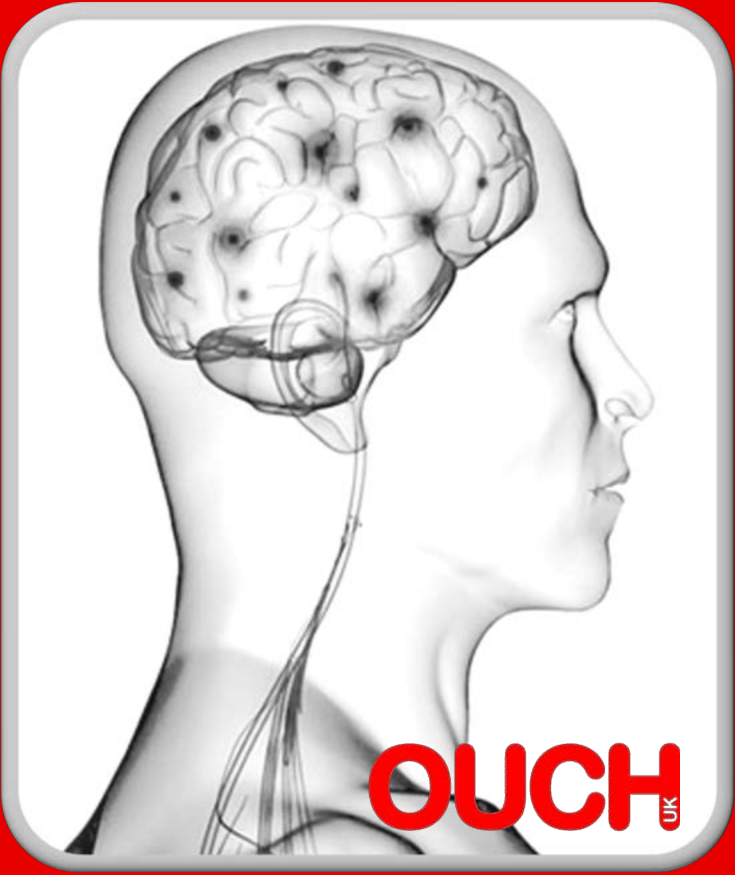
CHit CHat

The Official Newsletter of OUCH (UK)

The Organisation for the Understanding of Cluster Headache



SUMMER 2020

Coronavirus Edition

WWW.OUCHUK.ORG
MAKING OUR PAIN INVISIBLE

Professor Peter Goadsby
Patron of OUCH (UK). World authority on cluster headache and is chair of the IHS classification group. Currently conducting research at Kings College Hospital into use of CGRP [calcitonin gene related peptides] for the prevention of cluster headache.

Colin Allen (Vice Chairman)
Colin is an Episodic Sufferer. His long service in the charity as Advice Line Manager and now as Vice Chairman, brings considerable knowledge to the board. Colin is 'retired' and lives in Liverpool.

John Doyle (Treasurer)
John joined Ouch(Uk) in 2019 to take on the role as Treasurer
John lives in Liverpool where he is a support worker.
He became aware of the charity through his association with our vice chairman, Colin Allen.

Dorothy Chapman
Dorothy has been an episodic sufferer for more years than a lady should admit to. She has been a member of OUCH (UK) since the early days of the charity and became a trustee in 2014. Dorothy enjoys liaising with our fabulous fundraisers and promoting their very varied and exciting events.

Scott Bruce
Scott is an episodic sufferer, based in Scotland. He has been a member since 2003 and joined the advice line team in 2007. In 2014 he accepted a trustee position and coordinates many of the regional meetings that the charity puts together.

Elizabeth Kelly
Liz is the charity's Advice Line Manager. Liz joined OUCH in 2006 and has worked as a volunteer on the advice line since 2007. Liz has helped hundreds of people during that time and she brings considerable experience to the role.

Sandra McDowell
Sandra is a supporter to her husband Andy who for several years was our advice line supervisor. Sandra herself has been a volunteer on the advice line for a number of years and has helped hundreds of callers to the advice line. She has also done and organised several fundraising events for OUCH.

Valerie Hobbs
Val is a chronic sufferer who joined OUCH in 2002 and in 2003 became an advice line volunteer, taking over the running of the advice line when the original manager retired. In 2006 Val became a trustee, but stepped down in 2010 to take on the administration of the charity and Liz Kelly took on running the advice line. Val has now become a Trustee again, with oxygen for CH in the UK as her remit.

Anne Turner
Anne first joined OUCH (UK) as supporter of a Cluster Headache sufferer and went on to become a Trustee in 2019. She now carries out some administrative work for OUCH, deals with membership and manages OUCH's online shop.

Jason Clark
Jason has been a supporter to OUCH for a number of years through his dad Brian who is a Chronic Cluster Headache Sufferer. Jason joined OUCH UK in 2014 as an Officer to originally help with HR & Employment Law matters, his role expanded to also help with the Benefits side of things which has grown considerably over the years. Jason is qualified to CIPD Level 7 in HR & Employment Law and is an Associate Member of the CIPD.

Officers

All the present Officers are sufferers or supporters of sufferers, and provide full support and help to the trustees, sufferers and their families.

Michelle Jackson (Advice Line)

Linda Duddy (Advice Line)

Ray Ward (Advice Line) Ray has been a sufferer for many years.

John Poore (CHitCHat Editor) John is a chronic sufferer who joined OUCH UK in 2018 and took on the role of Editor in 2019.

OUCH (UK) Membership Report 2020 - Anne Turner, Trustee

OUCH (UK) was officially launched in 2001 and became a registered charity in 2002. We now have a steady 200 to 250 new members joining each year. We send out membership renewal reminders and we offer the option of joining and/or renewing for 1, 3 or 5 years. Of course, for various reasons, not all members renew their memberships every year.

Membership benefits include -

- the ability to post on the website forum and join in discussions
- a 10% discount on items in our online shop
- a substantial discount on tickets for OUCH conferences
- access to a small number of members only pages of our website
- email updates with news about the latest medical research, surveys, trials and issues of CHit Chat

At the beginning of May 2020, there were 731 current members of OUCH, who self-reported as follows. (There were some gaps in responses.)

