

# CHit CHat

The Official Newsletter of OUCH (UK)

The Organisation for the Understanding of Cluster Headache

# CLUSTER



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# HEADACHE

**Summer 2026**

**Birmingham Conference Edition**

**14th June at 'The Exchange'**



[www.ouchuk.org](http://www.ouchuk.org) - Advice Line 0800 6696 824



### **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.



### **Dr Nicholas Silver**

Consultant neurologist in Liverpool. Clinical and research interests in cluster headache and its optimal management.



### **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, and deals with 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 OUCH support sufferers, support research and build awareness in any way he can. He accepted the position of Trustee and Treasurer in 2022.



**Dr Bahra** is a consultant neurologist with a specialist interest in headache. Dr Bahra is part of the general neurology team at Whipps Cross Hospital and headache and facial pain services at the National Hospital Neurology and Neurosurgery and, the John Radcliffe Hospital, Oxford. Dr Bahra's research was in cluster headache at the Institute of Neurology, UCL. She is a Life Member of OUCH. She is part of the BASH Headache Guideline Group which published the updated national headache guidelines in 2019.



### **Pedro Caires** (Deputy Advice Line Manager)

Originally from Portugal, Pedro has called London home since 2011. Living with Episodic Cluster Headaches since 2019 inspired him to get involved with OUCH (UK) after attending the 2024 summer conference. He now volunteers as Deputy Advice Line Manager and supports fellow sufferers. Pedro lends a hand with social media and other areas of the charity too, always keen to help raise awareness and support the community.

## OUCH(UK) Officers

**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.

**Phil Hamblet** (OUCH Forum adviser) Phil has suffered from episodic CH for many years. He now volunteers for OUCH(UK) and helps to monitor the website Forum to answer queries and give advice.

**Tina Neave** (Advice Line) Tina joined OUCH(UK) after her husband was diagnosed with Chronic Cluster Headache in 2008. She feels it is important to raise awareness of the severity of Cluster Headache. She knows how difficult it is to watch a loved one suffer and wants others to understand that supporters too are affected by this condition. OUCH(UK) has supported her in the past and she has now volunteered in order to give something back.

**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.

**Ben Gibbins** (Advice Line) Ben is an Engineer that suffers from Cluster Headaches. In typical Engineer fashion he tried to fix it himself, but then found OUCH(UK) who helped guide him to the tools to help live a fairly normal life. Ben joined the Advice Line in 2025 hoping to help others navigate their pain.

**Carl Straw** volunteers as Advisory Officer for HR & Employment with OUCH, where he supports the organisation with HR and employment advice and guidance. Carl has a long career in HR at both a strategic and operational level and is proud to contribute his experience to a charity that raises awareness of Cluster Headache and provides much-needed support and guidance to sufferers and their families.

## OUCH(UK) Officers



**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(UK) he enjoys building and competing with his radio controlled model boats, playing croquet and generally keeping fit.



## OUCH(UK) Expenditure

The Board of Trustees is seeking our members' views on how to put our funds to best use.

It is important that your views are aired - after all, it is your money.

We are very lucky that all trustees and officers of the charity give their time freely and receive no remuneration whatsoever, other than legitimate expenses. Some of the funds are used to facilitate the daily running of the organisation.

You may wish to consider some of the following initiatives as potential funding targets, although you should not feel restricted by them in your suggestions.

### RESEARCH

#### RAISING AWARENESS

#### CLINICAL STUDIES

#### FUNDRAISING

All suggestions, of a legitimate nature, will be considered. Unfortunately, I'm afraid that a Caribbean cruise for each member, although welcome, would not be deemed legitimate.

Colin Allen

Vice Chairman - OUCH(UK)

Cluster Headache Spotlight Series.

Released on Cluster Headache Awareness Day, the first episode featured comedian, actor, writer and director Chris Addison sharing his experience of cluster headache.

Episode two:

Alexander was just two and a half when his attacks began. In this episode, he and his mum, Mel, joined Dr Munro to share what it is like to live with cluster headache in childhood, from diagnosis and treatment to the impact on family life.

