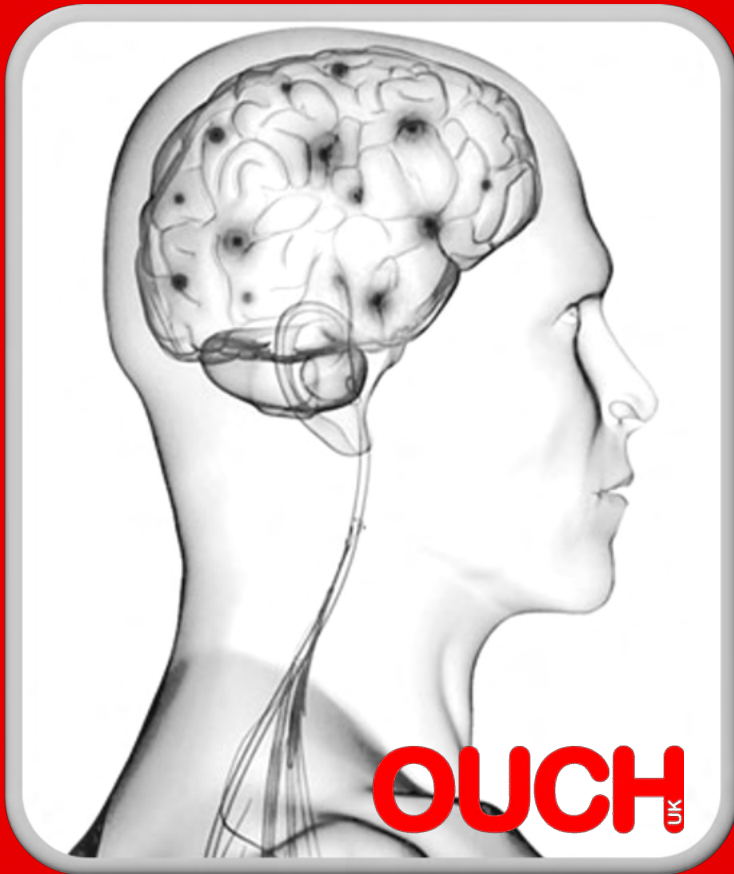


# CHit CHat

**The Official Newsletter of OUCH (UK)**

**The Organisation for the Understanding of Cluster Headache**



**SUMMER 2022**

**London Conference Edition**

**18th September at LSE**

**Book early to ensure your place.**

**[WWW.OUCHUK.ORG](http://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.



### **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.



### **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.



### **Linda Duddy** (Advice Line Supervisor)

Linda is the charity's Advice Line Supervisor. She suffers migraine, hemicrania continua and chronic clusters and joined OUCH in 2014. Having benefited from support from OUCH in tough times, she has worked as a volunteer on the advice line since 2016 to give back.

## OUCH(UK) Officers

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)

Is from County Durham and was diagnosed with episodic cluster headaches in 2009. She has been a member of OUCH UK since 2011 and from September 2020 she has been volunteering on the Advice Line.

### **Kevin Lawrence** (Advice Line)

Has been a CH sufferer for 18 years and have been chronic for 10 years, seen all the ups and downs of the illness from losing a few jobs and being unable to work for a year and luckily some great pain free times in between. I have been a keen follower of OUCH, TAC's (CH) research and news and have volunteered for trials of new medicines. I work in medicine and enjoy playing guitar, fostering lost dogs/cats, camping, cycling, backpacking to unusual places like Ukraine, Columbia and enjoy running a local music group.



< **Dale Nolan** 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.

**John Poore** (CHitCHat 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.



### ADVICE LINE GOES DIGITAL

We are delighted to announce that the advice line is, indeed, going digital! Some of you may be aware that the telecoms industry is changing and that conventional systems will come to an end in December 2025 and numbers will move in to the cloud.