1.	**Members**	
	Sufferers	660
	Supporters of sufferers	71
	Making a total	731
2.	**Type of headache**	
	Episodic CH	227
	Chronic CH	168
	Paroxysmal Hemicrania	3
	Hemicrania Continua	6
	SUNCT / SUNA	5
	Migraine	9
	More than 1 headache condition	20
3.	**Diagnosed by**	
	Neurologist	333
	GP	160

All our Trustees and officials are volunteers and sufferers or supporters of sufferers. The charity receives no government or commercial funding but relies entirely on annual membership subscriptions along with fundraising activities and donations by our generous supporters. These enable us to maintain our website, run our all important telephone and online Advice Line, provide printed and online information for the public and health professionals and generally help raise awareness of the devastating pain of this illness.

We have contact with neurologists around the country who specialise in headache, not least our distinguished patron, professor Peter Goadsby, now at King's College, London. We are a member of Headache UK, an umbrella organisation of headache charities, and we contribute to the All Party Parliamentary Group on Headache Disorders. We also have representatives working with the following organisations -

- National Institute for Health and Care Excellence (NICE)
- Home Oxygen Service (HOS) National Patient Safety Group
- Disability Benefits Consortium
- European Headache and Migraine Association (EMHA)
- British Association for the Study of Headache (BASH)

So, if you're not a member already, OUCH would love you to join us!

Summer Conference

Unfortunately the planned Summer Conference to be held in Liverpool during July had to be cancelled due to the Coronavirus, at this stage no further plans have been made for a future conference - watch the website for more news.

New: OUCH members now receive a 10% discount on purchases.

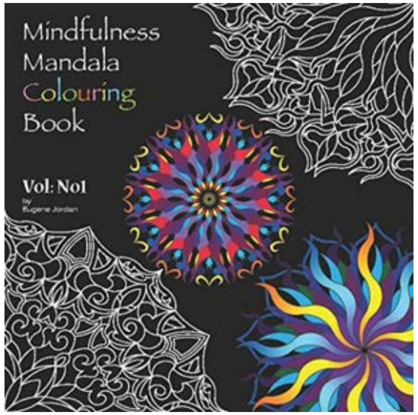
We've been selling some Cluster Headache awareness products at OUCH meetings for a long time, but the online shop has taken sales to a new level. We've added some new stock ranges and purchases can now be made online at any time of day or night for delivery right to your door.

If you haven't visited the shop yet, just click **Shop** at the top of our website to see our full range of awareness products 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 let us know at **shop@ouchuk.org**



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

OXYGEN AND COVID 19 - Valerie Hobbs

Well by the time you read this issue, we will hopefully be gently coming out of lockdown throughout the UK.

In December, the Trustees discussed standardisation of oxygen supply criteria in the UK. Currently, each nation in the union has a separate set of criteria for prescribing oxygen, with the exception of Wales which goes along with England, to make life easier both for sufferers and prescribing GPs. Just to give you an idea, in England a GP can prescribe oxygen using the HOOF form Part A, but in Scotland oxygen can only be prescribed by a secondary clinician, i.e. a consultant, and that is just one example.

Then Covid 19 came along and with it the realisation that oxygen might become difficult to get hold of as it was quite rightly anticipated that oxygen would be prioritised for Covid 19 patients. About a week into lockdown, a Welsh member received a call from the local community oxygen nurse, telling them that all their oxygen would be collected as it was needed to prepare for a surge in demand for oxygen for Covid19 patients, in particular those who were not on ventilators, but in temporary hospitals for recovery. Our member was horrified and contacted us and within a couple of days we had contacted the oxygen suppliers to ask whether there were sufficient supplies of home oxygen for all home oxygen users. They assured us there was no problem with supplies, but they did ask us to tell our members NOT to panic order supplies. They also informed us that the oxygen recall from home oxygen users was voluntary and you could return all, some or none; the choice was up to the user. The oxygen companies also pointed out that both Covid 19 patients on ventilators and those in recovery hospitals would be using oxygen from the huge oxygen containers we all see outside hospitals and that home oxygen cylinders wouldn't be used by inpatients.

We e-mailed everyone our database explaining the situation and saying if you wanted to 'do your bit' for Covid 19, to ensure that they did not panic order, and if contacted by their Health Board they could decide whether or not to return all, some or none of their cylinders.

To back this up OUCH (UK) wrote to Matt Hancock the Secretary of State for Health by e-mail and by hard copy and also to the First Ministers of Scotland, Wales and Northern Ireland, urging that a unified standard prescribing practice be adopted for the duration of the pandemic and further, that we had urged our members not to panic-order and to surrender cylinders if asked while maintaining a sufficient supply for themselves. We received acknowledgements of the letters, but as yet no substantive reply! OUCH (UK) will keep up the pressure to try and get a standard prescribing criteria throughout the UK and to continue it after Covid19 has fled these shores.

Some sufferers have had to 'shield' but not just because of CH, most of them have other underlying health conditions that render them a high risk.

We know of two or three members who have had the virus and have come through it and we wish them all a speedy recovery.

PLEASE STAY SAFE, FOLLOW GOVERNMENT GUIDELINES ON THE EASING OF LOCKDOWN, AND USE YOUR COMMON SENSE!

PRESENTATION To GP's, GP Nurses, GP Trainers

by Scott Bruce

In October, 2019, Trustee Scott Bruce spoke to GPs, GP Nurses and GP trainers at an NHS Forth Valley Headache Masterclass, covering cluster headache. This was a wonderful opportunity to speak to these health professionals from a sufferer's point of view and share with them what a sufferer has to live with.

MIKE POLLOCK AWARD

We were delighted to announce that the winner of the Mike Pollock award 2019 was Toryn Ahmet Tucker. What a well deserved win and most especially because he was chosen by the CH community.

Who could forget the fantastic video Toryn made about cluster headache, not only in support of his mother Clare but also of all cluster headache sufferers.
The video can be seen on our YouTube channel. Here's the link if you haven't already seen it:

https://www.youtube.com/channel/UCBuPXWRtboMYcfGvy5ercaQ

"A Picture of Pain" by Bear Peterson

I tried to paint a picture,
Of how I really Feel.
But I could not find the colours,
To make it all seem real.
Not one colour was hot enough,
To show the burning pain.
Not one colour bright enough,
To make me wince again.
Not one was dark enough,
To show the isolation.
In the end I saw one thin line,
Worn, frayed and almost broke,
To my mind that one thin line,
Is a single thread of hope.

SAD NEWS

We were deeply saddened to hear that Vicky Quarshie, well known and much loved Headache Specialist Nurse, based at Hull Royal Infirmary, passed away after a short illness at the end of April.