Episode three featured Frederick Wood who was diagnosed with cluster headache at 11. Now 17 and preparing for university, they joined Dr Munro alongside their mum Rachael to talk about growing up with one of the most painful conditions known to medicine, how they manage it, and the support available.

Episode four: What happens in the brain during a cluster headache attack? In this episode, Dr Munro was joined by leading headache neuroscientist Dr Phil Holland to explore the biology behind one of the most extreme pain events the human body can experience.

Episode five: Searching for answers. Isobel West has lived with cluster headache since the age of 15. In this episode, she joined Dr Munro to talk about her journey with cluster headache and the PhD research she is now carrying out at King's College London to better understand the brain mechanisms behind cluster headache.

Episode six: When pain meets the law. In this episode, Dr Munro is joined by Mike Smalley, who has lived with cluster headache since the age of 14, to discuss how an awareness of employment law can help those living with cluster headache to understand their rights at work and the protections available.

The final episode of the cluster headache spotlight series: Pregnancy and parenthood. In this episode, Daisy joined Dr Munro to share her experience of managing cluster headache during pregnancy and with a toddler, and why specialist support and planning can make such a difference.

Listen on the NMC website or your usual podcast platform, or watch on YouTube:

[www.nationalmigrainecentre.org.uk/understanding-migraine/heads-up-podcast/](http://www.nationalmigrainecentre.org.uk/understanding-migraine/heads-up-podcast/)

[www.youtube.com/watch?v=JoZuGN7dAo4](https://www.youtube.com/watch?v=JoZuGN7dAo4)

# WANTED

**As a result of the retirement of our Editor of CHit CHat (John) we are looking for someone to step into his shoes.**

**Do you feel that you may be able to help with the continuation of CHit CHat? If you have just a basic knowledge of desktop publishing that will be sufficient. John will be available to offer guidance and assistance as required during the handover period.**

**If you would like more information you can contact John at [chitchat@ouchuk.org](mailto:chitchat@ouchuk.org) who will be willing to answer any questions that you may have.**

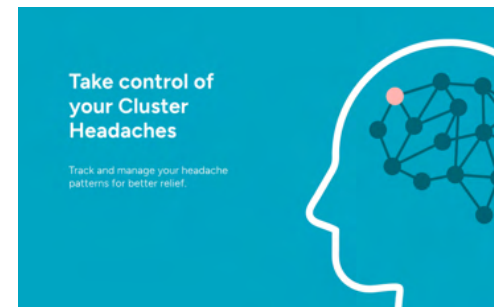


Join us in Birmingham for the OUCH (UK) Summer Conference 2026!

TICKETS ARE AVAILABLE SECURELY ON OUR WEBSITE

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 discounted ticket. Member pricing will show on the booking page when you are logged in.

	OUCH Member	Non-Member
Adult	£6	£12
Child under 12	£1.50	£3



The **MyClusters** app recently featured on the OUCH (UK) website has now had over 1000 downloads by users from over 50 countries!

It is a Cluster Headache tracking and analysis app that makes it easy for users to log their CH attacks in under 20 seconds, get personalised insights into their attack triggers and patterns, monitor their medications - and quite a lot more! It was built by a cluster headache sufferer, Darshan Ramanagoudra, after he had a ten-month bout of multiple daily CH attacks.

Darshan is now seeking partnerships across the globe with researchers into cluster headache, its psychological burden for sufferers and its effects on their quality of life. Users of the app can choose to share their data anonymously and contribute to studies into this devastating disorder.

The app continues to develop - the latest new features released include :

- a snapshot profile of the user's CH pattern and lifestyle factors
- cycle tracking: add cycle start and end dates, get cycle specific reports, statistics, and remission period calculations
- export pdf reports, making it easier to share reports with medical professionals
- add preventive medications, treatments, alternate therapies with reminders
- even faster logging of CH attacks

Future releases will include:

- social sharing of reports
- import/export csv files of headaches
- sending weekly emails with reports

