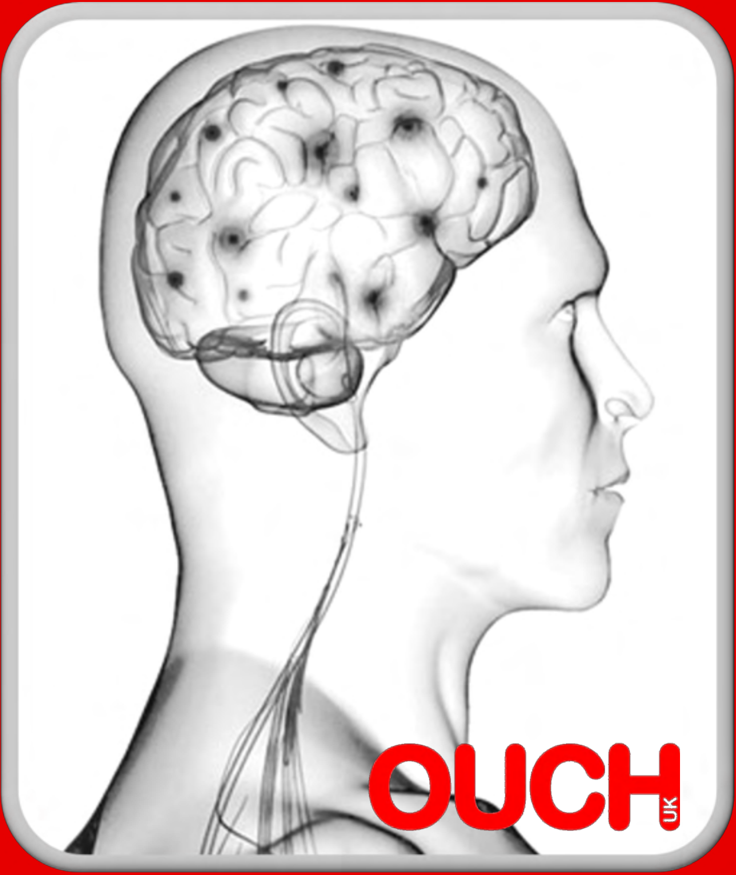
CHit CHat

The Official Newsletter of OUCH (UK)

The Organisation for the Understanding of Cluster Headache



AUTUMN 2021

20th Anniversary Edition

2001 - 2021

WWW.OUCHUK.ORG

MAKING OUR PAIN INVISIBLE

A SPECIAL YEAR for OUCH (UK) - 20th Anniversary

This year we are celebrating the 20th Anniversary of the formation of OUCH (UK). Here follows a brief summary of the key stepping stones - a full history can be found on the OUCH (UK) website.

An inaugural meeting was held in Rugby in 2001 and the Charity formed with a board of six trustees, in 2002 OUCH (UK) obtained charity status.

With funds hard to come by personal donations were most appreciated. One of our single biggest fundraising events has been participation by an ever growing team of runners in the London 10k. Inaugurated in 2003 by Victoria Fairchild a team or runners raised £3,000. The following year organisation of Team OUCH was taken on by Karen Charlton – her father Les was an episodic sufferer and a trustee. The event went from strength to strength every year and in 2013 – our final year of participation in the 10k – the team ran in Les' memory and the final total was in excess of £15,000.

Also in 2002 Susi Nericci - a founding trustee - inaugurated the OUCH helpline, at that time fielding about four or five calls a month, the first national conference was also held in this year.

In 2004 OUCH was given a grant by British Telecom to finance a mail shot to 45,000 GPs in the UK with details of recognising, diagnosing and treating cluster headache.

By 2005 OUCH's helpline was dealing with anything from 20 to 60 calls a month. We set up a training scheme for volunteers and it continues currently in that form today.

In 2006 the new Home Oxygen Therapy scheme came into effect and cluster headache was specifically mentioned in the specification for the scheme.