Vicky has been a dedicated advocate of OUCH (UK) and its cause for a very long time and was also a compassionate and much loved nurse to her headache patients. She was chosen for our Les Charlton Award last year and I had the great pleasure of presenting her with the award in November during a show she arranged at Park Street Centre to raise funds for OUCH. I met some of her patients there who clearly adored her. She was also a member of the BASH Council, a founder of the UK Headache Specialist Nurses Group and a Trustee of Park Street Performing Arts Centre where she helped and encouraged people to become confident performers.

Vicky's work was her pleasure and it was unlimited, spilling over into her personal time where she helped so many people that there has been a huge outpouring of love and appreciation since the news of her passing. Right up until the week before she died, Vicky was planning what she could do next to raise more awareness of cluster headaches and funds for OUCH.

Vicky's devotion knew no bounds and she will be missed by very many people. We extend our deepest sympathy to Vicky's family, her friends, colleagues, students and patients.

Dorothy Chapman (Trustee)

Park Street Performing Arts Centre (on FB)

In April, Park Street lost a big part of our team. Vicky Quarshie was a friend to everyone, a performer like no other and an influence on many. Our loss will be felt forever.

To remember her, we have made the very easy decision to name part of our iconic building in her memory.

Everyone will recall with a smile how Vicky made those outlandish costumes, towering hats and frankly scary wigs while sat in our little cafe, passing the time with whoever was in there, shouting at us to bring her coffee and the way kids all called her name as they walked in. Who could forget her tireless work on "Old Deuteronomy's Coat", a hand-made masterpiece of a thousand threads for our fantastic 2019 production of "Cats"?

So, we are delighted to say that we are renaming and revamping the cafe in her honour. We're calling it:

"The Purple Heart Cafe Bar".
Vicky would approve, we think.
She loved all things purple, hence the chosen name.
Love, The Park Street Trust and Staff

My memories of Vicky are that she was kind, caring, thoughtful, friendly, a good listener, nurse, cook, singer, mother, daughter & friend. Vicky could read you like a book and knew instinctively what you needed, whether it be a cuddle, an ear, advice or time. She wasn't shy at letting you know what you could help her with either; e.g a tractor tyre for one of the shows!

I was asked by Karen Pickering (a member of the Alternative Aquatics Group) to go with her to a new group being set up by Vicky, singing for Health and Wellbeing. I went, hoping it would do me some good, as I'd been feeling down since a fire at my home a few months previously. Vicky welcomed me to the group with a cup of coffee and a cheery hello, as if she'd known me for years, which soon put me at ease, as she did with everyone she met. We did some easy exercises first and then sang some karaoke as a group.

It didn't matter whether you could sing or not, we were all applauded for our efforts anyway.

I came away that day happier than I'd been in a long time and returned at every opportunity after that I could, to see my new friends. I even talked my husband Chris into coming on his rare days off during the week.Vicky even talked some of the group into doing crafts for sale at the charity gala and making props for future performances, which we all loved doing. We have lots of happy memories of watching Vicky singing in 'Search for a Star' and numerous other performances on the Park street stage, charity singalongs and the hoe down line dancing event etc.

We will all miss Vicky. My Friend. Love Joy Collins-Reed

My Friend and Headache Nurse Vicky Quarshie by Vivian Bielby

I'm a cluster headache sufferer and Vicky was my headache nurse but to me she was way more than that. The first time I saw Vicky I had an attack in her office, so she saw exactly what I was going through. Whenever I went to see her, she was so calming and if ever I was having a bad time she was always there, just on the other end of a phone.

Vicky also had another cause close to her heart at Park Street Centre for Performing Arts which she loved as she was a performer. Once when I went for my GONI, I was depressed and she could see I needed to talk so I told her why. Then she told me about her group so I thought I would give it a go and it was great. I went in alone and down but came out feeling better and with a few friends. A few weeks later my sister Joanne came and she loved it too.

Vicky was putting a charity concert on for OUCH (UK) in November and I asked if me and my sister could do something and she said yes. Later on that day she said to me, 6 months ago did you think you would be singing on stage? I said no!

The day of the show came and I had a chest infection so I couldn't sing but my sister did and she was great. She made me cry as she said she was singing because of me. Vicky was so proud of her.

Vicky is so badly missed. She was not just a nurse and teacher - she was a friend and confidant.

VICKY QUARSHIE you were a star on earth and now you are a star in the sky. Sing loud up in heaven and look down on us from up there.

Love Vivian

OUCH (UK) Advice Line - an insight - Elizabeth Kelly

Our Advice Line has been running for 18 years, and I have been Manager for the last 5 years, I have noticed that the subject matter of calls has changed over time.

When I first worked on the Advice Line (Helpline back then) in 2007, the main subject was getting GP's to prescribe injections. This changed to include problems getting oxygen too and referrals to a Neurologist who understood about Cluster Headache. Slowly issues surrounding benefits began to gain momentum which built through the years to a point where every call had an element if it was not entirely about PIP. Things have now returned to problem GP's and getting referrals. All these subjects can be carefully guided by our Advice Liners.

The numbers of calls each week are on average around 12, but these tend to rise as Episodic sufferers come into bout two to three times a year, and during awareness campaigns. Then some days can have 5 or 6 calls in one day, I have been on duty myself last year when there were twelve calls in one day. The only exception to that is this year, as we went into lockdown, there were no calls at all for just over two weeks, which is usually unknown. This has now changed and gone back up to normal levels.

Working on the Advice Line has been very rewarding as I have felt I have really been able to help people and give something back for all I have learned about my own disease to try and take the fear away to enable others to manage their own condition.

We are looking for a volunteer to assist on our Advice Line. Many of you will have had your first contact with another sufferer via our Advice Line and know how important it is we continue to provide this service.

The hours would be 10am to 2pm on any day between Monday to Friday each week, and to be available for sickness and holiday cover if needed. You would need to have a good background knowledge of CH, but we don't expect you to be expert! We would give you training and you would have a folder of background information to help you. If you have some advice line experience that would be great too. If you are interested please email liz@ouchuk.org

A day on the Advice Line for OUCH (UK) - Ray Ward

Without doubt my biggest asset as an Advice Line person is the fact that I am a Cluster Headache sufferer and have been so for over 26 years.

I have been on the advice line for about one year now and at last I have found a way of making this horrendous condition useful to try and help other sufferers .

I wanted to put something back in to OUCH because this wonderful charity helped me many years ago when I needed it most.