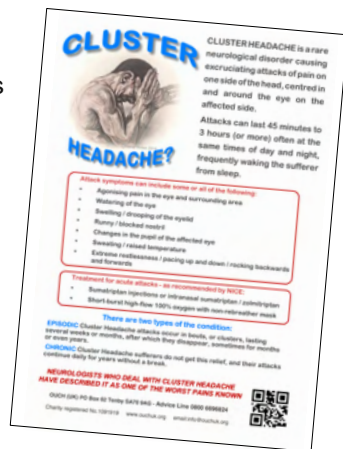
The app users themselves are very welcome to come forward with requests and suggestions to add to the development list – just email [darshan@myclusters.nl](mailto:darshan@myclusters.nl)

[Become a user now!](#)



## Cluster Headache Awareness Campaigns

A key aim of OUCH (UK) is to raise awareness of Cluster Headache within the medical profession and the general public. We are also keen for CH sufferers to be aware that OUCH UK may be able to give advice and support when they need it most. As you may know, March 21st every year is Cluster Headache Awareness Day. OUCH UK makes a special effort to increase awareness of CH on that day. We have an awareness poster outlining the symptoms of CH with the NICE approved treatment guidelines, and various Awareness badges and car stickers. These items are all still obtainable from our online shop. We urge sufferers to take these posters and some OUCH UK leaflets along to their local GP surgeries, pharmacies, dentists and hospitals.



We also issue press releases focussing on the various treatment guidelines which are available to assist GPs in prescribing for CH sufferers in advance of them getting a confirmed diagnosis from a headache neurologist. This is particularly important nowadays in view of the extremely long waiting times before patients can see a consultant, during which time they may suffer horrendous pain with no treatment whatsoever.

In addition, we have also been working to provide all hospitals in the UK with our OUCH posters and leaflets - we would love to know if you spot any of these on your hospital visits. Don't forget - if you would like to help distribute these further, you can get them in packs of five from the OUCH UK online shop for a nominal charge. Many thanks for any help you can give!



Raise awareness everywhere you drive with our brilliant car sticker! 100mm diameter



Round Pin Badge Cluster Head Awareness 38mm diameter

Awareness leaflets, three fold, packed with information

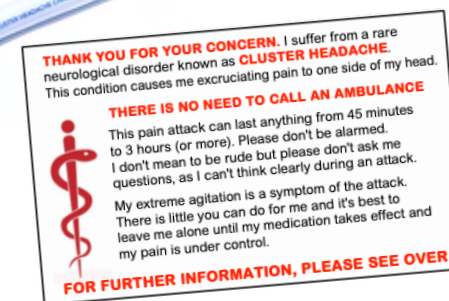
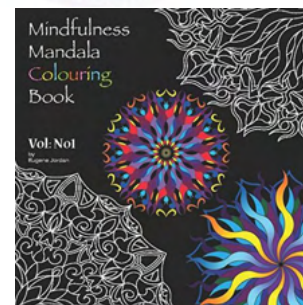
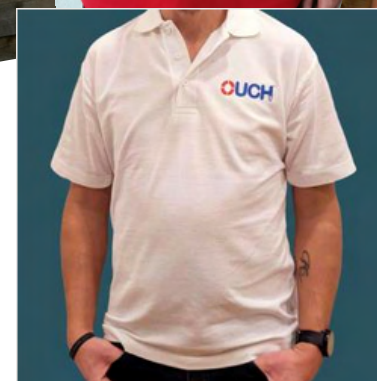


## OUCH (UK) ONLINE SHOP

If you haven't visited our online shop yet, have a look on our website at [www.ouchuk.org/shop](http://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.



OUCH  
Lapel Pin Badge in Red & Blue



We are Fiona and Steffy; Headache Clinical Nurse Specialists at King's College Hospital and we care for and support patients diagnosed with primary headache disorders, including cluster headache.

We have been very lucky and are incredibly grateful to OUCH (UK) for their generous support, which enabled us to attend the International Headache Congress (IHC), which took place in São Paulo, Brazil from the 10th to the 13th of September 2025.

This was an extremely valuable opportunity, and we are grateful for your support in facilitating our professional development as healthcare professionals and clinical headache experts.

We would like to share with you some interesting information and important updates from the Congress.

### **Fiona:**

This year's congress featured outstanding lectures and meetings, offering valuable opportunities to both learn about and engage in cutting-edge developments in headache treatment and research.