2007 was a landmark year when one of our members, a human resources specialist, discovered Employment Tribunal case law – Hood v London Casinos Management, 2002, which stated cluster headache was a disability. The news aided many members in funding and benefits applications.

2008 saw OUCH at the House of Commons with Headache UK, when one of our members spoke on her life as a CH sufferer and Professor Goadsby appealed to Parliament to improve funding for training doctors so that the neurology training covers a much wider base and headaches in particular. He also urged the Members of Parliament present to support funding for research on headache conditions, treatment and diagnosis.

2009 saw a step change in member meetings, when the Trustees decided to adopt a programme of regional meetings.

2011 was a sad year for OUCH, when our then chairman, Les Charlton, passed away. It was agreed that the OUCH Achievement Award would be known as the Les Charlton award for services to headache sufferers. Mike Pollock took over as chairman and in that same year, on a trip to the USA, he discovered that using ultra-high flow [demand valve] oxygen, the attack time was significantly reduced. Mike became passionate about making this available to all CH sufferers.

2013 saw successful and well attended meetings in York - the first in the Yorkshire area - and London. This year also saw the appointment of 4 additional trustees.

2014 brought a meeting in Shrewsbury, attracting members from Wales, the north-west and border country. Also in that year Mike Pollock presented a paper to the All Party Parliamentary Group on Headache Disorders on the demand valve and identified a cost saving of £2.5 million to the NHS if all CH sufferers had demand valves supplied.

2015 was a sad year for OUCH when our much loved and respected then chairman, Mike Pollock, died of cancer after a long battle bravely fought. Mike had been a member since 2002 and in 2004 he became a trustee and also a helpline volunteer. He was treasurer between 2006 and 2011 and became chairman in 2011. Mike is remembered through the Mike Pollock award presented annually. This year, Liverpool Institute of Medicine was the venue for a regional meeting.

2016 saw the first meeting in the north of Scotland, at Aberdeen and was well attended.

2017, May 5 and 6 of that year during Headache awareness week, BBC breakfast featured a trustee of OUCH talking about their experiences as a CH sufferer. A busy and eventful year also saw the first meeting at the historic and world famous St Bartholomew's Hospital, known to all as Barts. It was a sell out attendance.

2018 - our first meeting in the North East took place at the Royal Victoria Infirmary in Newcastle and was again a sell out event with top line speakers from the medical world and presentations from sufferers.

2019 - a summer meeting St Thomas' was the start point of OUCH's online shop which has been very successful.

2020 - with the onset of Covid it became the year "all about oxygen".

2021 - we are all looking towards a brighter future.

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.

Gary White (Advice Line)
Has suffered cluster head pains for longer than he cares to remember.
I chose to become a volunteer and help other cluster sufferers because I found the advice very helpful from my own call to the advice line. I really like the continuous improvement applied and the team team meetings, when work doesn't get in the way of attending.
I work as part of a team implementing technology projects and like to spend my time away from work fishing – or rather, watching fish take my bait and not my hook.

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.

Lundbeck Foundation annual Brain Prize

The Trustees of OUCH (UK) are pleased and proud to tell you all that our patron and chairman, Professor Peter Goadsby is one of four recipients of the prestigious Lundbeck Foundation annual Brain Prize for his work with Professor Lars Edvinson, Professor Michael Moskowitz and Professor Jes Olesen with regard to finding the mechanism of migraine, which led to the development of a new treatment for the condition.

The Lundbeck Prize is awarded for those researching diseases of the central nervous system and specifically to those who continue to work in the neuroscience research field and who have made an outstanding contribution to the study of diseases of the central nervous system. Professor Goadsby and his esteemed colleagues will receive their award in October in Copenhagen from the Crown Prince of Denmark and the chairman of the Foundation.

Conversations between cluster headache sufferers in one of Professor Goadsby's clinics in London led to the formation of the charity OUCH (UK) and he became its patron in 2002. His continued research work at UCSF, the Royal Free Hospital and at Kings College gives hope to many sufferers of what is sadly nicknamed 'suicide headache'.

We send Professor Goadsby and his colleagues our warmest congratulations.