To this end, OUCH UK has taken the decision to adopt a new, digital system starting from this month. This will give more freedom to our volunteers to receive and return calls. Whilst we will still be keeping the same 0800 number for calls to the advice line, it will now enable us to provide a number from which calls are returned that sufferers can store on their phone, bringing an end to calls being returned from a 'withheld number'.

We are excited about this new, improved upgrade, to enhance the delivery of our valuable advice line.

## Could it be you?

Dear Member,

### ADVICE LINE VOLUNTEERS NEEDED

Have you ever called our advice line? Have you ever wanted to do something for OUCH (UK) to help other sufferers and raise the profile of the charity?

Well, we are asking for your help! We need to take on some new volunteers to assist us in providing the service our valuable [advice line](#) does for sufferers all over the UK. The request is open to all members, whether you be a sufferer or supporter.



### What's Involved?

- Committing to either one day a week, or a couple of days a month, where you pick up the calls from our messaging service and return the calls at your convenience; if you work during the day, you could return the calls during the evening.
- You will receive online training sessions with our Advice Line manager and be provided with the Advice Line manual.

If you are interested, and for more details, please e-mail your CV to us on [advice@ouchuk.org](mailto:advice@ouchuk.org) and let us know if you have any previous experience of telephone advice work, what your past work experience has been [these are not an absolute requirement, but will help us build a picture of who you are], and any other relevant information you feel will show us why you are a suitable candidate.

This is a great chance for those of you who want to do their bit for other sufferers and support this unique and much needed charity.

Thanking you in anticipation,

Kind regards,

The Board of Trustees of OUCH (UK).



### JOIN US . . .

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, 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)

**Join OUCH(UK) at: [www.ouchuk.org](http://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

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. "



## At the London School of Economics

**Sunday 18th September 2022**

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 Anna Andreou, leads headache research at the Headache Research Lab at the Wolfson Centre for Age-Related Diseases, King's College London and the Headache Centre, Guy's and St Thomas' NHS Trust.
- OUCH (UK) Trustees and Officers

We are currently adding to the line up so watch this space.

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 will be provided.

## Tickets are available securely on line

As a thank you for past support, we are offering substantially reduced ticket prices this year. We hope that keeping the cost low will enable more sufferers to attend our first face-to-face conference since 2019.

OUCH(UK) members will receive a fantastic 60% off the price of each ticket. This discount is **AUTOMATICALLY** applied when you book your ticket online.

Member Adult £3.00 / Child £1.00, Non Member Adult £7.50 / Child £2.50

To receive this discount, you **MUST** be logged into the OUCH(UK) website.

### 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 [scott@ouchuk.org](mailto:scott@ouchuk.org) in complete confidence.

We hope to see you there.

### When

18th September, 2022 10:00 AM through 5:00 PM

### Location

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

## DOUBLE HONOUR FOR MAKAI

In January of this year, we had the pleasure of announcing that we had chosen 15 year old Makai Joyce to be the recipient of both the Les Charlton and Mike Pollock awards for 2021 after Makai's grandmother, Sandra Ward, nominated him for the annual Mike Pollock award. This was her nomination:

*"As a long term CCH sufferer and OUCH member, I would like to nominate my grandson Makai Joyce for this award. My daughter, his Mum, Sophie, is also a chronic cluster headache sufferer with mental health problems too. Makai is the eldest of her 4 children at 15 years old. He has grown up helping Sophie with her oxygen treatment and looks after his younger siblings amazingly when she is having an attack. Sophie is a single Mum so he has taken on being the man of the house - one of his brothers is autistic and one has ADHD, so they are a handful. Despite this, Makai has turned into a bright, kind, helpful young man and I am so proud of him. He has smashed his mock GCSEs after months of lockdown when his mum was really bad and his siblings were all at home. In a very chaotic household he remains calm and supportive and I would love it if he could be recognised for being the supporter he is."*



The winner of the Mike Pollock award is usually chosen by the CH community. However, the board of trustees was so impressed with the support Makai provides for his family, it was decided he should receive an award in time for Christmas. We were already considering suitable candidates for our Les Charlton award, chosen annually by the trustees in commemoration of the great man. The closing date for the Mike Pollock award nominations was not until 15th January, 2022, so we decided to present Makai with the Les Charlton award as well as a special edition framed Mike Pollock award for meritorious conduct. We felt that Mike and Les would be very happy to have jointly recognised and rewarded Makai's outstanding commitment and caring attitude to his family. Congratulations once more to this very special young man and best wishes for the future.

