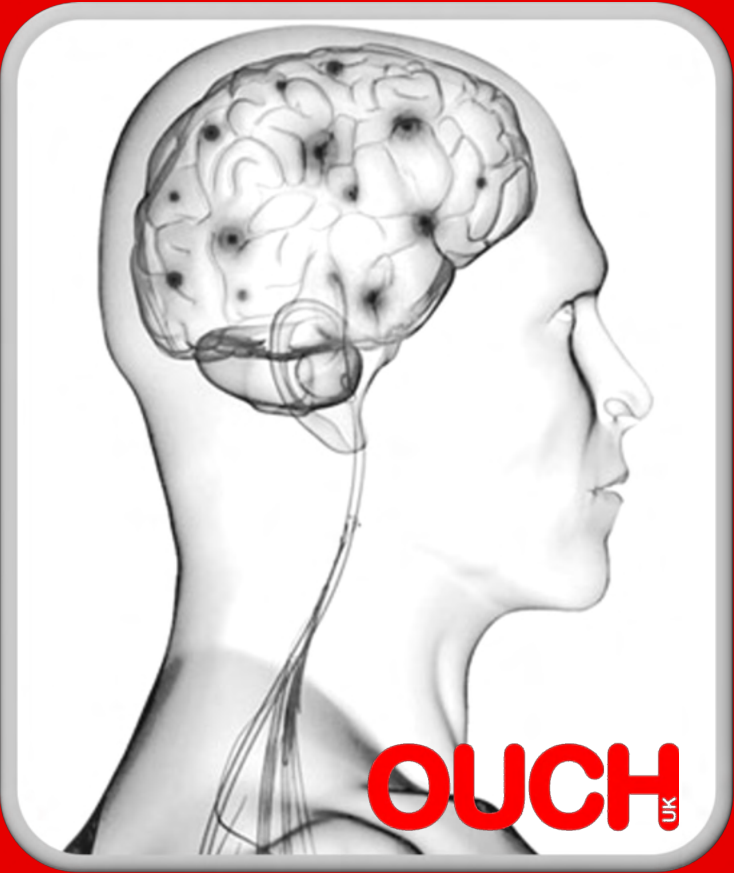
CHit CHat

The Official Newsletter of OUCH (UK)

The Organisation for the Understanding of Cluster Headache



Spring and Summer 2023

London Conference Edition

9th July at LSE

Book early to ensure your place

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.

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.

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.

Dale Nolan (Treasurer)
Dale joined OUCH in 2021 after his son Oscar's diagnosis of CH at age 17. Dale is keen to help the organisation move forward in any way he can and accepted the position of Trustee and Treasurer in 2022.

Neil Boast - Many of you will already know our new trustee, Neil, either because you've seen his extremely helpful and informative videos on facebook about how to use oxygen safely, or he has delivered oxygen to your home. Although Neil doesn't suffer CH himself, he is a dedicated supporter of cluster headache sufferers after witnessing CH attacks while making oxygen deliveries. He is only too happy to do whatever he can to help sufferers and will be on hand to give advice on any oxygen related queries.

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

Audrey Leng (Advice Line & Membership)
Audrey was diagnosed with Episodic Cluster Headache in 2009 and has been a member of OUCH (UK) since 2011. Over a decade ago, Audrey made a call to the OUCH (UK) Advice Line and through that one call and subsequent emails, she was able to get the right treatment to manage her Cluster Headache effectively. She has been volunteering on the Advice Line since September 2020 and more recently has been dealing with membership administration.

Liz Eden (Advice Line)
Liz is the mother of a Chronic Cluster Headache sufferer. She called the Advice Line once when she was at her wits' end and says she learned more about Cluster Headache from that 40 minute call than she had for the previous two years. Now retired after being a long-term manager at BA, she wants to give something back and help sufferers and their families the same way she was helped.

Vicky Ricketts (Advice Line)
Vicky has suffered with Cluster Headache and also Hemicrania Continua for many years. She says OUCH (UK) has been a lifeline for her and she is very happy indeed to be able to give something back.

Gary Brampton (Advice Line)
Gary suffered his first Cluster Headache attack at the age of 18. His daughter is also a sufferer now.

Jennifer Kiernan (Advice Line)
Jennifer was diagnosed with Chronic Cluster Headache in 2010. She is a support worker in ophthalmology, giving advice and support to people with sight threatening conditions. She is also studying to become a nurse and has plenty to occupy her at home with her family and her border terrier (terror)!

Rachael Wood (Support for children and young people with Cluster Headache)
Rachael joined OUCH (UK) in March 2020 after her son Frederick's diagnosis of Chronic Cluster Headache at age 11. She is keen to help other parents and children navigate their way through a Cluster Headache diagnosis and to assist with practical advice and support for families living with Cluster Headache.

Jamie Charteris (Artwork, design and humour)
Jamie has been an Episodic Cluster Headache sufferer since the late 1980s and was diagnosed as such in 2014. He considers himself very lucky, as usually he has eighteen months to two years 'off' then has a bout of a few months. Jamie has been a cartoonist, predominantly for the greetings card industry, for over forty years. He also illustrates and writes fiction.

John Poore (CHit CHat Editor) John is a chronic sufferer who joined OUCH UK in 2018 and took on the role of Editor in 2019. As well as helping with OUCH he enjoys building and competing with his radio controlled model boats, playing croquet and generally keeping fit.

OUCH(UK) Membership Report 2023

Please consider subscribing as a full member. Your membership of OUCH (UK) enables us to reach out and help others who suffer the same terrible condition that you do. Our charity will grow as the membership grows and our collective voice gets louder and louder.
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.

Join OUCH(UK) at: www.ouchuk.org

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

OUCH (UK) Financial report 2021/22

We thought you might be interested to know something about OUCH's finances.

1. Income

First of all, all our income comes from membership fees, direct and indirect donations and volunteer fundraising - we have no government or other support. Below is an approximate breakdown for the financial year 2021/22:

- This year, direct charitable donations through our website and fundraising accounted for around 65% of our income, 26% of which was from one significant and amazing fundraising contribution.
- Just under 20% of income came from membership fees - this has been a steady and regular source of income which we can rely on for planning purposes.
- The income from more indirect sources such as Amazon Smile and Paypal Giving, where people registered OUCH (UK) as their preferred charity to receive a donation, fell to under 5% from as much as 25% in previous years.
- Finally, the introduction of the One Lottery weekly lottery participation contributed just under 10% to our overall income.

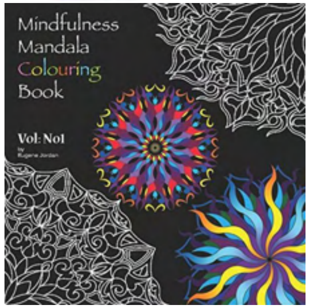
2. Expenditure

So what do we use this hard earned income for? We do, of course, aim to spend it wisely. We are fortunate in that we have no offices to run and currently no staffing costs – all our trustees and officers give their time voluntarily and mainly work for OUCH from their own homes. Expenditure was roughly as below:

- 30% of outgoings were used to fund OUCH's all important website and Advice Line, and all the associated printing and postage costs to continue building awareness and providing information regarding the condition.
- 40% of outgoings are related to the upcoming Summer conference, our first in-person conference since the pandemic. (Although the Summer 2022 conference was rescheduled for July 2023 the financial commitment was made in 2022).
- 20% of outgoings went on essential banking fees, insurance, professional services such as auditing and accountancy and insurance, along with an assortment of printing, stationery, postage and freight charges, shop items and staff expenses.
- The remaining 10% included contributions for services rendered to CH sufferers by charitable organisations such as The National Migraine Centre.