OUCH (UK) Financial Report 2020/2021

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 year 2020/21:

- This year, direct charitable donations through our website and fundraising accounted for a little over 50% of our income.
- Around 25% of income came through more indirect sources such as Amazon Smile and Paypal Giving, where people registered OUCH (UK) as their preferred charity to receive a donation.
- 25% of income came from membership fees - this has been a steady and regular source of income which we can rely on for planning purposes.

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:

- 50% of outgoings were used to fund OUCH's all important website and Advice Line: in this pandemic year, it also included spending on new technology such as Zoom and related equipment to enable online meetings to happen now and on into the future.
- 25% of outgoings went on essential banking fees, insurance, professional services such as auditing and accountancy, subscriptions, along with an assortment of printing, stationery, postage and freight charges, shop items and staff expenses.
- The remaining 25% included payments for services rendered to CH sufferers by charitable organisations such as The Brain Charity.

CLUSTERS WORD SEARCH

A	H	U	R	A	N	U	S	C	R	N	C	S	E
B	E	P	I	S	O	D	I	C	O	A	U	S	X
O	E	V	L	A	V	D	N	A	M	E	D	N	C
R	E	L	A	R	E	T	A	L	I	N	U	A	R
T	G	N	T	E	H	C	A	D	A	E	H	T	U
I	P	E	T	O	S	B	E	A	S	T	A	P	C
V	A	U	A	X	E	O	U	N	R	T	I	I	I
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E	A	O	K	G	R	A	C	C	H	O	E	T	T
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L	N	G	D	S	G	N	T	T	E	I	A	Y	G
L	U	Y	E	C	I	U	E	Y	E	P	A	I	N
N	S	O	R	C	A	A	S	S	R	N	I	L	I

AUTONOMIC - OUCH - UNILATERAL

EXCRUCIATING - ABORTIVE - ATTACKS

NEUROLOGY - EYE PAIN - SUNA

SUNCT - HEADACHE - OXYGEN

BEAST - DEMAND VALVE - TRIPTANS

EPISODIC - SEARING - CHRONIC

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 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

At the beginning of September 2021, there were 776 current members of OUCH, who self-reported as follows (with some gaps in responses):

1.	**Members**	
	Sufferers	694
	Supporters of sufferers	82
	Making a total	776
2.	**Type of headache**	
	Episodic CH	238
	Chronic CH	191
	Paroxysmal Hemicrania	4
	Hemicrania Continua	5
	SUNCT / SUNA	1
	Migraine	5

We would like to thank all our members, donors and fundraisers for their vital support in keeping us afloat.

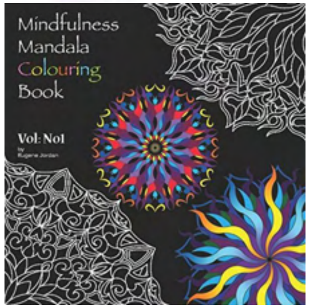
" Have you ever thought of using your own experience with CH in helping others?

If so we are always looking for Advice Line Volunteers, full training will be given, so please email:

adviceline@ouchuk.org

for more details"

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

Christmas Cards 2021 - Help support your Charity

Our beautiful Christmas cards are a great way to raise awareness. "This year our Christmas card designs have been drawn and kindly donated to OUCH by Jamie Charteris, a fellow CH sufferer. Thank you Jamie!"

They are available from our OUCH (UK) ONLINE SHOP

www.ouchuk.org/product/christmas-cards-2021


Christmas Eve


Christmas Lights

Available in packs of 10 cards, 5 of each design.

Price £5.00

The greeting inside reads MERRY CHRISTMAS, with the OUCH (UK) logo on the back.

We still have a few 2020 and 2019 cards at a reduced price £3.00 per pack of 10.

OXYGEN AND COVID - Valerie Hobbs, Trustee

Before we touch on the pandemic, I think it's worthwhile to relate the history of oxygen therapy in OUCH.