For some gentle relaxation why not try these puzzles . . .

|   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|
|   | 1 | 2 | 5 |   |   |   | 3 | 6 |
| 4 |   | 5 |   |   | 6 |   |   |   |
|   |   |   |   | 4 | 3 |   | 7 | 2 |
|   |   |   |   | 7 |   | 3 | 4 | 9 |
|   | 9 |   | 2 |   | 4 |   | 1 |   |
| 1 | 7 | 4 |   | 8 |   |   |   |   |
| 9 | 5 |   | 4 | 1 |   |   |   |   |
|   |   |   | 9 |   |   | 1 |   | 4 |
| 3 | 4 |   |   |   | 5 | 9 | 2 |   |

Easier . . .

|   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|
| 8 | 1 | 5 |   |   |   |   |   | 6 |
| 9 |   |   | 6 |   |   |   | 2 |   |
|   |   |   | 5 | 1 | 4 |   |   |   |
| 4 |   | 6 |   | 2 |   | 9 |   |   |
|   |   |   | 8 | 5 | 6 |   |   |   |
|   |   | 2 |   | 4 |   | 6 |   | 8 |
|   |   |   | 2 | 9 | 1 |   |   |   |
|   | 4 |   |   |   | 3 |   |   | 1 |
| 1 |   |   |   |   |   | 2 | 7 | 9 |

More challenging . . .





## 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](http://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!

Thinking of buying presents? If you're planning to buy gifts  
from Amazon, or just buying for yourself, why not shop  
through AmazonSmile, with OUCH (UK) as your chosen  
charity?



At AmazonSmile, customers can buy exactly the same  
products, at the same prices and with the same convenient  
shopping features as on Amazon. The only difference is  
that when you shop through AmazonSmile, Amazon  
donates 0.5% of the purchase price to OUCH (UK), at no  
cost to you. Every little bit helps us to fund our services.

So far we've raised almost £250 through AmazonSmile. It's  
very quick to register, so please consider signing up today.  
Then just remember to start your shop at:

[smile.amazon.co.uk](http://smile.amazon.co.uk)  
to donate to OUCH (UK) for free.

Note: To use AmazonSmile on your iPhone app, join  
AmazonSmile, then open "Settings" within the app, tap  
"AmazonSmile" and tap "Turn on AmazonSmile".

## Mr GEEZ Artistic Project . . .

When the Beast knocks is an artistic project by Mister Geez about his periodic Cluster Headache condition.

Cluster headache (aka the Beast) is a condition characterised by recurrent attacks (20 to 240 minutes) of excruciating unilateral periorbital pain. Headache or migraine is a bit of a misnomer for one of the worst pain known to human beings.

Born out of frustration and despair, this project is a way to expose the Beast by raising more awareness and understanding.

The artist decided to track the Beast in two cycles or “bouts” (2018 and 2021) by recording audio notes after each attack.

Datasets were created from the audio logs with informations such as attack duration, intensity, location and personal feelings.

Data visualisations of each cycle were programmatically created from the datasets to gather insights about the attacks patterns.

Photographs of Mister Geez re-enacting attacks while playing the audio logs were shot in studio settings.

Some of the artwork has been hand printed with the cyanotype alternative process for those beautiful blues contrasting with the harshness of the theme.



These are just a sample of the images from the project, the full project will be on display at the OUCH(UK) Conference in London this September.