OUCH (UK) ONLINE SHOP

If you haven't visited our online shop yet, have a look on our website at www.ouchuk.org/shop to see OUCH's range of awareness products. These include colourful t-shirts, badges, wristbands and our extremely popular information cards, which can be shown during a CH attack to explain to others what's going on.



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

At the London School of Economics

Sunday 9th July 2023

OUCH (UK) 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 talks by the UK's leading Cluster Headache specialists, information sessions and an opportunity to meet and talk with other Cluster Headache sufferers to share experiences and meet and make new friends.

Our medical speakers will take you on a journey through Cluster Headache and other primary headache disorders, telling you about the current treatments available as well as what studies and trials are on-going and what the future holds for Cluster Headache treatment and management.

Confirmed Speakers for the Event:

- **Professor Peter Goadsby**, Professor of Neurology, King's College Hospital, London, patron and chair of OUCH (UK)
- **Dr Nick Silver**, Consultant Neurologist, The Walton Centre
- **Dr Vivek Mehta**, Consultant in Pain Medicine, QMUL and Clinical Network Director, Pain, St Bartholomew's Hospital, London
- **OUCH (UK) Trustees and Officers**

Breakout sessions:

- **OUCH Advice Line Breakout Session**, including resources for sufferers and supporters, diagnosis, preventative and abortive treatments, oxygen, patient rights
- **Oxygen Workshop**
- **Supporters of Sufferers, and Children and Young Adults Breakout Session**

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

Back by popular demand in the afternoon will be a targeted set of group discussions on various topics that affect sufferers; this is a chance to question the OUCH (UK) team and each other about treatments and employment support, as well as more general questions.

A light sandwich lunch, morning and afternoon refreshments will be provided.

Tickets are available securely on line

As a thank you for past support, we are offering **free tickets** for members this year. We hope that this will enable more sufferers to attend our first face-to-face conference since 2019.

When you book your ticket online you **MUST** be logged into the OUCH (UK) website as a current member to be able to book your free ticket.

Member Adult FREE / Child FREE, Non Member Adult £5.00 / Child £2.50

If you aren't a member already, why not sign up to support the charity and get a range of discounts and benefits.

IF YOU ARE ABLE TO DONATE

If you feel you are able to make a donation to help fund the cost of the conference and other OUCH(UK) activities, it would be much appreciated.

SUFFERERS IN RECEIPT OF UNEMPLOYMENT BENEFITS

At OUCH (UK) we completely understand how devastating CH can be for 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 dale@ouchuk.org in complete confidence.

We hope to see you there.

When

9th July, 2023 9:30 AM to 5:00 PM

Location

London School of Economics
Houghton Street
London, WC2A 2AE
United Kingdom

We had another very young recipient of the Mike Pollock Award in 2022 - 14 year old Frederick Wood, who was diagnosed with chronic cluster headaches at the early age of 11.

Although Frederick missed a lot of school in the first couple of years following his diagnosis, he managed to catch up and do very well at school. He is a very talented musician and in September 2022 he was accepted into the Royal Conservatoire of Music in Glasgow to study piano as a Junior. He attends every Saturday for 30 weeks of the year from 10am to 4.30pm, portable oxygen tank in tow, and is determined his condition will not hold him back.

In November, Frederick's Explorer Scout Group joined the Church of Scotland and a Community Centre, The Atholl Centre, to organise a Christmas Tree Festival and Frederick asked for OUCH (UK) to be the charity to benefit from funds raised. Frederick said it was very important to him to raise money for the charity because of the support he and his family had received. They raised more than £1000 and Frederick also raised awareness of the condition with a great display of posters and leaflets.

We think Frederick is an inspiration to other young sufferers and a deserving award winner. He has done amazingly well with the help of a treatment plan that works for him but he has shown the resolve to achieve his goals, despite his CH. Congratulations Frederick, well done. We know that Mike would be proud to present you with this award himself. We wish you all the very best for a bright future!

OUCH (UK) Board of Trustees

Photo:
Frederick with his award, the Christmas Tree Festival, and his awareness display.
Also pictured alongside Frederick is Mike Pollock, our Chairman whose memory is honoured by the award.

My name is Frederick and this is my CCH story…

I am 14 years old and live with my parents and cat, Murphy, in Highland Perthshire, Scotland. My hobbies are music: playing the piano, pipe organ, accordion and singing in 3 choirs. I've been having piano lessons since I was seven years old. I also love trains and am able to drive them using the Trainsym simulator on my gaming PC. At school I love English, HE and of course music! My life is great at the moment, but a few years ago things were very different…

Two days after the first COVID lockdown was imposed in Scotland on 23 March 2020
I began to be in pain. I was 11 years old at the time. At first the pain felt like 'earache'. My Mum gave me some Calpol and a hot water bottle for my ear but it didn't help. After a few days the earache became a pain in my head, behind my eye, sometimes on one side, sometimes the other. The pain was increasing in intensity and duration. My parents said I needed a trip to the GP but of course, the GP surgery was closed. The country was in lockdown. My Mum was trying to do home-schooling with me via the internet but I was in too much pain to do anything. I couldn't even play the piano – I couldn't get out of bed most of the time.

Over the next few days and weeks the pain continued to increase. I was given pain killers from our GP over the phone but nothing helped. The pain escalated to an excruciating level making me scream and writhe in agony every single day – it was terrible and I know now that it was awful for my parents to watch. Nothing they could do would help me. My parents took me to A&E and an emergency appointment with a dentist and an Ear, Nose & Throat specialist but none of them knew what was wrong. My pain still continued. My longest attack was five hours.

My parents managed to get me a face to face appointment with my GP and I actually had an attack of pain in front of her. She admitted she had never seen anything like it. I was then immediately referred as an emergency case to a Paediatric Neurology Consultant at Ninewells Hospital in Dundee, by this time I had been constantly enduring horrific pain for 6 weeks. I couldn't be left alone, I couldn't sleep, our whole family existence centred around me – my Mum said that in some ways it was like having a new-born again, except I couldn't be comforted with a kiss and a cuddle. I was admitted to hospital 3 times.

Over the next 14 months the pain continued as my Neurologist tried to help me, multiple medications were prescribed, MRI scans were undergone, nothing seemed to really help, or if it did, it was only a temporary relief. For weeks I was taking a cocktail of 13 tablets every day – that's a lot to cope with when you're only 11.

cont'd over

I tried to do bits of school work when I could, but it was too much for me most of the time. Whilst the world battled COVID me and my family were in a horrible battle of our own. I tried so many times to have a piano lesson online, but nearly always an attack would strike and my Mum would have to shut down the laptop as I screamed in agony.

Eventually, after nearly 2 years of acute suffering I was diagnosed. We discovered that I have Chronic Cluster Headache.