The Advice Line is available 24 hours a day and 7 days a week for people to leave their details together with any message. We respond to calls Monday to Friday between 10 am and 2 pm. Weekends are for emergency calls only.

When I am on duty I like to listen to any messages as soon as I get up at around 7am. I take down the details of the messages that have come in from the previous late afternoon or evening. Usually, the messages are short with a name and telephone number to call back. Sometimes, but less common, people will tell you why they are calling within the message. This helps because I can prepare and research before I call them back. I don't mind if people don't leave any clues in their message, in fact, I prefer it in a strange way because I have to think on my feet and it sharpens my bashed up brain.

I usually start calling people before the 10 am start time.

I find this helps if you have a lot of calls left over from the previous day because some calls can go on a bit and it gives me more time with each person if needed.

Some calls can be an hour long and I don't ever want to rush anyone.

Some callers just need to vent their frustration about a GP or a Neurologist and they have never spoken to anybody that truly understands their situation.

I always introduce myself and say from the start that I too suffer with cluster headaches. This seems to have a calming effect on the caller and it saves them from trying to describe the pain they are going through, and in turn takes the frustration away. They know that I know what they are going through.

We get all kinds of people call the advice line, parents of children suffering this horrible disease, people who are suffering other life threatening illnesses as well as cluster headaches. People who are suffering from helplessness and want to give up.

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A day on the Advice Line for OUCH (UK) - con'd

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A couple of weeks ago a person called the advice line and they had been through hell. They told me that they wanted to commit suicide because they felt that nobody was listening to them and they felt they couldn't go on . They had lost their job and were about to lose their home.

I could have referred them on to their GP or the Samaritans etc but this person just kept talking and explaining what they were going through and I just listened making the odd comments. I told him at the beginning that I was also a sufferer of cluster headaches and after they had told me everything they wanted to get off their chest, they asked me how I coped and that was the turning point for them.

I didn't say anything special, no magic words I just explained how I coped with life. This person changed their dark thoughts and we had a good conversation, not for what I said but for just listening to them.

They phoned me on the advice line and asked to speak to me, I phoned them back and they thanked me again. Of course, if things didn't sound right or go well during that call I would have notified someone.

Thankfully, most calls are easier to deal with and it's a nice feeling to know that you have tried to help someone.

Being on the advice line is very rewarding, it can be frustrating when we hear that GP's are not prescribing the correct medications or refusing to prescribe because of cost.

2 pm soon comes around when you are busy on the advice line although calls may run over a little sometimes. On advice line days I have my lunch at just after 2 pm and that's it all done until the next shift and I am really happy to do it for this truly fantastic charity known as OUCH UK.

Support OUCH (UK) with our Christmas cards

Our Christmas cards for 2019 featured two beautiful photographs taken by OUCH Officer, Linda Duddy and were very popular indeed. Thank you, Linda!

Our charity Christmas cards are a great way to raise awareness and we already have some good suggestions for Christmas 2020.

Just keep an eye on the website as to when they will be available from our OUCH (UK) ONLINE SHOP

PIP Success to March 2020 - Jason Clark

Obviously, the current crisis situation is having a big impact on Benefit claims and appeals.
As PIP assessments are now carried out over the phone rather than face-to-face, it is worth confirming here that claimants have the right to be supported by a friend, partner or family member during the process.
The DWP has released their latest statistics about benefit claims. A mixed bag, but there are some standout figures which are difficult to explain, most notably the fact that fewer than one third of new PIP claims are successful.
This is a continuing trend, which has seen monthly declines in the percentage of successful claims, from 42% when the award was first introduced.
Transferring from DLA to PIP is also an unhappy experience for many. A quarter of people lose their benefit completely, with another 22% having the amount they receive reduced.
On the other hand, nearly two-fifths of claimants see their benefit increased when they make the transition.

It was always clear that the DLA indefinite award would be consigned to the past – something which has caused considerable upset to many people with long-term conditions, who are never going to get better, but still have to undergo regular reassessments.
Nearly three-quarters of new PIP claims last for only two years, and if you are very unfortunate, you may have to go through the whole procedure again after nine months. The government has said that they will increase this to 18 months as a minimum award period.
People with mental health conditions generally get the shortest awards, and are more likely to have their benefits reduced or stopped altogether.

The Tribunals Service statistics show that claimants are winning PIP and ESA appeals at the highest rate ever recorded.
Overall, an extraordinary 73% of social security appeals are successful, with the claimant getting a better award than they originally received from the DWP.
Success rates for individual benefits:

- Employment and Support Allowance (ESA) 77%
- Personal Independence Payment (PIP) 76%
- Disabled Living Allowance (DLA) 69%
- Universal Credit (UC) 61%

However, many claims that are initially unsuccessful simply don’t make it to appeal. The number of social security appeals has dropped by 22%, compared to the same quarter a year ago.
The steepest decline has been in ESA appeals, down by more than half, which is explained in part by the replacement of some ESA awards with UC.

PIP appeal numbers have also fallen, by 15%.

Representing my Dad at PIP Tribunal - Jason Clark

Representing my dad at a PIP Tribunal:

Leading up to the tribunal it can get nervous and you might think is this worth it?
The simple answer is yes, it is.
I was greeted by the very nice clerk who explained the process and what will happen. There is a panel of 3 at the tribunal: a judge, a disability expert and a doctor. The meeting was recorded.
Be prepared with your medical evidence and know it inside out, what your current treatments are and what you have been on in the past. In the tribunal I was asked the majority of the questions by the doctor about my dad's condition. This included questions on day to day activities, previous treatments, O2 and the demand valve, what happens when in an attack, the functionality of my dad when in an attack and the frequency of attacks.
I was also questioned on the difference between my dad now and when the original application went in. I was asked about what he needs to do to be able to function on a day to day basis, what would help him and the support he needs. I was questioned about the number of times he has had to go to the hospital and if anyone went with him. I was also asked about any other specialist he was seeing.
The judge and disability specialist only asked me a couple of questions which were mainly to do with the original application and the DVLA. They asked me what I think the score should have been and why. I felt the score should reflect that my dad is not able to travel an unknown route without someone with him, because during an attack no one knows what's happening, he is not able to administer O2 without assistance, and any medical treatment would require someone to explain his condition to ambulance paramedics or at a hospital if it came to that.
I was then asked to make a final statement. I stated that I was not there just as a representative for my dad but also as an officer of OUCH UK. I see the struggle that sufferers go through on a daily basis and the pain they must endure. I said that if this simple mobility/pip payment can help someone that suffers from a condition that is said to be the worst pain in human history, then it should be allowed without question.
I was then thanked for attending and advised that they couldn't make a decision there and then. We got the decision in the post that we had been successful and that payment was also going to be back dated.
At the end of the day I don't know what you suffer but I see my dad struggling and I will tell you this - no matter how bad it gets, keep fighting and fight all the way, you will get there in the end and it will be worth it.
If you have any questions, you can email me at rights@ouchuk.org

Supporters need support too! - Sandra McDowell

Hello everyone, allow me to introduce myself. My name is Sandra McDowell and I am a Trustee of OUCH (UK). I live on the Isle of Mull, which is a small island off the West Coast of Scotland. I am married to Andy, who is a chronic cluster headache sufferer and I have been a member of OUCH for about 16 years. I was the first CH supporter to help on the Advice line.