Speaking as a lifelong sufferer who became chronic in middle age, discovering from OUCH the benefits of oxygen was one of the best things that happened in my CH life. That was 19 years ago! At that time the only NHS oxygen available was a low flow cylinder 2 – 4 litres a minute. When I joined, OUCH had a high flow regulator loan scheme, run by our own 007 [his membership number] Curt Eijvergard and I tried it and it worked for my attacks and bought my own regulator.

In 2003, OUCH mounted a campaign to get members to write to their MPs and ask them to approach the NHS to adopt high flow oxygen therapy as standard for cluster headache sufferers. We were successful. The masks at that time were okay, but only delivered about 26% oxygen – we need as near 100% oxygen as possible. One of our members discovered that if we used a non-rebreather mask – like those paramedics use on portable oxygen cylinders – we got near 100% oxygen. To me, the non-rebreather mask meant that I could abort an attack within about 20 minutes – half the time it took with the NHS standard mask. And this turned out to be the case with other oxygen users. With help from the oxygen companies and a change to the home oxygen order forms [HOOF] the non-rebreather masks became standard kit for CHers.

Then in 2009, our late chairman, Mike Pollock, on a trip to the USA discovered that using an ultra-high flow [demand valve] oxygen the attack time was reduced to 8 to 10 minutes. OUCH did an anecdotal comparison study comparing demand valve oxygen with standard high flow oxygen. The actual demand valve mouthpiece will be familiar to those who have had entinox pain relief, particularly ladies who have children! The oxygen is only released when the patient inhales and it is then shut off when the patient exhales – it's not blasting out all the time as with high flow oxygen. Because it works in this way it is very safe to use – it's not being absorbed into skin or clothing, or leaking out round the edge of a face mask. The flow rate is governed by the patients inhalation, but you are getting 100% oxygen. And because the oxygen doesn't blast out 100% of the time, it is very economical to use. In 2014 Mike Pollock presented a paper to the All Party Parliamentary Group on Headache Disorders on demand valve and identified a cost saving of £2.5 million to the NHS if all CH patients had demand valve.

Demand valve is available throughout most of England and Wales, if you are unable to get demand valve contact the Advice Line for guidance, or val@ouchuk.org. OUCH is working to ensure this treatment becomes available throughout the UK, but this takes time and the pandemic has not helped.

Back in December 2019 we began to hear of the first cases of Covid 19 in China and its gradual spread over the world. By March 2020 we were under lockdown and struggling to buy toilet rolls and PPE! Then for the CH world there came a further supply problem – oxygen cylinders. One of our members was contacted by their local respiratory nurse to say that they needed to arrange a time with them for the oxygen company to collect their cylinders as they needed them to supply the Covid hospitals springing up in the UK. The member asked could they keep the cylinder they were currently using, and just surrender their spare cylinder/s, but was told by the nurse, no, the covid patients need it more than you do, after all it's just a headache. The shocked member contacted OUCH and asked did they know about this surrender of oxygen cylinders from CHers. Shortly after this call, another member in the same region contacted OUCH with a similar problem. OUCH contacted the four oxygen supply companies in the UK and they assured us that there was not shortage of oxygen cylinders, but they did ask if it were possible to do so for oxygen users to surrender their spare cylinders and order a replacement for the one they kept when it was getting low, not when it was completely empty. They also gave us a key piece of information that the respiratory nurse had not mentioned – the surrender of oxygen cylinders was voluntary and not compulsory. The concerned member spoke to the respiratory nurse again who said yes, they could keep their existing cylinder and only surrender the spare cylinder if they wished. The member said they would surrender their spare, as long as there was a speedy supply when a replacement for the existing cylinder was ordered. We wrote to all our members and put announcements on our website and on our Friends facebook group to ask that if possible spare cylinders be surrendered, but that it was entirely voluntary to do so.

Further discussion with the oxygen companies told us that if the patient was using oxygen in a hospital setting, the cylinder oxygen would be of no use. Hospital oxygen is in the enormous containers you see at the back of hospitals and is supplied through connections at the patient's bedside. The only possible use in Covid for cylinder oxygen might have been if the patient was at home and needed back up oxygen, but high flow oxygen and demand valve oxygen would not have been prescribed for recovering Covid patients, it would have been low flow or via concentrator.