One of the most impactful sessions we attended was the Classification Committee meeting. It was a privilege not only to listen in but also to contribute to discussions that may help shape future diagnostic criteria and classifications; a crucial step toward improving patient care globally.

There were also dedicated presentations on cluster headaches, highlighting emerging evidence that CGRP-targeting therapies, such as Emgality (Galcanezumab), can offer meaningful benefits to patients living with this headache disorder. Data suggests that patients experienced an average reduction of five additional attack days per month compared to placebo. Ongoing research is now exploring potential predictors of treatment response, which could be instrumental in tailoring therapies and improving outcomes.

Another important topic discussed was the genetic basis of cluster headaches. Recent findings indicate a higher likelihood of developing cluster headaches in individuals with a family history of the condition. Additionally, it was noted that these patients often experience fragmented or reduced sleep; a connection that many patients may recognise from personal experience.

Overall, the congress served as a powerful reminder of the importance of ongoing research into this debilitating primary headache disorder. New discoveries

continue to open doors for more effective treatments and reinforce the need for an individualised approach in clinical care. We remain committed to applying these insights to better support our patients and improve their quality of life.

### **Steffy:**



The congress provided valuable updates on headache research and clinical practice, with several sessions highly relevant to the care of people living with cluster headache. A recurring theme was the ongoing challenge of delayed diagnosis and the profound impact cluster headache has on patients' quality of life. There was strong emphasis on the need for improved awareness among non-specialist healthcare professionals and clearer referral pathways to specialist services.

In terms of treatment, cluster headache management was well represented. High-flow oxygen therapy was repeatedly highlighted as a first-line acute treatment, with discussion around improving access, appropriate delivery systems, and patient education to ensure timely and effective use at home. Triptans, particularly subcutaneous formulations, were also reinforced as a key abortive option, with practical guidance on safe prescribing and patient support.

Preventive treatment strategies were another important focus. Verapamil remains the mainstay preventive therapy, with updated guidance on dose titration and ECG monitoring. Sessions also explored options for people with refractory or chronic cluster headache, including emerging evidence for CGRP-targeted therapies, such as the Galcanezumab subcutaneous injections, and neuromodulation techniques, such as non-invasive vagus nerve stimulation (nVNS). These discussions were especially valuable in understanding how newer treatments may offer hope for patients who have not responded to traditional approaches.

The congress strongly reinforced the importance of patient-centred care, shared decision-making, and supporting patients beyond medication alone, including education, advocacy, and psychological support. This aligns closely with the work of OUCH (UK) and the needs expressed by many people affected by cluster headache.

Overall, attending IHC 2025 has strengthened our clinical knowledge and has directly informed our practice, enabling us to better support patients with cluster headache. Once again, we would like to express how extremely grateful we are to OUCH (UK) for making this opportunity possible.

Diary Entry, July 2014:

*"Today was rough. Hardly slept. Work is carnage. 5 attacks and used three sprays, I know it's supposed to only be two a day but I'm losing it, I can't take it anymore. Nearly fell down the stairs when pacing in pain, kinda wish I did. One more day. Just keep swimming (dory image). I really hope they can help, I can't do this anymore."*

Hi, I'm Ben, a 37 year old Mechanical Engineer. Above is an extract from a diary I kept in some of the worst years of my life. This is from 2 days before my appointment with a special headache Neurologist. That appointment changed my life. That appointment gave me hope.

I'm 15, sat in the kitchen waiting to be picked up by my Dad to be taxied somewhere. My Dad finds me banging my head against the wall screaming in agony and can't calm me down or reason with me. It must have looked bad as he bundles me in the car and off to the local hospital, where I ended up strapped to a bed. After what felt like a thousand years there's an injection and a rush felt coursing through my whole body. The pain is gone but boy do I feel weird. Doctors etc mutter something about migraines and told to book a doctors appointment. GP reckons it's migraines, there is history in the family, to avoid cheese, chocolate etc. The pain happens a handful of times in a few weeks. Then nothing. Totally forgot about it.