## New dedicated procedure clinic available for TAC sufferers

The National Migraine Centre is a charity set up for people who are struggling with migraine and other headaches. Despite our name, we are very happy to see people with Cluster Headache and all our specialist headache doctors are trained in managing this excruciating Primary headache disorder. If we know someone is suspected or confirmed to have Cluster Headache, we do our best to fast-track them to be seen as soon as possible.

Part of the management may include administration of Greater Occipital nerve (GON) blocks. We have recently been able to offer procedures at our regular weekly clinics. We offer this at our clinics in north west and south west London.

GON block is an injection of local anaesthetic and steroid around the greater occipital nerve, at the back of the head, designed to reduce the inflammation of tissue and relieve cluster headache attacks. These may ease in frequency or severity or they may stop altogether especially if given early in a bout. Although the injection takes place at the back of the head, an effective treatment will reduce pain at the front of the head too, such as occurs during cluster headache.

### The procedure

The injection is 2ml of mixed local anaesthetic and steroid given at the injection site just behind the ear. It can be given while you are sitting in a chair or lying down. It takes a couple of minutes.

Following the injection

There is often a sensation of numbness in the head, part of the neck or shoulder.

There can be a little bleeding at the site of the injection. It is best to have someone accompanying you for the first injection but usually there is no reason not to carry on with your daily activities as normal.

### What side effects might I get?

It is common to experience a lump at the injection site with an accompanying ‘bruised’ sensation for a few days. Sometimes a small patch of skin depression or hair-loss at the site of injection occurs. In theory, infection of the injection site could occur, although this is rare.

Also rarely, patients can faint, particularly if injection phobic.

Generally, the injection is well tolerated and can be a good choice for people with episodic Cluster headache. It is also safe in pregnancy.

There is a charge for the procedure - **we charge half our usual rate for patients with Cluster headache.**

You can book an appointment today by visiting our website

[www.nationalmigrainecentre.org.uk](http://www.nationalmigrainecentre.org.uk)

*Note: a GPs referral is not required for an appointment at the NMC.*





## 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!**

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In the past, OUCH and its fundraisers used Virgin Money Giving to promote fundraising events and to receive donations. However, this service ended in November 2021.

You can now 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 in a similar way to Virgin Money Giving.

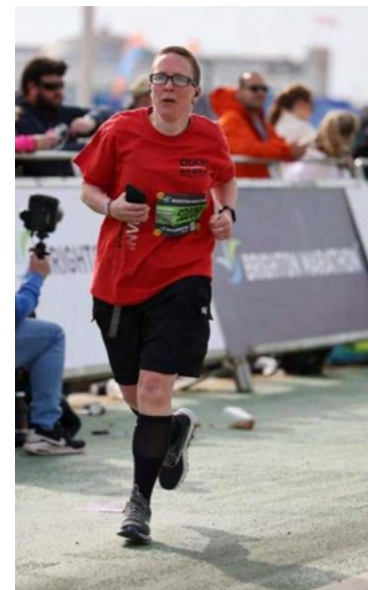
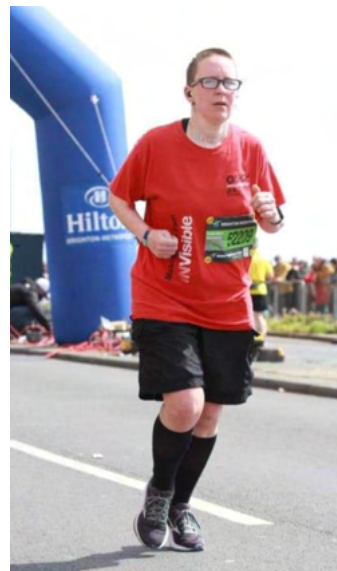
Contact: [info@ouchuk.org](mailto:info@ouchuk.org) to get your link and fundraising pack.

Thank you!