It was a relief for all of us to finally have a diagnosis because now my parents were hopeful that the correct treatment could be put in place. The problem we now faced was that most treatments for Cluster Headache are aimed at adults as the condition is so rare in children like me. My Neurologist agreed to let me try high flow rate oxygen and it was an instant success! It was installed one afternoon in my bedroom and when an attack came my Mum helped me to put on the mask. We couldn't believe that the pain could disappear so quickly. We were used to my attacks going on for hours at a time. My Mum telephoned my Neurologist to give him the good news whilst I had a rest, she left a message with his secretary. Only 10 minutes later he called back to say that he had to check that the message was correct, because they didn't usually get such good news in Neurology!

I started to go back to school part time for a few mornings a week when I felt well enough and gradually increased once I had oxygen tanks at school as well. I started to play the piano again for short periods although I found it difficult to remember some aspects especially reading music fluently. Although the oxygen took the pain away I was feeling very nauseous for some time after the end of the treatment, but my Mum found out from the OUCH UK helpline that I needed to have a demand valve and she organised that for me with my Neurologist. I could also have the Sumatriptan injections but I don't really feel ready for that yet.

The next stage for me was to try a preventative drug. There were some scary moments when the dose was too high for my heart and I was admitted to hospital again. Thankfully we found the right dose for me. I was 13 by now and had started to get a little bit of my life back. With covid restrictions lifted I was able to restart my piano lessons. I had missed so much, but was determined that CCH was not going to take away my favourite thing. I really concentrated on my practice sessions and played whenever I could to make up on lost time.

I use the preventative now when the attacks build up in frequency and it does help to break the cycle. Over the last 18 months my family has been learning how to live our new normal. Medical oxygen canisters have become part of our lives – at home, at school, in the car, on day trips, up mountains, on holiday – they go everywhere with us. I kept practising the piano and passed my Grade 5 with a Distinction in August 2021.

In February 2021 I had auditioned via video link (because of covid) for the Juniors programme at the Royal Conservatoire of Music in Glasgow. I had to wait a long time but I got the good news that I'd been accepted in April.

It was good timing because I was away in North Yorkshire on a camp with my Scout group. I'd been half way up a mountain that day when a Cluster attack happened. My leader had brought my portable oxygen for me and I managed to control the attack (with the best view I've ever had!) I was pretty exhausted that night and so to hear the news about my place at the Conservatoire was just what I needed. I feel so privileged to have been selected because I am one of just 160 current Junior students between the ages of 11 and 18 from the whole of Scotland and even the north of England.

I am hoping for a career in music in the future and now that I have a good treatment plan in place and the support I need, I am determined that CCH will not stop me.

Play our lottery for a chance to win up to £25,000!

onelottery

RAISING FUNDS ETHICALLY FOR SMALL GROUPS, CLUBS AND CHARITIES

Here's a new way to support your charity - we've joined a lottery!

- Tickets only cost £1 per week
- 50% of all tickets sold from our page go to us
- Support us and you could win prizes of up to £25,000!

Buy tickets through the OUCH (UK) page to help our cause.
www.onelottery.co.uk/support/ouch-uk

Play for a chance to win cash prizes and OUCH(UK) receives 50% of every ticket sold from our page!

Being part of One Lottery means that with your support we can generate regular sustainable funding. Buying a ticket through One Lottery is one way you can help us to continue to grow and provide our services. So whether you buy 1 ticket or 10 tickets, thank you!

Supporters must be 16 years of age or over.

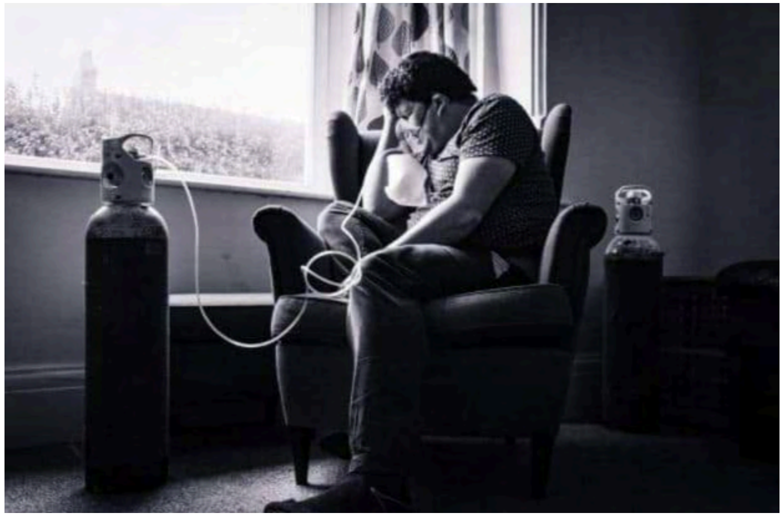
Good luck!

Test your general knowledge with this Quiz

1. If the Northern Lights are called the Aurora Borealis, what are the Southern Lights called?
2. Where is the famous Spanish riding school?
3. Which character in Dad’s Army is regularly referred to, but never seen?
4. What is tridecaphobia the fear of?
5. What was the first man made object to break the sound barrier?
6. What was the first advert on British TV?
7. Which temperature has the same value in Celsius and Fahrenheit?
8. What is the highest stand-alone mountain (not part of a range) in the world?
9. Which Japanese Admiral said after the attack on Pearl Harbour, “I fear all we have achieved is to awaken a sleeping giant and fill him with a terrible resolve.”?
10. Which super volcano sits at the confluence of Idaho, Montana and Wyoming states?
11. Cephalalgiaphobia is the fear of what?
12. What is a Growler?
13. Which natural phenomena was seen during the battle of Fredericksburg (American civil war), which both sides considered a bad omen?
14. The Confederate warship, CSS Shenandoah, sailed to which port to surrender after the cessation of hostilities, rather than to Union forces?
15. What colour is zero on a roulette wheel?

Answers on page 43

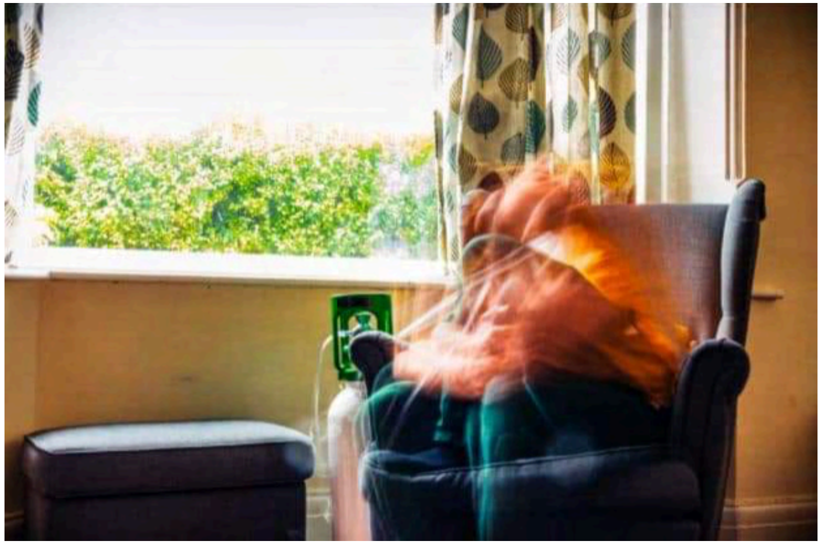
The Chair - this series captures the pain of living with cluster headaches. A rare neurological condition, cluster headaches is considered to be one of the most painful experiences a human could endure. I can experience 8 of these attacks a day. At my darkest points my life disappears from one painful episode to the next. Through photography I am able to reconnect with the world around me and rebuild a passion for life. "The Chair" is a series of self portraits taken during a single attack. My goal was to capture the moment during an attack and turn the pain I face every day into something both beautiful and eye opening to the audience.



