alisdair Williams, a CH sufferer for 20 years, also smashed the London Marathon to raise funds and awareness for us. Alisdair is pictured here after completing the Coventry Half Marathon, sporting his OUCH tee shirt.

Thank you, Alisdair and many thanks to all who contributed:

SOUTH COAST CHALLENGE – 100k Continuous Walk

DANNY WALSH raised a whopping £620 in just 3 days in advance of his Continuous 100k South Coast Challenge walk from Eastbourne to Arundel. The challenge takes place on 31st August. Danny is diagnosed CCH but considers himself lucky as he has not only a good treatment plan in place but also a very supportive family and employer. Danny wants to do something to help the charity to support others who are less fortunate than him and who may not have such good support.

ANGELA VINCE is getting set to run two 10k races in aid of OUCH (UK) - the Eastbourne 10k on 30th June 2019, and the South Coast 10k on 11th August 2019.

Angela wants to raise awareness because her brother, Chris, is currently going through the worst and longest bout of cluster headaches that he has ever experienced since first being diagnosed in 2008. Chris is very proud of his sister for her support.

Good luck Angela and many thanks!

https://uk.virginmoneygiving.com/AngelaVince

96 MILE WALK WEST HIGHLAND WAY

These two gorgeous girls, LINDA DUDDY and JANE WHITZ, will be walking the famous "West Highland Way" (96 miles/154kms) in Scotland for OUCH(UK). The event isn't until September but I'm sure we'll be hearing from the girls leading up to it.

Both are chronic CH sufferers and they aim to raise awareness for the condition and funds for the charity as they go. Donations are already coming in, many thanks to all who have already contributed.

Training has already started and we can look forward to the pals posting their training antics and vlogs along the way! We can't wait!

Read more about the event and if you wish to contribute, you can donate to this link: https://uk.virginmoneygiving.com/Clusterheads

EVEREST OF CANOEING - 125 MILE NON-STOP CANOE RACE

DEVIZES TO WESTMINSTER CANOE RACE. 20TH APRIL 2019

The gruelling, non-stop 125 miles from Devizes to Westminster is the world's toughest canoe race, known as the "Everest of canoeing". The race starts at Devizes...along the Kennet and Avon Canal to the Thames, before reaching the most dangerous part, the tidal Thames and the last 17 miles. There are 77 portage (locks) to negotiate when they get out and have to carry their kayak. They have to have support teams who will provide them with food and drink.

Tim Beaver and Bill Playle

pictures with kind permission of
Sasha Balla Photography

Jeff Crib & Neil Boast

Neil Boast, our well known, friendly, CH-supporting oxygen man, intended to be taking part again in this event this year until an injury put paid to his plans. To begin with, Neil was meant to be partnered by his friend, Jeff Cribb but Jeff had to pull out due to injury. We thank Jeff very much for his contribution of painful training sessions! Neil and Jeff had already been raising lots of donations leading up to the race. Not one to give up, Neil planned to attempt the race solo - but luck was against him again and he was devastated when he had to pull out of the race due to severe pain following a shoulder injury.

Although Neil was bitterly disappointed, two good friends were getting ready to step up and complete the fundraiser for OUCH!

OUCH (UK) and its members well remember Tim Beaver, Neil’s partner in the 2017 race. Tim and his partner for this year, Bill Playle, happily picked up the baton to paddle for us.

We were very grateful to Tim and Bill - OUCH members everywhere greatly enjoyed following boat 307 to the end where they were placed 16th in the Senior Doubles and won the century cup and the team trophy. Well done boys!
Tim, Bill, Neil and Jeff – you are heroes all and we can’t thank you enough!

Devizes to Westminster Race Report by Tim Beaver:
Crew 307 met up at Base camp, Chippenham the evening before the race and a support crew meeting held to finalise who was supporting at each point. For the words support crew, please read: Best Support Crew in the World and my sincere thanks and gratitude go to Charlotte Emily Beaver, Zoë Woodham, Diana Naftanaila and Maria Playle who were nothing short of brilliant.
It was an added bonus to meet up with Stefan Erlandsson and his crew who were doing the race and go through some of the support points with them as they had travelled from Sweden to take part.
Check in at the start line on Devizes wharf was seamless and we started just after midday.
The long pound of 14 miles to the first lock was uneventful and we reached Wooton Rivers in good nick. Maintaining a steady pace saw us negotiate the Bruce Tunnel and the series of locks at Crofton in good order coming out the other side 2 mins up on schedule. By now my shoulder was hurting which was worrying but Charlotte got some painkillers into me and I didn't really feel it unless lifting the boat at locks.
On the run in to Hungerford we caught a South African crew who stayed with us until Kintbury where we able to pull away. A good run into Newbury and a swift adding of additional layers saw us leave there on schedule.
The next 19 miles to Reading were a bit quiet, I had thought we would have seen more crews but there was hardly anyone about. Once we had the influence of the river we set a good pace, feeling strong, however, we did make an error at Fobney and lost some time having been slow into the boat and getting swept round in the current. An enjoyable run into Reading and an efficient kit change at the compulsory stop at Dreadnought Reach.
By now, we had started to leak a bit of time and zero flow meant that Father Thames hadn't taken a leak for a long time! This coupled with some amount of tiredness meant we began slowly to leak time, I think in hindsight the canal being low as well didn't help. I started to find it difficult to get food down as swallowing became quite difficult and the longer sections of the Thames meant I was getting quite hungry.
On through Sonning where we managed to collide with the fallen tree we had been warned about! And down to Shiplake where it was really good to see Paul Lowe, Joanne Lowe, Gary Lowe and Naomi Elizabeth marshalling, having given up their own Easter for people like me to achieve their goals. Paul Lowe duly delivered the pre-race promised Jaffa Cake and on we went. By the time I got to Marsh Lock I was suffering a bit but we ran the portage and once back in the boat had a good run down to Hambledon managing to pass Ian Abrams and Gordon Bullock who were in good spirits and going well. A bit slow through Hambledon but a good run down to Hurley where the Marshalls warned us of a problem at Marlow. On arrival there, a police launch instructed us to portage upstream of Marlow Bridge and we were guided on a long portage through a park and churchyard to a put in point below the bridge, the cause being ordnance found in the river. On down to Cookham and then Boulters locks which is a long section and the energy levels depleted.