This is where my story really begins. As supporters, we obviously don't go through the physical pain that sufferers sadly do, but we do experience a lot of emotional pain. I am hoping to raise more awareness of what it is like to live with a sufferer and how we can help them, and importantly, help ourselves too.

How many times have you said to yourself, 'if only I could take away his/her pain' or 'if only there was something I could do to stop his/her attack?' My guess is, every time he/she has an attack. Unfortunately, I don't have any advice on how to do those things, because the simple answer is, there is nothing that we can do to help whilst they are in an attack or to prevent them from happening, apart from making sure the medication is handy.

The best thing we can do for them is to talk to them! Communication is the best way to help our loved ones. We need to find out what they would like us to do when they have an attack. Do they want us to sit with them? Do they want us to be in the same room as them? Don't be offended or upset if the answer to these questions is no: a lot of sufferers like to be on their own. Every sufferer is different in how they deal with their attacks: for example, Andy prefers to be alone, but if it is a really bad one, he likes an ice pack on his head, which is something I can help with, as he is unable to get it himself. So, talk to your loved one and come up with an attack plan.

Quite often it may be helpful for you to attend Doctors' appointments with them, as you may have different questions to ask too, especially at the beginning of your 'journey' when you are both still learning and coming to terms with this horrendous condition.

CH attacks can be a tough time for everyone in the family, and sometimes words can be said that aren't meant. We also have to think about what we tell our family, especially any children we may have. The age of the children will determine how much you can tell them and how much they will actually understand. Our children were old enough to understand at the start that daddy had a very sore head, but would be ok. As they got older, we were able to explain to them in more detail about cluster headaches.

It is also important to look after yourself: as a supporter, life is tough for you as well. Have some time to yourself, go for a drink with some friends, go for a walk, go to the cinema, or just spend some time chilling out so you can recharge your batteries. With this condition, it is all too easy for you and your sufferer to feel overwhelmed with everything and depression can easily set in for you both. Find

the time to spend with each other and set some time aside for yourselves when they are not getting attacks, even if it's just out for a meal, or even a walk. It is good to maintain some normality in your life. I always say to everyone I speak to on the Advice Line, the trick is finding a way for you and your loved one to control CH and not let CH control you.

OUCH is not here just for sufferers; we are here to help supporters too. You can phone the Advice line on 01646 651 979 and leave a message asking for me to phone back if you specifically want to speak to another supporter. You can also email me at sandra@ouch.uk.org.

The most important message I want to get out to you guys, is that you matter to OUCH (UK) just as much as sufferers and we want to help and support you too. So please reach out whenever you need to. As the heading of this article says, 'Supporters need support too!'

OUCH Word Search - enjoy!

R	A	O	E	I	G	S	C	O	V	I	D	I	B
N	E	P	A	T	I	E	N	T	T	H	S	R	R
C	Y	L	I	N	D	E	R	S	S	E	U	S	A
M	U	C	B	D	I	T	S	N	I	M	F	A	R
E	O	I	O	V	E	S	R	E	G	I	F	D	E
M	C	N	U	O	H	U	E	G	O	C	E	V	T
B	I	O	T	U	E	R	D	Y	L	R	R	I	S
E	D	R	R	C	A	T	R	X	O	A	E	C	U
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S	S	C	I	P	A	M	S	I	U	I	S	L	C
H	I	N	C	L	C	U	I	S	E	A	V	I	D
I	P	O	I	L	H	T	D	N	N	F	C	N	H
P	E	E	C	N	E	R	E	F	N	O	C	E	L
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BOUT
HEADACHE
CONFERENCE
OXYGEN
DISABILITY
ADVICE LINE
CYLINDERS
TRUSTEES
CLUSTER
MEMBERSHIP
HEMICRANIA
NEUROLOGIST
EPISODIC
SUFFERERS
DISORDERS
CHRONIC
COVID
PATIENT

OUR FANTASTIC FUNDRAISERS

We would like to say a massive THANKS to all our fundraisers and their wonderful sponsors. Without these fabulous people we could not continue to provide an advice line for sufferers, nor could we print booklets, leaflets, do vital website updates or (hopefully once this crisis is over) arrange future conferences. We hugely appreciate you all...you know who you are.

Commiserations to those who had fundraising events planned but were cancelled due to the pandemic.

Let's all look forward to better days ahead.

SOUTH COAST CHALLENGE - SEPTEMBER 2019

Many thanks to Danny Walsh for this fundraiser. Danny wrote after the event: "So the walk was at the weekend, it was tough. I managed 72km and then had to withdraw on medical grounds! Heres a pic of me at the 50km mark!

I've made a commitment to go back and finish the last 28km to my sponsors (I just need to let my body forgive me first from the weekend, lol)"

Danny did go back and complete the challenge and we'd like to send massive thanks to him and all of his supporters.

Well done, Danny!

CORIN RIDOUT - 3 EVENT LONDON CLASSICS CHALLENGE.

Corin Ridout successfully smashed the London Classics Challenge for OUCH (UK) during 2019. The three events included the London Marathon, Ride London 100 miles and finishing in September with the Swim Serpentine 2 miles. What an amazing challenge this was!

Corin said it had been really great to chat about cluster headaches with various other participants and spectators across the 3 events and although the donations were helpful, it had all been about supporting his brother, a CH sufferer, in his mission to make more people aware of the condition and also to highlight where sufferers can get help and support.

Corin felt very proud to represent us all and we are very grateful to him, not forgetting the wonderful people who donated to his events. Many thanks to you all.