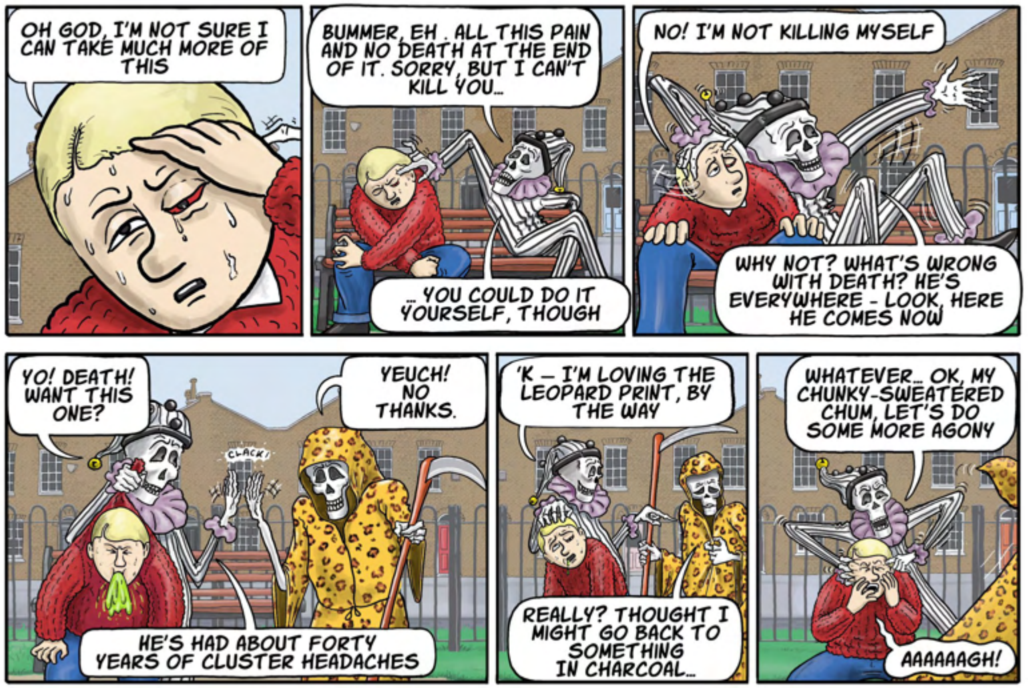
The Chair II - The beginning of a cluster headache attack, intense pain results in a slow rocking back and forth. My focus and mind starts to slip as the pain becomes overwhelming.

The Chair III - Riding out the Storm. As the pain peaks I force into my eye socket and push on as hard as possible. I tuck my legs under myself and sit in a very uncomfortable position to try and rock back and forth to distract myself from the pain.

The Chair IV - The Comedown. After riding out the majority of the attack, I start to come round cognitively and my rocking decreases as the pain subsides. The fatigue is still overwhelming for the next hour.



Comic Strip . . . by Jamie



Have you got the time and necessary skills to help your charity?
OUCH (UK)
needs volunteers.
If you feel you have the time and commitment, please contact:
submissions@ouchuk.org

www.ouchuk.org

"Clusters" a Poem by John Rennie - 2022

Here in the evening
Before the inevitable,
Unavoidable threetime
Visitation of feeling of
Intense pain. Yet again.
One, Three and Five.
Although I've strived
To avoid with opioid
Each cruel visitor
Will duly arrive
Without invite and
Stay for far too long.
Every evening
Is the night
Before execution
Here in this
Solitary cell
I await my
Impending sentence
Knowing what's to come
This event that's
So relentless
Caught up in this cycle
Three unwelcome visitors
Will call and I know I'll
Have to accept them.
This dreadful fear
Hangs in the air.
A sense of hopelessness
And helplessness
Is all consuming
Reasons confusing
Seasons refusing
To give up the treason.
Shadows will linger
Far after each visit
Lying low in my mind
Trying so hard to find
Their way back into
My damaged temple
Visited by three demons
And razed to the floor.
Please, please, no more
I can't take it anymore.
But, knowing I will
Concede to a bitter pill
Until the next evening.
Then, they'll visit again.
One, Three and Five
With the inevitable,
Unwelcome pain.

A GALLERY OF FUNDRAISING

BRAVE HEARTS

2014 – 2022

The following pages feature photos of the amazing people who have pushed their boundaries and conquered their fears to raise awareness and funds for OUCH (UK). They have helped to keep the charity going throughout the years and even when everything ground to a halt and events were cancelled during the COVID crisis, they never ran short of ideas on how to continue to raise funds for us and they took on virtual challenges instead. We want them all to know how much their loyalty and dedication means to us. There are some we don't have photos of - but to every person who ever put their energy into the many and varied fundraising events you dedicated to us – you are all stars. THANK YOU to you all for your courage and also for every cut, bruise and blister you acquired on the way on our behalf!

MANY THANKS, of course, go to the generous people who dug deep into their pockets time and time again.

The Board of Trustees OUCH (UK)

Vicky Quarshie - the amazing and very much missed Headache Specialist Nurse who sang her heart out to raise funds for us.