Cont'd

Then on down through Bray, Boveney and on to Romney lock where again we were more than ready for food. This section we definitely slowed on. On down to Old Windsor and Bell, two sections where my crew-mate, the legendary Bill Playle had a few wobbles, I think due to energy depletion but the tough nut that he is just got on with it. Delayed by a queue of boats at the portage point which seemed to become the norm from thereon. A pretty smooth run through the remains sections to Royal Canoe Club where our support crew prepped us for the Tideway. I got a bit emotional here as the realisation dawned that we would finish no matter what the Tideway held in store. Stiff upper lip Beaver and on we went through Teddington and onto the Tideway 17 miles from home. That slog never gets any easier and I was a bit weak minded on the top section asking Bill to stop on the bank twice so I could sort an issue with my drinks bladder and then take on some food energy. After that we just slogged it out and were relieved to see the finish line, within sight of which we had to deal with the wash from a massive tourist boat, difficult to do once you are knackered. Under Westminster Bridge to huge applause and assistance from the Steps crew to get us safely off the water and up the Steps.

A huge thanks to all the Marshalls and organisers of the Devizes to Westminster International Canoe Race. We placed 16th, won the century cup and the team trophy, I also now get on the list of paddlers with 8 or more straight through completions. 12th finish in the event.

I am disappointed we didn't break our goal of 20hrs, can't help feeling I let Bill and our support crew down but it goes nowhere near the absolute sadness and shock I feel in learning someone lost their life in the event, an absolute tragedy.

Thank you to everyone who followed us and gave us messages of encouragement through the race and beyond.

TEGAN'S 14" HAIRCUT!

Liam Dennis is well known for his past award-winning feats to raise funds for OUCH(UK). Now Liam's daughter, 12 year old Tegan, has had more than 14 inches of her beautiful hair cut off (she loves it...phew!) to support her dad and his charity.

Tegan's hair will be given to the Princess Trust who provide real hair wigs to children and young people who have lost their own hair due to cancer treatment and other conditions.

Tegan has obviously been inspired by her dad to do something worthwhile and this is such a very worthy cause!

A massive thank you from all of us, Tegan, you look great!

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

- 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 have answered yes to these 3 questions then you may be eligible to help us with a study that we are conducting using a technique called functional magnetic resonance imaging (fMRI) to scan the brain during the different phases of a cluster headache attack. The imaging technique does not include harmful radiation and is safe.

This study involves a clinic visit to ensure eligibility with one of the Headache doctors at King's College Hospital followed by a further 3 whole day visits to the Clinical Research Facility at King's College Hospital.

You would be reimbursed for travel and your time.

If you are interested in taking part or would like additional information please contact Dr Diana Wei at the King's College London Headache Group on

Clusterheadache-research@kcl.ac.uk

CLUSTER HEADACHE AWARENESS DAY 2019

OUCH(UK) with our colleagues in the European Migraine and Headache Alliance were proud to host the 4th Cluster Headache Awareness Day. OUCH(UK) represented cluster headache patients at the European parliament. Trustee Scott Bruce delivered a short but powerful speech on the role of patient support groups.

This year the theme was focusing on the future and what we do despite the terrible pain we experience. Here are some examples we received of how CH sufferers push on with life despite the pain:

LIVING LIFE IN SPITE OF CH.

JANE WHITZ: I trail run and take photos. I am also a full time educator and carer to my incredibly interesting twin boys .At one point CH consumed my life, but gradually with the support of other sufferers, a good treatment plan and being really stubborn, I managed to workout a better way forward. It takes time to come to terms with the pain and life changes, but it’s not impossible. I took this photo at dawn today, when on a run. It reminds me that everyday is a fresh start.