## Tracy Wakefield Brighton Marathon - April 2022

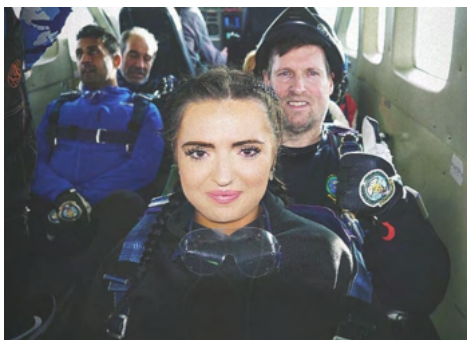
Tracy ran yet another marathon for us in April, in a time of 6.18.4, a new personal best - beating her previous best by 26 mins and 20 secs and even though just a week after saying she was definitely not doing a marathon next year - she's now looking at two in 2023! I wonder how many pairs of trainers have gone into Tracy's brilliant fundraising/awareness raising efforts so far...

What a champion.  
Thanks again Tracy  
from all of us!



### Layla Norris Skydive 11<sup>th</sup> February 2022

Hi everyone, my name is Layla I am 29 years old and in 2017 my whole world was turned upside down by a diagnosis of cluster headaches. What does that mean? I have to explain this to everyone as most people have never heard of them, but basically, it is the most severe pain known to man, in the head. They come in clusters hence the name and are extremely difficult to live with and each sufferer suffers differently. Personally, I have between 2-8 attacks a day, lasting between 15 minutes to 3 hours. Most of mine happen between 9 pm-4 am currently but I can have the odd attack in the day. I use oxygen and sumatriptan injections to help me with the attacks after trying numerous medications and nerve blocks that don't appear to have worked. My life really did change. I didn't want to leave the house, I didn't want to socialise, I didn't want to do anything because as well as the physical pain these awful attacks obviously bring, it's the mental distress they bring that I struggled with. After coming to terms with my diagnosis I found OUCH via my neurologist. OUCH (UK) has honestly been a lifesaver to me, they have built a community of sufferers that means we can talk to each other, discuss treatments we've had, support each other on days that aren't brilliant which is why I completed my skydive. I wanted to raise awareness and money for a charity that has been by my side and helped. This is an illness that none of my friends or family had heard of and I hadn't until I was diagnosed. It was a relief to talk to people that understood.



I chose to skydive because I am petrified of heights, I thought if I can get through the days of having attacks, there isn't anything I can't do so set myself the challenge. It was the best day of my life, I jumped from a plane! Not only had awareness been raised, but money for the charity was also raised, and proved that I could do what I thought was impossible with the help of my friends, family, the whole OUCH community, and my wonderful partner who supports me daily.

I will continue to campaign to raise awareness, I will continue to raise money for OUCH and I will continue to keep hope that one day there will be a cure for this awful illness. I plan to complete the 3 peaks challenge late this year or early next

(depending on attacks) and will come up with other ideas to keep the word out there and raise vital funds.

I would like to thank everyone who kindly donated to OUCH UK, and everyone that supported me on the day. Newacott.com for donating and advertising tirelessly, and the staff at Netheravon airfield.

I guess this illness has taken away a lot from my life, but it also taught me that we don't know how strong we are, until being strong is our only option, I hope everyone's days are as pain-free as possible.

Layla

### Carol's Fundraising Plant Sale



My son has suffered from cluster headaches for several years & OUCH has been an invaluable source of advice & support to both him & me. As a small gesture of thanks, I try to arrange at least one fundraising event each year in aid of OUCH.

This year I asked members of a U3A gardening group in Stockport (that I run) if they would be willing to propagate plants during the year to create a collection to sell for OUCH. We all propagated plants using different techniques - hardwood cuttings, softwood cuttings & seed germination - to produce 120 different plants for the plant sale.

We were provided with a free stall at the local picnic in the park Queen's platinum jubilee event. We had a really enjoyable day & sold over a hundred plants. All the proceeds which totalled £225 (not inc gift aid extra) have been donated to OUCH.

Carol Wilson

**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**

**\*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). For Terms & Conditions, see [easydonate.org](http://easydonate.org)**