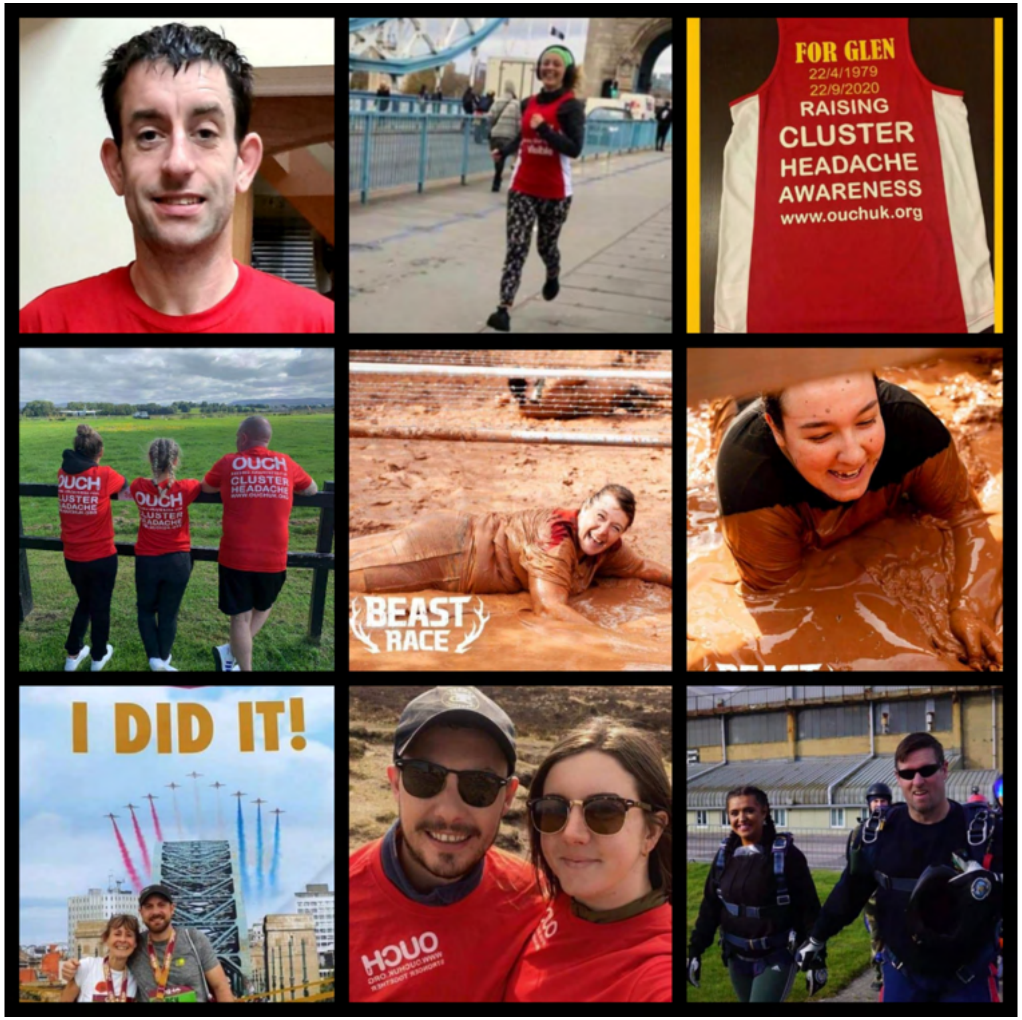
Skydiving,

Trudging through mud,

Climbing,

Miles of walking and running for OUCH (UK)

Braving the freezing sea on Boxing Day,
A gruelling cycling challenge,
Climbing a mountain,
Jumping from a plane,
Exercising and lots more miles of running!



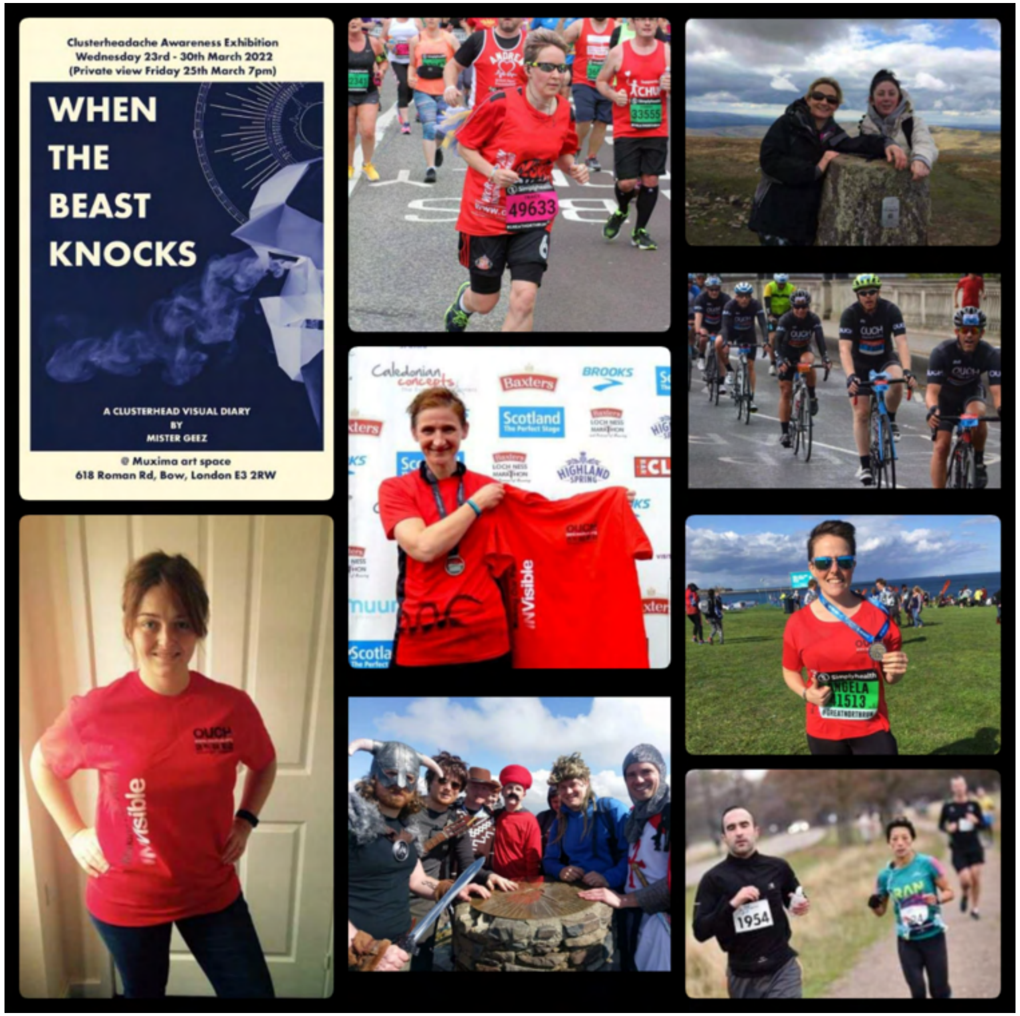
More running,
Mud galore,
Another mountain climbed,
More leaping from planes!

Fundraising family and boxing champ!

Sailing round Britain.

Christmas Tree Festival.

Gruelling canoe race.



CH art exhibition.

More running, for miles.

Ride London.

Fancy dress characters climbing for the cause.