AUTUMN WOLF RUN - 7th SEPTEMBER, 2019

We love to see all the different challenges our members take on to raise funds for us. Here's a particularly muddy one. Louise Charlton tackled this obstacle course to defy her usual autumn visit from "the beast".

Louise said "I completed it in 1hr 55mins. It was really hard but great fun and I couldn't have done it without the support and warmth and changing assistance of my wonderful mum, dad, and wife (Kate Charlton, John Charlton, and Fatime Kecskemeti)

Thank you to everyone who has donated and shared and wished me good luck."

Thank you from us, too!

BOURNEMOUTH HALF MARATHON

6th OCTOBER 2019

Kieron Jennings smashed the Bournemouth half marathon on October 6th 2019 to raise funds for us. Kieron's fiancée had been diagnosed with cluster headaches and he said that OUCH has played a massive part in he and his fiancée understanding cluster headaches. In return he wanted to run the marathon for OUCH and also help to raise awareness of the condition.

His target was to do the run in under two hours, although he wasn't sure he'd achieve it but he completed the run in 1 hour 59 minutes, all of his hard work having paid off. He also had one very proud fiancée!

A big thank you to Kieron and everyone who sponsored him from all of us at OUCH(UK).

TEAM GREAT SOUTH RUN

10 MILES FOR OUCH (UK)

OCTOBER 2019

SAM BOWER and friends Antony, Sam K, Steve and Rayo, ran 10 miles to raise funds for OUCH in The Great South Run in October 2019. When Sam's wife was diagnosed with cluster headaches last year, they found so much help on our forums that Sam got a team together to raise money and awareness for the condition. His pals from work were glad to help and make up a team.

Many thanks to Planet Cruise who helped by funding entry fees! Well done, Team OUCH!

TRACY WAKEFIELD - GREAT NORTH RUN/GREAT SOUTH RUN 2019.

The amazing Tracy Wakefield ran the Great North Run again for us in September closely followed by the Great South Run in October 2019. Yet again our Mike Pollock award winning supporter wore some more trainers out to raise awareness of CH and funds for OUCH. She's also a great model for our tee shirts and vests!

Many thanks as always to you, Tracy for all your help and to everyone who donated to Tracy's fundraisers. Every penny raised is a grand help. Here are a few photos of Tracy after her latest achievements on behalf of OUCH(UK).

Vicky Quarshie show with rock band Stealer, Park Street Performing Arts Centre.

Park Street Performing Arts Centre

Proudly present
An evening of live music from:

Stealer & Friends

Raising money for OUCHuk

The
Organisation for the
Understanding of
Cluster
Headaches

'The worst pain known to mankind'

SATURDAY 16TH NOVEMBER 2019
DOORS OPEN 7:00 PM

Tickets
£6:00

Book via:
ticketsource.co.uk/parkstreet

29 Park Street,
HULL, HU2 8RR
01482 222452

Here's young Danny French with his dad, Shaun, on stage with band Stealer at Vicky Quarshie's show in aid of OUCH in November. What a great talent. Vicky encouraged this young man to get on the stage, she had a gift for bringing out the best in everyone. I hope this lad carries on as Vicky would want him to. Many thanks to Stealer for the fab show, it was such a great night and to tie it all together, the guitarist on the right is a CH sufferer, someone else Vicky helped. Thanks again to Park Street Performing Arts Centre for hosting the show. We are so grateful to everyone involved.

Can You Help - Volunteer Fund Raiser, Trustee or Officer.

OUCH UK relies on donations from its members for its existence and the Trustees are now looking for someone with experience in the fund raising sector that could help to boost the funding for OUCH UK, whether it be from corporations or lottery funds.

If you feel that you would be interested and prepared to volunteer as our fund raiser please send your details to info@ouchuk.org

The Great Self Isolation Bake-off

Lisa Munro is a popular lady, well known for keeping everyone's spirits up both in and out of the CH community. OUCH (UK) members will be sure to remember Lisa's husband, Brian, who did a very exciting fundraiser for OUCH because of Lisa being a CH sufferer, when he sailed around Britain on the Lauren Sophia in 2016, gathering followers on the way. When lockdown started, Lisa wasn't idle and she started a Facebook group called The Great Self Isolation Bake-off for those friends with a passion for baking and cooking. In Lisa's own words, here's how it took off and is still gathering speed. Lisa has chosen some photos of some of the fabulous creations sent to her group.

Having been in lockdown for a week, I knew that sitting around wasn't going to cut it for me.

I am usually always on the go, and whilst I was starting to enjoy the slower pace of life, I had to do something.

On the morning of 25 March, my youngest daughter Abbi and I were chatting about some ideas to keep us motivated. She suggested that we did weekly family baking challenges. Not usually being that competitive, I declined, highlighting the fact that she would win EVERY week. I explained that we should do something bigger and better, getting others involved - and that was the birth of my brainchild, The Great Self Isolation Bake-off!

I set up the page excitedly and advertised it on my own Facebook page to see if any of my friends and family would be interested. I initially didn't invite anyone personally. Slowly but surely, the page started to get busier with people sharing recipes and photos of their food, not solely baking which made the group even more interesting and helpful to everyone. Weekly challenges and keeping a wee bit of fun has also helped.

The group started to grow each and every day and with members from all over the world, is currently sitting at a whopping 4,252 members

On 6 April, a local Marketing Company, Prospect 13 got in touch to advise that I had been shortlisted for a New Day Award for people who had gone over and beyond to support the local community. I can't actually explain how I felt, it was so exciting to have been put forward for this. I never had any agenda other than

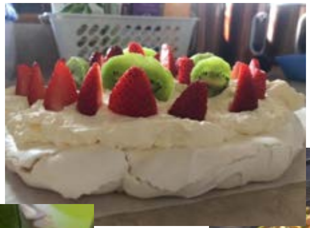
bringing people together during these uncertain times. On Wednesday 13 May, there was a live presentation on Prospect 13's Facebook Page where it was announced that I had won!! Excited was a bit of an understatement - a lot of prosecco was consumed and tears of joy were shed, and a very drunken live video on my Page!! There were 8 of us in that category, way more than any others, and so many very worthy winners who had all gone over and above to help the vulnerable or just simply to share a bit of joy.

Thursday was a bit of a right off for me, and the live video that I usually do every Thursday was slightly sheepish after the video the night before!

Friday 15 brought more exciting news when I was contacted by the local paper asking if I would do an interview with them for a feature that they wanted to include about food groups that had been created during lockdown and how they felt that they helped people.