I'm 22, first day in a new job, one that I've just moved from the UK to Louisiana in the USA for. Midway through a Health and Safety presentation, a headache. Swallow a hand full of normal painkillers out of bag and try to concentrate. Can barely see, vaguely hear what the presenter is saying. Got to keep it together, this is my first day. Rode it out, exhausted afterwards, missed the welcome meal. A few days later another headache, sod it a few rum and cokes will sort that....it didn't, back to hotel in agony. I must be be dehydrated or jetlag or something. Happened a few times but new country and job and no medical side of things set up yet. Just suffer it and carry on, it will pass. After a few weeks, nothing, totally forgot about it.

Im 24, moved back to the UK, out mountain biking on my own. That hurts, I'm sure I've drank enough. Oh wow, that really hurts. Screaming in the woods. I bet those people think I crazy. Wow this isn't right. Later that night, woke up, same pain. I need help. Is my head exploding?

Doctors..... Migraine.... Doesn't seem it but OK. At least I've got these tablets in case it happens again.

Well they did nothing..... Oh I can't take this. Again? Nooooo! 3 to 4 times a night. I guess I don't need sleep anymore.

Months go by... Off work... losing the will to go on, depressed. Sat in the shower in agony, crying my eyes out, can't do this anymore. I gotta be there for my sisters, I gotta keep going, dory.... God damn dory... Just keep swimming, just keep swimming (I must have sung/screamed this a million times in the last 12 years).

Doctors.... here's some antidepressants, it could be these weird headaches, I'll refer you to a neurologist, here's more tablets.... that don't work.

Local hospital neurologist, you might have cluster headaches, keep a diary.... Oh you have a list of every time it happened...? Oh it's in Excel with graphs? You must be a teacher or an Engineer...

Nasal sprays and some tablets that the Internet says are something to do with heart problems.... I'm confused.

Spray and pray! OMG it worked. Took a while but way quicker than riding it out normally. Ooh I'm fixed I can deal with this, I have hope.

Again I'm having 5 attacks most days but can only use 2 sprays (if I can get them) this isn't great... Found some website that seems to be about cluster headaches, I should look into that...

No attacks anymore. Not had one for a few months. Life is good, totally forgot about it.

Oh it's back... I'm done. Seen local neurologist several times (different person each time), frustrated.

### **Now the breakthrough:**

GP refers me to a headache specialist neurologist. 2 hours each way.... It better be worth it.....

48 hours after that appointment I had oxygen delivered, my life changed that day. Attacks dealt with in 10-20min.

Then back to normal life. No feeling weird or drained from sprays or injections.

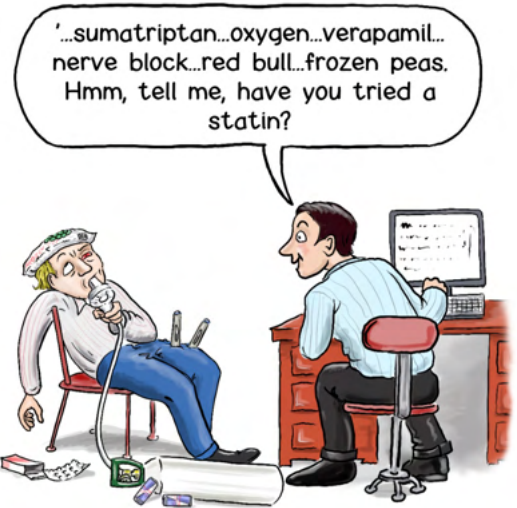
The beast haunts me still but now I can fight back.

Nerve blocks, gammacore and directed to this website called "OUCH (UK) .... Wow these people understand, I'm not alone.

I fought this beast over half my days a year, but I now have a toolbox of things that helps prevent, lessen and abort these damn things.

Life is winning. I still have bad times, but the highs now outweigh the lows. I have hope.

**The lighter side - by our resident artist Jamie**



**Help for fundraisers**

If you are organising a fundraising event you are able to set up your own Personal Campaign Page directly through our website, with any donations coming straight to us.

Fundraisers will be able to fill in the details of their event, including their info, story, fundraising target, optional progress thermometer, honour roll, text, images, etc.

Once completed, it then needs to be approved by OUCH admin before it becomes active.

It can then be shared via a link and supporters can donate directly via this page.