STEVEN M. WILKES: I bring up my 8 year old son and ensure that he tries all sports and all art forms.

RUTH STRUGNELL: Trying new things - I'm trying not to let CH make my world smaller, so whether it's traveling somewhere new, eating something different or just reading a book by a new author I try not to get stuck in a rut. At the end of 2017 I learned to crochet - these are a few of the 20+ projects I finished last year.

NORMA BURT: Have recently retired because CH were taking my life over but I will not be beaten by this beast I have a list with things I want to do and I will do them all. Number 1 is to stop being a prisoner in my home, not to just look though the window and think will I be alright to go out but to go through my front door. I am meeting some of my friends on Saturday and have booked a holiday in a few weeks. I have a life and I am going to live it.

LIVING LIFE IN SPITE OF CH.

DEAN TAYLOR: I draw, I’m also a professional Barista and make specialty coffee, I also care for my Father who has mixed dementia! Whilst I struggle with the pain, I struggle with the loneliness it causes when an attack happens, I simply refuse to let it dictate my life, I have a wonderful supportive family and my hobby and work are my relaxation my cluster headaches will never be what I’m remembered for!!!

KAREN MAY: I manage to hold down a job I love thanks to incredibly understanding employers; raise two kids and even go away camping to music festivals with them. I’m also currently training to run a Tough Mudder event in May!
Living with cluster headaches is excruciating and exhausting, but the right support network from family, friends, doctors, employers and services (Bloodstock festival were incredible!) means life is still worth living in spite of them.

AMY NAHOME-SINDEN: I have a very demanding full time job, am mummy to the most incredible little boy (21 months old), applying to start a university degree (whilst still working), undergoing a lot of training at work, and looking to expand the family again in the next year or so. As difficult as it can be, I am determined not to be beaten.

SARANNE PB: Despite the demon attacks I live a great life. I work 30 hrs a week with looked after children, I help care for my separated and elderly parents and regularly enjoy my hobby of photographing nature and attending as many gigs as I can. It's tough, and I do need to cancel a lot of plans at very short notice but I won't be beaten and just take my O_2 and Triptan injections everywhere. Few weeks ago I bought my first campervan and have a special cubby hole in there especially for them. I also live with Rheumatoid Arthritis but I'm resilient, determined and loving life. Must also add here that I truly believe that all this is only possible for me because I have an amazing support team too. My fiancé, family, friends and colleagues have travelled the 25 year journey with me, we have all learnt together and they are all amazing. I may be chronically ill but I'm also mightily blessed.

MICHELLE TABITHA BRIDGE: See this lil lady, Maya. She keeps me going. We've learnt that we can get out & lose ourselves in the countryside, during mid morning. We aim to walk between 3-5 miles. We've learnt that fresh air is my best medicine, it clears congested nasal passages & promotes deep breaths. Even after recent spinal stim implant & strict restrictions, we still went out, although we needed another human with us, to hold the lead & bend. Maya is so in tune with me, that there's been many times, that she decides I'm to go home.
Clusters are a very isolating condition & take so much from you, its important to fight & keep something, at all costs.

WAYNE BOVALENTINE: I work as a Glazier on High rise buildings and organise a ROCK'N'ROLL festival.

SHARON NOBLE: I make cards etc and donate them to charities. Living with the illnesses I live with including chronic cluster headaches makes life difficult but also makes me appreciate the small things I also love spending time with my husband and Collie and seeing nature.

VAL HOBBS: I graduated from the university of Swansea with a BA hons at the age of 64, having been a lifelong sufferer of CH, and being chronic since the age of 51. I was a legal Secretary before becoming chronic

ELINA REGAN: I'm lucky enough to be full time mum to these amazing little boys. My cluster headaches give me nothing but horrific pain and literally suck the life out of me and then I'm woken up by these beauts every day and have to keep going. They run me riot, laughing and smiling all day and I've found they help me see the beauty in the simplest things by looking at the world through their eyes. We go on the swings together at our local park, we jump in puddles and go on bear hunts at the nature reserve. We do awful dances together but their spirit keeps me going every day and for that I'll always be so grateful to them and so proud of them. The beast always returns but they help me get back up on my feet and keep me living.

GEORGINA HARDING: My saviours are my lovely beagle and my big hairy horse, along with my two boys, wonderful hubby and my friends and family. I am a nurse manager and work almost full time, but I try to make sure that we have a good and balanced life that is full of fun and variety. I haven't been able to ride my horse for six weeks due to constant attacks, they leave me exhausted and unable to focus on much. Thank you for all you do. You are all awesome x

MCKENZIE BEE: I look at this picture everyday. Reminds me how far we've come. She's my reason.

CINDY REYNOLDS:
Although I'm an American, I did travel to Italy while living with chronic clusters. It was equally amazing and difficult, but I did it!

JUST RELAX & CHILL

Word Search - OUCH

T	T	G	B	F	C	O	N	F	E	R	E	N	C	E
S	U	M	A	T	R	I	P	T	A	N	D	W	S	M
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