During the short time that the group has been running, I decided with a gentle push from a close friend, that the group will put together a recipe book. Members have been asked to email a photo and recipe so that we can create it. It saddens me that I really wanted to do this to raise 50% for Cluster Headaches and 50% for Mental Health but due to my current work situation, I decided that I was unable to do this. I know that there will be many of us hiding our illness in order to keep our positions safe. Having been exceptionally low during Cluster cycles, I do feel like I am still doing some justice to our group in a round-about kind of way.

I hope that you are all staying safe and that you are all pain free.



Sailing around Britain star expands his horizon!

GOOD LUCK TO SAILING AROUND BRITAIN STAR BRIAN MUNRO!

It's four years since Brian Munro sailed around Britain raising awareness of CH and funds for OUCH (UK). Now he's on a new mission and we think our members will still be interested in reading about his latest venture.

Our sailing hero was meant to be fundraising for RNLI, in memory of his good friend George Peggie Senior, by circumnavigating Britain but while he will still be raising funds for them, he has now changed his course. Instead, he left by air on 9th June to answer a call for help.

Brian and two crew members will be doing a transatlantic sail from St Maarten in the Caribbean to rescue a boat before the hurricane season hits, for one of the Yacht Racing Sailing Academies in the Solent. As Brian has said, sailing West to East across the Atlantic is no mean feat. This will be over 4000 miles of upwind sailing, which will be 5-6 weeks at sea and will be by far his biggest ever sailing challenge.

Bon voyage, Brian from all of us here at OUCH (UK). We wish you all the very best of luck on your latest venture. Fair winds and following seas!

FUNDRAISING 2020

HALF MARATHON!

Here's a fabulous fundraiser from Harry Walker. As a CH sufferer, Harry wanted to do something to support our charity so he and his friends decided to do a socially distanced half marathon. They realised they geographically lived in a circle, so one of his friends drew up a map and they all joined the map and ran it at the same time.

Although his main aim was to raise awareness for the condition, Harry suggested raising a bit of money and hoped it could be for OUCH (UK) and the rest of the boys were happy to adopt our charity. They originally set out to raise £500 as they had a week in which to raise the money. Amazingly, they met that goal within 3 hours - and in the end they raised a stupendous amount of more than £2,500! What an incredible achievement.

Well done to you all! We can't thank you boys enough and we would also like to extend massive thanks to all the very generous sponsors!

How it started….two fellow cluster buddies, with lots of additional health issues who love the outdoors, were having a long chat.

Me: I really want to do the West Highland Way Linda, it's definitely on my bucket list.

Linda: oh yeah, I will do it with you.

Me: Oh fab, I was hoping you'd say that ....when!?

There it was, Linda knows I am like a little terrier when I set my mind to something and I felt we both needed a challenge. We have done a few things over the years. She's got me on trains (when I was scared to leave the house), I have made her help me with my running, and we did a 10km and some 5km virtual races together. We have a tendency to egg each other on.

Linda is an organiser, frankly I am relieved about this, because I am forgetful and scatty at the best of times. Recently I was diagnosed with ADHD, which explains a lot! So she started looking at dates and places to stay, baggage transfers etc. Oh and gear...we love outdoor gear and spent an enjoyable day in Preston mooching round the outdoors shops together. Linda had generously bought us both guides to the walk, mine had a few pencil notes about the route, hers had all these fancy coloured tabs and stickers on it. I cooed over her stationary prowess as I ate my chips in Debenhams cafe and we talked strategy.

We plan a weekend trial run in the Pennines. On the whole it went really well and we surprised ourselves. We also got lost on the 2nd day and Linda was convinced the mountain rescue would find our crow pecked corpses on the moors. Things I learnt from this trip. My feet are like tissue paper despite all the trail walking and running I do. Linda gets very hangry and meals and snacks need to be meticulously planned (due to panic of hunger induced migraine)...woe betide you miss the pubs serving times!! Thankfully we didn't.

Day 2 - Drymen to Rowardennan

The biggest challenge on this day is the Iconic 'Conic Hill' (see what I did there). We had made brilliant time leading up to the hill itself. We stopped to take it all in and decided that we could do this. Frankly, we didn't see why everyone made such a big fuss about the hill. The views going up and at the top were magnificent. I somewhat changed my assessment of how easy this hill was on the way back down the other side. Mrs Smug pants with poor coordination/balance was finding the steep descent really hard. Linda who is more sure-footed, gambled down like a gazelle. Over lunch we have a mutual appreciation chat about how well we had done and how well we were feeling. No sign of 'you know what' for either of us – shhhhh!! We had a way to go yet and made great time, so arrived at our hotel much earlier than we anticipated. It was a great mental boost. Later, over a massive plate of slow roasted beef and fresh vegetables, we both admitted that we felt accomplished to have overtaken two young lads up the hill. We will gloss over the fact that they had massive rucksacks - just let us have this moment yeah?

Day 3 - Rowardennan to Crianlarich We made sure we were up and out very early. This was our longest and hardest day. I was quite nervous but having being told by a snotty woman that we couldn't do this mileage in one day, we were both fully fired up. Linda was a little grumbly and saying 'it's just a shadow' over breakfast but then reminded herself that her neurologist always says shadows can be considered low-grade attacks and decided to take an injection. She was feeling much better by the time we set off. I don't think anything could have prepared us for the bit we nicknamed 'The Shires', in fact I am sure Frodo and Sam found the road to Mordor easier. The boulders, the tree roots, the goats!!! Another one of the many highlights on this part of the journey was stopping for a coffee at Inversnaid Waterfalls. Despite the massive flooding the few weeks before, the weather was sunny and hot. Just before Beinglas Farm (also known as 'are we nearly there yet farm'), we found the bridge missing. The detour added another few miles onto a very long day. We stood sighing at the remaining stumps of the bridge and the water. Before I had a chance to think it through, Linda was down the bank and across the water, so I had to follow – yikes! We then realised that with my combo of a weak leg and all-round fatigue, I just couldn't get out the other side. After much laughter and me nearly wetting myself, I was half hauled and half scrabbled up the steep bank. I then lay like a beached whale in a fit of relieved giggles and mud. After refuelling at the farm we set off for the final 5-6 miles to Crianlarich, which, at the time felt like the longest miles of our lives. The skies were darkening, my head was making noises and we were keen to get settled for the night. We had been promised a cold Stella by the B&B and we were both glad of it when we got there. I was completely tattered (shattered) and my feet were a mess. Linda looked concerned and we had a very early night - in twin beds like the Clusterhead version of Morecambe and Wise.