Contact: [info@ouchuk.org](mailto:info@ouchuk.org) to get your link and fundraising pack.

Thank you!

**Behind My Eye . . .**

**A massive thank you to the talented Dave Pask who has given us permission to share the lyrics of this amazing cluster headache song he has composed (link to the song below) which has been very popular on YouTube, Instagram and Facebook. The perfect soundtrack.**



<https://youtu.be/L0rZN5eu1oo?si=rTNm0ggVP-WToP0v>

Three in the morning, a match strikes behind my eye  
 No warning, no reason, no place for me to hide  
 I've learned not to scream now, learned how to bite the floor  
 Thirty minutes of hell, then forty-five more

You'll see me tomorrow, looking just fine  
 You'd never believe what happens inside

There's a fire behind my eye  
 Like a drill through the bone and it won't let me lie

I'm pacing the walls, I'm crawling the ground  
 I'd beg God to kill me if He came around  
 It peaks and it burns, thirty minutes or more  
 Then it's gone without reason — like it was before

But it's coming back — it always comes back  
 There's a clock in my skull and it's counting the black

February, October — it picks its own season  
 Six weeks of attacks and it needs no reason  
 My eye's running red and my eyelid droops low  
 I sit in the dark 'cause the light is too much to know

They say have you tried ibuprofen, or sleep?  
 I almost laughed — now I just quietly weep

There's a fire behind my eye  
 Like a drill through the bone and it won't let me lie

I'm pacing the walls, I'm crawling the ground  
 I'd beg God to kill me if He came around  
 It peaks and it burns, thirty minutes or more  
 Then it's gone without reason — like it was before  
 But it's coming back — it always comes back  
 There's a clock in my skull and it's counting the black

I don't need your pity  
 I need you to know  
 There are people like me  
 Who just don't let it show

We're not being dramatic  
 We're not being weak  
 We're just trying to survive  
 Till the cycle peaks

**There's a FIRE behind my eye**  
 Like a drill through the bone and it won't let me lie

I'm pacing the walls, I'm crawling the ground  
 I'd beg God to kill me if He came around  
 It peaks and it burns, thirty minutes or more  
 Then it's gone without reason — like it was before

But it's coming back — it always comes back  
 There's a clock in my skull  
 And it's counting  
 And it's counting  
 The black—

## Fantastic Fundraisers

Lee Smith

RAISING AWARENESS

CAMBRIDGE HALF MARATHON

Thank you, Lee, for raising awareness with a half marathon.

That was great timing leading up to Cluster Headache Awareness Day!

Lee's target was 1:45 and he came in with a brilliant time of 1:40.

Well done, Lee!



## Some of the reasons given for making donations to OUCH (UK):

To support my fab brother-in-law and all those who have these horrible headaches.

I organised a murder mystery event at my pickleball club, I am donating the proceeds, plus my own personal donation to OUCH. OUCH has supported my son and myself as his Mum over the years with advice & information.

Donating on behalf of a good friend who passed away and asked people to donate to his chosen charity - OUCH.

Requested by my Nephew who sadly died. He suffered from cluster headaches during his life.

I am a cluster headache sufferer.

This charity is very close to our families hearts.

I am a sufferer (episodic).

I hope this helps!!! I have someone who means a lot to me with Cluster headaches, and I hope this small donation helps out with anything, have a lovely day and thanks for all the amazing work you do.

Donating as my sister-in-law suffers from cluster headaches.

Donated on behalf of a good friend who is a sufferer of cluster headaches.

My mate suffers from them and they're absolutely horrendous. Far more needs to be done to support him and others that suffer from this excruciating pain. Thank you.

## Fantastic Fundraisers

Frederick Wood.

Marking Cluster Headache Awareness Week.

Diagnosed with CH at just 11, Frederick Wood appeared on episode 3 of the National Migraine Centre's series of podcasts about cluster headaches.

Speaking with Dr Katy Munro alongside his mum, Rachael, they described living with one of the most painful conditions known to medicine, growing up with the condition, navigating school, finding the right support and the impact it can have on daily life.



Frederick also held a cake bake sale at his school to raise funds for OUCH (UK). The sale raised a fantastic £500! How's that for a successful week!