We have had contact from two or three members who have had Covid, at least one has had it very badly and left the patient with Guillan Barre syndrome – a rare neurological condition. The patient concerned was on a ventilator for some time and at first was unable to walk. They are much better now, but they have long covid as well as the Guillan Barre syndrome. We wish them well as soon as possible.

cont'd . .

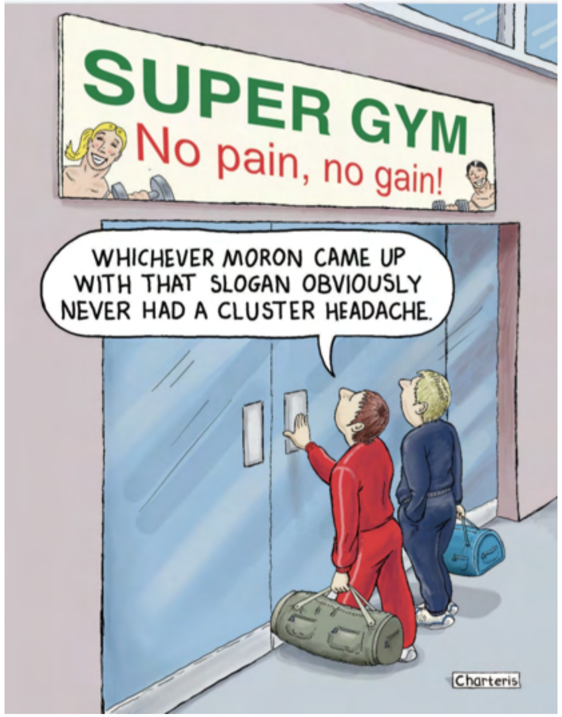
OXYGEN AND COVID - Valerie Hobbs - cont'd

On the demand valve front, please let us know if you are having difficulty accessing this treatment. We are working on getting demand valve oxygen as standard for CH sufferers and we need to know what problems you are experiencing. Please either call the Advice Line, or e-mail val@ouchuk.org

If you want to know more about demand valve oxygen, please read the documents in the downloads section of the OUCH website.


Demand valve


Non-rebreather mask



Oscar's incredible story

Hello everyone, my name is Oscar and I was diagnosed with episodic CH in June 2020. It felt like awful timing as it was in the middle of my A levels. But of course there is no such thing as a good time for a CH episode.

I was forced to take some time off school for various periods throughout the year and found that certain medications made it hard for me to work or concentrate. However, I found that in between attacks, painting was a perfect way to direct my energy and time. With my favoured subject of painting being portraiture I decided to see if I could portray something close to the feeling of CH in a painting. Obviously it is difficult to convey the extremity of the piercing pain felt during an attack but I decided to give it a go.

I represented the stabbing feeling through the tortured and contorted flesh and the stress and restlessness of the rest of the body through the rigid and tensed limbs. The bright colours of the skin were chosen to emphasise the heat and the flush felt during an attack.

Whereas in sharp contrast the surrounding background has a lack of detail and just one colour. This hazy background highlights the sense of isolation during an attack. It conveys the feeling of everything else merging into a blur as the pain takes the spotlight, almost as though you are underwater.

I find painting to be a really good way of dealing with my CH and highly recommend taking up a form of art as it can be very therapeutic.