(cont'd on next page)

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Day 4 - Crianlarich to Bridge of Orchy.

WHW Day 4 - Crianlarich to Bridge of Orchy

Linda had so much trouble waking me this day, she thought I may be dead. I certainly felt it and I could she her concerns at whether I would make it through another day on the way. We were both agitated and kept our distance the first half of the hike. I was struggling big time, overwhelmed, grumpy and in pain. Linda was pushing me on by keeping up the pace required and by bravely patching up my skinless feet every night and morning. That's friendship, blimey they were utterly disgusting (minging). After stopping at the Green Welly, a VERY large cake and a few words off Linda later, I completely got over myself. Linda and I, over our lengthy years with clusters and migraine, have discovered that we are both very tolerant to codeine without rebound headaches, so Linda plies me with two during our pit-stop and we did the next half laughing and chatting. It was a lovely surprise to get to the Bridge of Orchy, much quicker than we could have imagined, especially after the morning's struggles. Partly helped by me giving Linda my mars bar and instructing her not to allow me to have it until I had done 5 more miles. It was the best Mars Bar I have ever eaten.

Our digs were the best on the trip and we were in fine spirits...mainly gin and wine. We chatted with some younger lasses over dinner and shared some food with them.

WHW Day 5 - Bridge of Orchy to Kinlochleven

Day 5 - Bridge of Orchy to Kinlochleven via Rannoch Moor then Glencoe and Devil's Staircase

Breakfast was 'interesting'!! Linda was struggling due to severe phono-phobia. She didn't see this was what was going on and insisted that everyone was making WAY too much noise! I tried to assure her it wasn't that bad and maybe she had an attack brewing...she didn't take kindly to this and glared at me as I stirred my tea ('do you have to do that so loudly!?). I looked away and smirked. Smirking to her face may have got me a smack in the mouth at this point and I was half laughing at myself too because 'been there, done that'. It's funny that we can't often see these things in ourselves, but when you see a fellow sufferer in this mode, it's actually funny to recognise yourself. Later, when she realised she actually wasn't well, she was utterly mortified. We had a right laugh about it but I totally understood. This is the benefit of having a fellow cluster head with you. She got me and I got her. We both took a 'Frova' as it was to be an epic day (22.8miles) then set off.

I hobbled out and up from the hotel. Linda and I knew that after the first few miles I would be able to shut the pain from my feet out of my mind. There are benefits to being a chronic suffer...you learn to cope with all sorts of things. Just before the Devils Staircase and after Linda had done a full handstand at the way marker (the joys of when your triptan works as it should), she did her best to refuel me so I could get to the top of the very steep accent. It was then another very long descent to Kinlochleven and my feet and quads really were not feeling the love. By the time we got to our digs the town was buzzing as the Salomon Trail races were on that weekend.

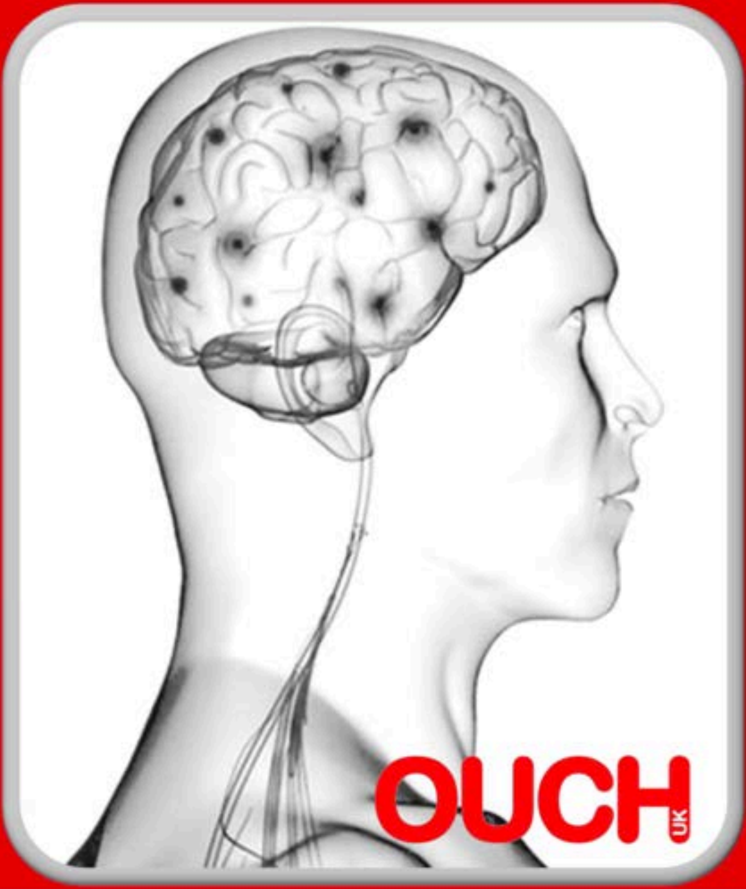
Day 6 - Kinlochleven to Fort William

After the best breakfast known to human kind, which is saying something because we had had some magnificent ones, we set off out and up, up, up from the valley towards Fort William. I watched in utter awe as trail runners flew past us in the Salomon races. I was barely, crawling up the steep climb and having to stop frequently for water, a rest and to catch my breath. Linda was still looking amazingly strong despite the heat. It was a blisteringly hot day and I often fell well behind Linda's pace. I was really ready for it all to be over now. There was hardly any shelter on this part of the way and we reminded each other to slap on the sun screen. The brightness was making my eyes hurt despite the sunnies and I had lost my hat, cue a migraine! Later on I completely lost sight of Linda but knew she would stop and wait as soon as she found a bit of shade. She was worried about running out of water and dehydration bringing on a cluster or migraine or both. We were making good time overall and eventually through sheer bloody mindedness we were finally on the road into Fort William and sitting by the Weary Traveller monument that marks the end of the Way. Everyone takes photos and has a chat and laugh. I can hardly believe we've finished.

WHW Day 6 - Kinlochleven to Fort William

Sitting in the pub that afternoon, eating another belly busting meal, we marvelled at our achievement and felt a huge sense of accomplishment.

100 miles, 8 drinks, 4 clusters, 2 migraines – rampant success!!!
Plus we raised a staggering £2,045.



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www.ouchuk.org

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