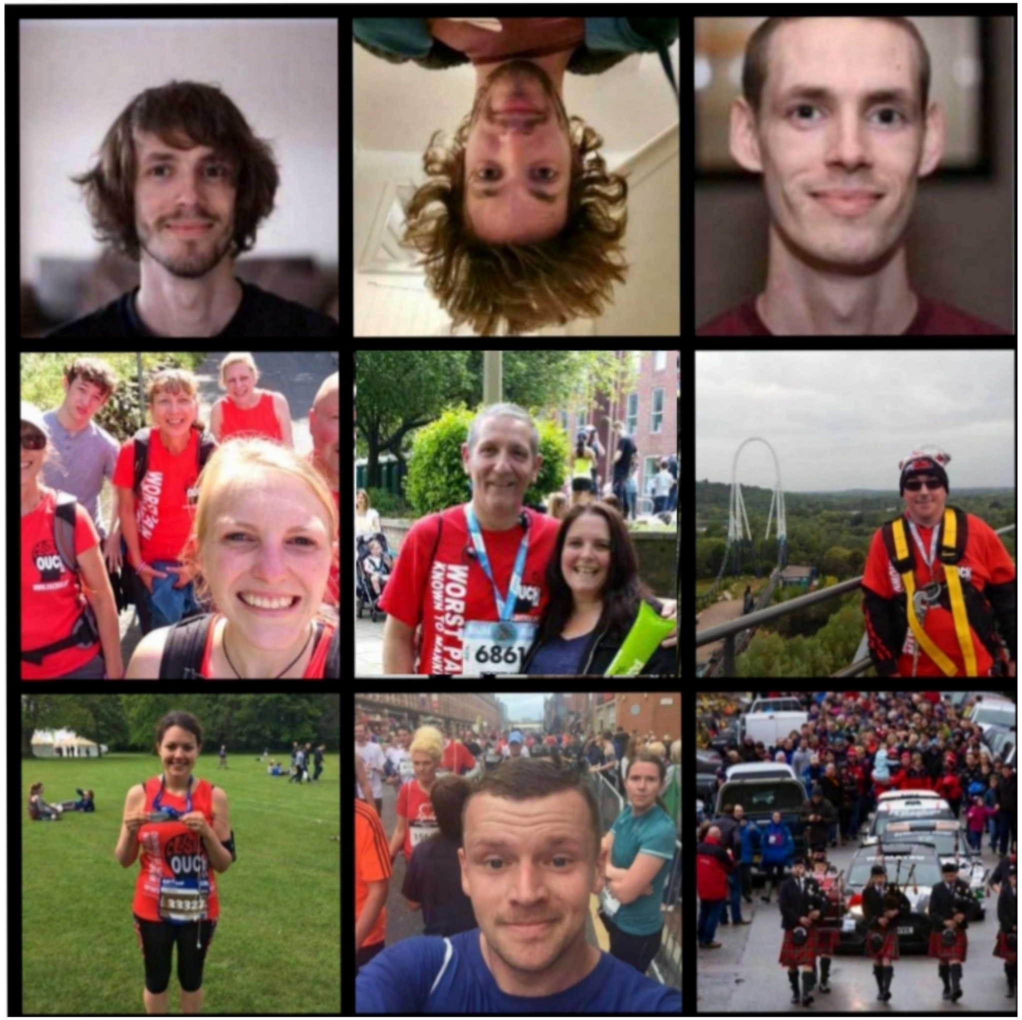
CH awareness,

Running,

OUCH (UK) art stall,

Canoe race.

Beautiful hair donation.



Radical haircut!

Climbing a mountain

Running a marathon

Climbing a roller coaster!

More marathon runners and Mull Rally march

FUNDRAISING HIGHLIGHTS

Marathon teams

Coffee morning

Hike

Cycle coast to coast

So much running!

FUNDRAISING HIGHLIGHTS

Canoe marathon

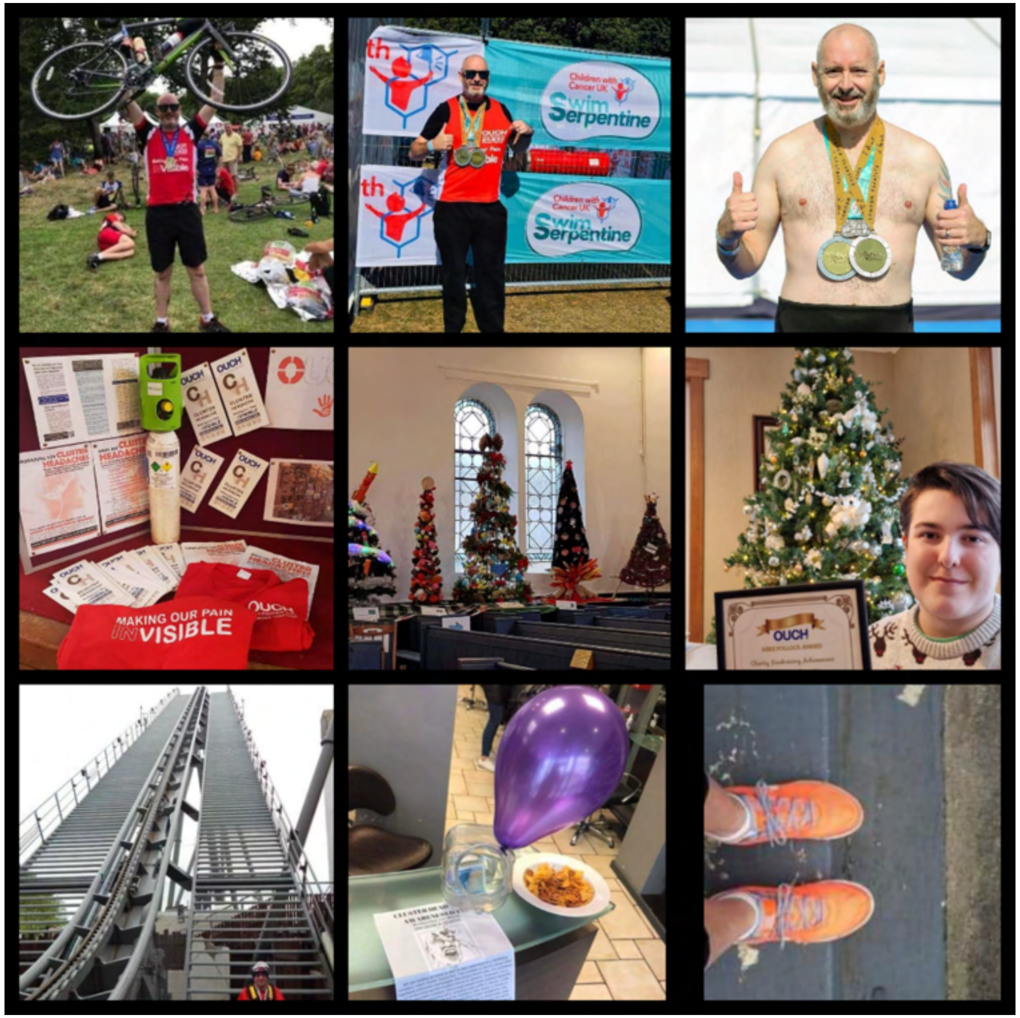
Fundraising bake

Mull walkers

London Bridge walkers and even more runners!

WING WALKING!!

Into the sea, dropping from the sky and more running teams.



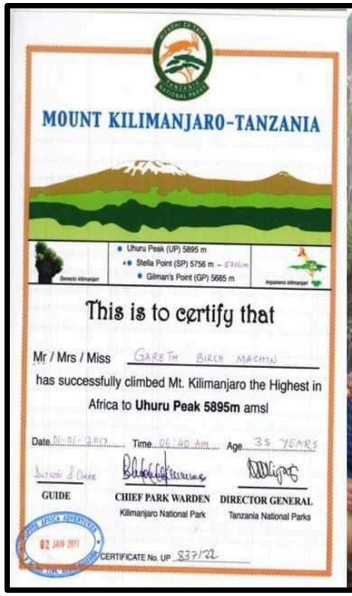
The Triathlon challenge for Glen.

The Christmas Tree Festival with Frederick.

The rollercoaster!

Beauty salon awareness.

The running shoes before the thousands of steps challenge!



MOUNT KILIMANJARO-TANZANIA

- Uhuru Peak (UP) 5895 m
- Stella Point (SP) 5756 m – 5706m
- Gilman's Point (GP) 5685 m

This is to certify that

Mr / Mrs / Miss GARETH BIRCH MACHIN

has successfully climbed Mt. Kilimanjaro the Highest in Africa to **Uhuru Peak 5895m** amsl

Date 01-01-2017 Time 06:40 AM Age 35 YEARS

GUIDE

CHIEF PARK WARDEN
Kilimanjaro National Park

DIRECTOR GENERAL
Tanzania National Parks

02 JAN 2011

CERTIFICATE No. UP 837122

What about this for an achievement - climbed Kilimanjaro for OUCH (UK)!
It's ONLY the highest free-standing mountain in the world!