A huge well done to Frederick and Rachael for sharing their experience and helping others better understand life with cluster headaches.

### DANCING IN SUPPORT OF OUCH (UK) AT CARDIFF UNIVERSITY

In honour of Cluster Headache Awareness Day in March, Meg Kiseleva spent a day around Cardiff University Heath Park campus offering short, fun basic tango sessions as a way of raising funds for OUCH (UK).

Meg has someone very dear to her who lives with cluster headache and says OUCH has been an invaluable resource for her to understand what they go through and learn how to support them better.

We are incredibly grateful for any amount of funds raised as it helps us run our vital advice line, maintain and upgrade our website, produce awareness materials, and organise conferences to support and inform our community.

Meg raised an incredible £450 for the cause. Many thanks, Meg and to all who contributed to this fabulous event.



## OUR FABULOUS FUNDRAISERS

**We can never thank our fundraisers enough.**

**We are incredibly fortunate to have such dedicated supporters backing our charity and without these amazing people we could not continue to provide an advice line for sufferers, print awareness materials, keep our vital website updated or arrange our conferences.**

**We appreciate every single one of you and so here's another massive THANK YOU to all our fundraisers and their wonderful sponsors!**

I work for ECO2 Management Services Ltd, and each year staff are invited to nominate a charity for our senior management board to consider for the company's annual donation.

This year, I put forward OUCH UK - and I'm delighted to let you know that the board has selected your charity, and you will be receiving a donation from us.

This nomination was incredibly personal for me. My partner, Jordan, was finally diagnosed with Cluster Headaches last year, and watching him go through it has been one of the hardest things either of us have ever had to cope with. The attacks have been frightening, exhausting, and completely overwhelming - not just for him, but for us as a couple.

What made everything even more challenging was how little understanding and support there seemed to be within general healthcare. Before his diagnosis, we spent months going back and forth to the GP, trying to explain the severity of what he was experiencing, only to be met with uncertainty or assumptions that it was "just migraines". Even after receiving the diagnosis, guidance and knowledge were still limited, leaving us to research so much alone. It often felt like we were trying to navigate something incredibly serious with very few people who truly understood it.

Because of that, the work that OUCH UK does - raising awareness, supporting sufferers and their families, and providing information that is otherwise so hard to access - has meant a great deal to us. Being able to nominate your charity, and seeing it chosen by our board, feels especially meaningful.

Thank you for everything you do. I hope this donation helps you continue the vital support you provide to so many people living with this condition.

Warm regards,

Kevin

*Dear Eco2 Management Services Ltd,*

*On behalf of our members, the Trustees of OUCH (UK) would like to thank you very much for your generous donation of £1,000. The charity could not survive without the generosity of donors and your contribution is much appreciated.*

*OUCH (UK) is run by a board of Trustees who give their time voluntarily. We receive no government or commercial funding and rely entirely on annual membership subscriptions and donations such as yours. These enable us to maintain our website, raise awareness of Cluster Headache and run our all-important telephone Advice Line for sufferers.*

*We are extremely grateful for your support and your contribution will be put to good use.*

*OUCH(uk) Board of Trustees.*



***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, employment law, basic accounting, IT  
skills or background of fundraising would be particularly useful.  
Any Advice Line volunteers will receive necessary training.***

***Please contact [submissions@ouchuk.org](mailto:submissions@ouchuk.org) for further information.***

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To donate £3, text OUCHUK to 70331

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\*Fundraising, payments and donations will be processed and administered by the National Funding Scheme, operating as DONATE, a charity registered in England and Wales (1149800) and Scotland (SC045106). In addition to any text donation, you will incur your standard network message charge (based on your service provider rates).

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ADVICE LINE [adviceline@ouchuk.org](mailto:adviceline@ouchuk.org)

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INFORMATION [info@ouchuk.org](mailto:info@ouchuk.org)

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Official newsletter of OUCH(UK)

The Organisation for the Understanding of Cluster Headaches

CHit CHat [chitchat@ouchuk.org](mailto:chitchat@ouchuk.org)

[www.ouchuk.org](http://www.ouchuk.org)

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