Have you got the time and necessary skills to help your charity?
OUCH (UK)
needs volunteers.
If you feel you have the time and commitment, please contact:
submissions@ouchuk.org

www.ouchuk.org

A charity gig for OUCH (UK) in 2015.

Good music, some games and the serious business of rolling coins for a bottle of whiskey!

FUNDRAISING HIGHLIGHTS

CHers on Tour!

The fundraising bake with OUCH (UK) cake

Head shave!

Spectacular Headache Nurse Vicky

The North Sea Boxing Day Dip lads

Football Club Awareness

MORE THAN JUST A HEADACHE – A GUEST BLOG BY PHILIP TAYLOR

Victoria, Philip's wife posted this in the Friends of OUCH (UK) fb group after Philip passed away.

"I don’t know how many of you know Philip Taylor, who has been posting since we found this organisation nearly 9 years ago. Sadly my dear husband passed away at the beginning of December due to an undiagnosed degenerative heart problem despite being under cardiology consultants for 8 years and having a pacemaker leading to a very sudden and shocking passing for everyone around him.

He was a kind and gentle man who had time for anyone who was in need of it and happily gave anecdotes or advice from his personal experiences and things he had learned about living with cluster headaches to any other sufferer or carer he came across. We even got to meet with other members of the OUCH (UK) group in Westminster, a journey I was so proud to see him make after several years of him being terrified to even leave our own front door. OUCH (UK) was so very important to him right down to the point of always having his OUCH (UK) wrist band on, even whilst he slept. I have kept this as a memory in a box I have begun to make for our children who are only 7 and 4.

Philip was an incredible writer and just before he died he published a book about his beloved football team, Manchester United, which is in fact much more than a book about football. In addition to this he wrote a piece for a lady well met in the children's school playground whom has a blog. She wanted to tell Philip how much his writing had already helped her readers but he passed before she got the chance to. I really want to pass on what he wrote as it is very much about his journey with Cluster Headaches. He would be honoured if he knew that his efforts had been shared with you all."

Philip's blog follows over the page . . .

TW: anxiety, depression and talk to su!c!de

Hi, my name is Philip and I suffer from Cluster Headaches. Now I know what you're thinking? "Ooh I suffer from headaches too. Do you have to go and have a lie down in a darkened room?" That's the problem with this disease. It has a silly ass name that no one takes seriously! If it was more commonly known by its medical name (Trigeminal Autonomic Cephalalgia) or I dunno, Head Cancer then maybe people may take it more seriously. And they should because Cluster Headaches are the worst pain that a human being can suffer.

Have a look on YouTube at an attack to get an idea of what we have to go through. Now I know that anyone reading this who has been through childbirth will be saying 'err, what's the worst pain sorry?' I know that childbirth is horrendous and I commend anyone who has been through it, be it natural, in a pool, pumped full of drugs or Caesarian. I have friends with Cluster Headaches who have given birth and they say that the pain is comparable but when you give birth, then you don't have to go through that pain again for probably at least a year. With Cluster Headaches it's the next day and the next etc.

I was diagnosed in 2014 when I was 42 years old and they just came from nowhere. I found myself in The Walk In Centre at Middleton Arndale having a full blown Cluster Attack but not knowing what was happening. I was shouting, screaming, swearing and banging my head against the wall. I most definitely did not need to go and lie down in a dark room. It was terrifying and I thought I was dying. The Doctor (who I had never seen before) recognised that my eye would water before an attack and he diagnosed Cluster Headaches.

Getting the right diagnosis and the right medication to treat it is a minefield and I got a lot of help from the wonderfully named OUCH (UK) (Organisation for the Understanding of Cluster Headache). They also had an online forum and Facebook page where I could interact with fellow Clusterheads. The validation and comfort in reading other people's stories and recognising things that happen to you is massive. You realise it isn't just you and you are not alone.

After the illness comes the Anxiety and Depression. I was Depressed because I was mourning the person that I once was. The gregarious Philip who had sung with two bands and was always first up on the Karaoke. Who used to travel up and down the country watching his favourite football team and going to gigs. There is no known cure for Cluster Headaches so I could conceivably be looking at another 30 or 40 years of the worst pain known to man.

This is why they are known as Suicide Headaches as so many people just check out, not so much during an attack but just at the thought of a lifetime of Clusters. I made two very poor attempts to end it all. Trying to wedge my head between the sofa and the wall and trying to drown myself in the kitchen sink. Pathetic as these were, my mantra was clear. I did not want to be alive and it was only the protective factor of my wife and children that stopped me jumping in front of the 81 to Derker.

I had to take voluntary redundancy as I could not cope in work and my wonderful Wife quit her job as a Teacher to become full time carer to both myself and her Mother despite suffering from Chronic Health Conditions herself.

The first steps on the road to some sort of recovery was through Cognitive Behavioural Therapy (CBT). This was a massive help in getting me to accept my health condition and looking at ways to change my behaviour to try and live with it.

"Fear cuts deeper than swords" said Syrio in Game of Thrones and I fully understand that mantra. The fear of going out and having an attack was often greater the attack itself. I don't think there is any part of Middleton that I haven't had an attack. If you ever walked into a supermarket and saw some crazy bloke with his pants down and injecting himself in his thigh, it was probably me.

The CBT meant that I wasn't confined to barracks and I began to travel to Liverpool to see my Neurologist at The Walton Centre.

There have been many battles, not least in going through the gruelling process of trying to qualify for PIP payments but with my wife by my side we are getting there. We have two lovely young children together Jimmy (7) and Sunshine (4) as well as Hayley (25) from my first marriage.

Another side effect of the CBT and counselling was it helped me open up and talk about significant events in my life that I had buried in my head and wouldn't talk about. I have now faced my demons and talk about them in my book 'The Final Countdown' where I also talk about my life following Manchester United in the 80's and 90's (available on Amazon!). Writing the book was very therapeutic and the reaction has been amazing.

If you do suffer from chronic pain then my advice would be to try and take a two pronged attack on it, both Pharmaceutical and through Talking Therapy. Remember that the light at the end of the tunnel need not be the light of an oncoming train.

Shortly after writing this blog post Philip sadly passed away.

Don't forget to check out Philip's book on Amazon,

The Final Countdown: Following Manchester United in the 80's and 90's from Sexton to The Nou Camp

Why not join us as a volunteer?

Have you ever thought of offering your services as a volunteer? Have you got skills that could help your charity? If you feel you have the time and commitment, OUCH (UK) is looking for volunteers.

Experience in PR, editorial, IT skills or background of fundraising would be particularly useful. Any Advice Line volunteers will receive necessary training.

Please contact submissions@ouchuk.org for further information.

Audrey Leng - Advice Line and Membership Officer

In the Summer of 2020 I saw an email seeking volunteers for the OUCH (UK) Advice Line and the rest, as they say, is history!
It seems wrong to say I enjoy this role as no one would call us if they were not suffering. There may be common themes to some calls (a struggle to be prescribed Oxygen or a lack of work place support, for example) but every Caller has their own specific reason for calling the Advice Line.

I think a combination of the training and support I receive, as well as my own lived experience with Cluster Headache, means I can try to offer useful advice. This may be signposting to a headache specialist Neurologist, a suggestion to discuss a particular treatment option, a recommendation to contact another charity or encouragement on how to challenge a refusal to prescribe Oxygen. However, often Callers are just relieved to talk to someone that knows what it feels like to have an attack.

I know that until I attended an OUCH(UK) conference in York back in 2013 I had never met another person with Episodic Cluster Headache. There is an instant connection.

A few newly diagnosed callers have tearfully enquired if this means that their life is effectively over. I won't be glib. It is an understatement to say that attacks are painful. However I hope that I can offer that ray of hope. With the correct medication and adjustments, it may be possible to work and to travel. I have gone through the process of getting Oxygen in an open plan office environment and having had an attack, sat in Economy Class, on a plane high above the Atlantic I do know there are challenges.

All volunteers on the Advice Line either have Cluster Headache or support someone that has them.

If I don't know the answer to the Caller's query then I am confident there will be someone else in OUCH (UK) that does.

The key message I would have is
don't suffer alone; ring us!

Throughout my life I had rarely experienced headaches, that was until the ripe old age of 71 years! 8 years since.

I suddenly started having headaches that I thought were caused by eye strain, a check-up with my optician ruled that out. Next it was off to my GP who could come up with no explanation but sent me for a CT scan to rule out a tumour, which proved negative. My GP did however prescribe Sumatriptan tablets, although they stopped the headache they were slow working and left me drowsy for the following day.

The next steps were consultations with 2 Neurologists both of whom could not provide a feasible diagnosis but offered a whole list of drugs to work through with guidance from my GP, some requiring ECG's to ensure that I could cope with the drugs. I was beyond the recommended age for several of the drugs although relatively fit.

Two years on and feeling desperate a friend at the retirement village where we live told me about OUCH UK), they knew of someone that suffered from CH. I searched Google for OUCH (UK) and lo and behold discovered that they were holding a Conference at Newcastle the following week, 18th September 2018. Both myself and my wife, Sylvia, as my supporter joined OUCH (UK) and booked in for the Conference. As we live close to Lincoln it proved to be quite a journey with snow falling quite heavily on the way.

At this time I had not been diagnosed with CH, however, this proved to be the turning point in my CH journey. In conversation with one of the guest Neurologists they suggested that I be referred to the Pain Management Clinic at St Thomas' Hospital, London. My GP was able to arrange that for me and within a month I had an accurate diagnosis, I had Chronic Cluster Headache.

My treatment plan was to try 3 monthly GONB's (Greater Occipital Nerve Blocks) and to have Oxygen at home. At the time of the consultation I was experiencing an average of 10/12 CCH's per month and with the treatment it gradually fell to an average of 4 per month over a 4 year period. At this point I stopped with the GONB.

Early 2019 I took part in a 3 month trial of the GammaCore device but unfortunately it didn't help me, but worth the try!

I was using Sumatriptan injections to treat the CCH's but finding that my recovery time from using the injections was increasing and leaving me spaced out for the following day. I believe that this was largely due to my age and upon review my Neurologist they suggested changing to Sumatription Nasal Spray instead, although slower to act, I tolerated the nasal spray much better.

During 2021 I started taking Levetiracetam which has helped considerably, and now for the past 6 months I am no longer having debilitating cluster headaches, I do still experience a couple per month which I can work through without medication. Regular painkillers have never helped my CH. I have also stopped having the GONB.

Both myself and Sylvia were so grateful that we had found OUCH (UK) that we wanted to give something back. Noticing on the OUCH (UK) website, back in 2018, that they needed an Editor for CHit CHat, I thought, I could do that! At the time I was producing a monthly magazine for our Retirement Park, as a volunteer, - CHit CHat should be well within my scope, so I applied, and as they say, the rest is history! This is now my 5th issue.

As well as helping with OUCH (UK) I enjoy competing with my radio controlled model boats.

This is a 1/24th scale radio controlled model of the Thames Sailing Barge - Westmoreland, the hull is 40" long.
The barge was built in 1900, owned and operated by Eastwood Brickworks, located on the river Medway in Kent. It would carry up to 50,000 bricks to London and return with clay. It was crewed by a skipper, a boy and a dog!

This is a 1/20 scale model of a modern harbour tug. Again radio controlled, I use it for club steering and tug towing competitions. The model is 34" long and can easily tow a barge of up to 9 feet long through a hazardous course!

My CH Supporters Journey - Sylvia - John’s wife

When John started his CH journey we had been married for 50 years and this was the first time that I couldn’t work out how to help him. He just needed to be left alone, quiet, unable to explain how he felt, something that I couldn’t understand, we had never experienced this before.

The first glimmer of hope and understanding came as the result of discovering OUCH (UK) and attending the Conference in Newcastle, which was 2 years after his first attack. At the Conference I was able to talk to fellow supporters and realised that our situation was not unique, I found this experience extremely helpful. Following the Conference John was able to receive the correct diagnosis, confirming that he was in-fact suffering from CCH.

Although I could begin to understand why John was acting the way he was it didn’t rest well with me as my nature is a very caring one and I was feeling rejection. I could sense the onset of an attack, often before John did and would have to stand back and wait for it to happen! When it did happen I had to stand aside, he would have his injection and lie down in a darkened place for up to 3 hours, I just waited until he reappeared very bleary eyed and dreamy, often he would stay that way for the rest of the day.

With attacks occurring between 10 and 12 times per month it was impossible to plan anything socially and we “dropped” out of our normal active lifestyle. As John started treatment things did ease a little, but I, in particular could not relax and was always waiting for the next attack. John became a little philosophical as to when the next attack might be but that was not so easy for me and I’m still very wary about making commitments for us - just in case. John’s positive view is - “if I can I will, if I can’t I won’t” - I just wish that I could be that positive.

On the positive side we do now enjoy playing Croquet together twice a week at our local club, and social club competitions. John plays in the club team in the League on the understanding that he may have to pull out at short notice.

Life is getting better all the time - we owe so much to OUCH (UK), thank you all.

Thank you Amazon Smile

For quite a number of years Amazon, through AmazonSmile have been donating to support small charities.

For every pound spent through AmazonSmile a small percentage was donated to OUCH (UK), this has amounted to a total of £1,904.51

Unfortunately, Amazon have discontinued the scheme meaning that we will lose that income.

Answers to Quiz on page 15.

1. Aurora Australis.
2. Vienna.
3. Elizabeth (Capt. Mainwaring’s wife).
4. No 13.
5. The tip of a whip.
6. Gibbs SR toothpaste in 1955.
7. Minus 40 degrees.
8. Kilimanjaro 19,341ft.
9. Admiral Yamamoto, who actually led the raid.
10. Yellowstone National Park.
11. Fear of headaches - particularly CH.
12. Iceberg.
13. Aurora Borealis.
14. She sailed into Liverpool with three Union ships in hot pursuit. The Captain surrendered his ship to the Mayor. This became the final act of the civil war, six months after Lee’s surrender.
15. Green.

We now offer another super easy way to donate to OUCH (UK) with our latest text giving service*. Here's how to do it:

To donate £1, text OUCH to 70201

To donate £3, text OUCH to 70331

To donate £5, text OUCH to 70970

To donate £10, text OUCH to 70191

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