If you would like to see more of my artwork, you can see them at:
https://tinyurl.com/3t6hz8b8

I have been a supporter of our daughter Emma for 21 years. Emma started the first symptoms of chronic cluster headaches at 13 yrs of age. Whilst pregnant with their daughter Issy, Emma stopped her medication and has been mainly pain free, that was 5 yrs ago.
Before OUCH was formed to offer us support and guidance, information was like gold dust, user groups here and in the USA helped with advice and medication suggestions.
So what can we, as parents or partners do to support our loved ones who suffer from this most debilitating condition?
Be kind, quiet and strong, be positive, all easy words to type, but not always easy to do.
Also supporting a sufferer can be all consuming on the bad days and nights. This is how Emma and I coped.
I am still on Emma's NHS notes as being able to speak for her, very useful when she was rolling from one attack to another.
Research, that took many hours before OUCH was formed, but knowledge and keeping calm are good weapons of choice when dealing with difficult medics. I got the local newspaper involved looking for other CH sufferers.
You could video an attack, with your loved one's permission, to show a doubting GP/Consultant, hard to watch, harder for them to let you watch, film and show. They want to shield you from their private pain. We used the KIP scale, that way I ask "what number", Emma told me, I knew if she was 'coming down', usually up until that point I sat with her, holding her hand, getting ice packs, switching oxygen tanks, or if at school hanging on the phone, (on speaker as I was working) she knew I was there, quiet, but there. The relief when KIP started to drop down.
Her friends understood fairly well, we turned our dining room into her sitting room, had mass sleepovers. For her 15th birthday I was sending her and friends out to the local pizza place 3 min walk, never made it CH wouldn't lift , on/off oxygen to keep it quiet, so the pizzas were delivered and everyone tried the oxygen.
Print off oxygen guidelines for CH and take to A&E, or paramedics, a very useful tool which Emma has used at a very busy A&E, it was her confidence and calm assertiveness that all she needed was a bottle of oxygen, correct mask and flow, and a chair in the corner.
Emma rarely let CH rule her life. When her medication was working she was having a good time. Celebrating her 19th Birthday party at Walkabout, when it was really her 18th .... she has a few more stories like that. At one Poole OUCH meeting there was a poll on who was unaffected by alcohol, up shot her hand, that caused a few laughs, she was 16 and a waitress at weekends with a bottle of oxygen in the bosses office to keep her going, and at college in the week, with a bottle of oxygen in the tutors car …. so these good fun times, were there from time to time.

Its hard to let a child grow up, take charge of their medication, their decisions on how much pain they can cope with to lead the life they want to lead. I never said "no you can't because you may get a headache" even if I felt like it, Emma decided, it's her pain. As parents and partners we support their choices, if possible with a back up plan. I carried the oxygen cylinders to hockey games, point to point races, theatres and we've even driven 3AF cylinders to Austria (to see the snow, we live in a snowless area) and France to see Disney.
Emma has travelled world wide, during pain free periods, although coming back from Ghana she was out of nasal sprays, and the Verapamil had stopped working.
CH makes strong people, they have to be strong to get up each day and carry on. As a supporter my aim is to help Emma carry on getting up in the mornings, fight her battles when she can't and hold her coat for her when she can!!

Emma's husband is now the one who gets the 'frozen peas', digs through the bedside drawer for that last nasal spray and carries the oxygen tanks upstairs, also, more importantly holds her hand.

LES CHARLTON AWARD 2020

Jane Arm (Whitz) was chosen by the Board to receive our Les Charlton Award 2020.

Jane has been a chronic migraine and cluster headache sufferer for decades and has come such a long way in recent years. Jane used to be scared to leave the house for fear of an attack and disliked travel for the same reason, which caused her great anxiety. Things changed after a few fellow sufferers coaxed her to an OUCH conference in London. There was no stopping her after that! She grew in confidence and started to travel which ultimately led to her and our own OUCH Trustee, Linda Duddy, walking the West Highland Way. Jane had been very poorly leading up to the walk but as she was fundraising for OUCH, she refused to quit and successfully completed the walk to the tune of 104 miles, raising £2000 in the process.

Linda and Jane had become great friends and so it was fitting that Linda had the pleasure of telling Jane the news that she was to receive the award. Linda said Jane was thrilled and stunned at the same time on hearing this. Sadly, Linda was unable to present her with the award personally, as planned, because of restrictions but Jane sent us her photo with the award after it was delivered.

It's fair to mention here that Linda was also an absolute star - but as a Trustee, she isn't permitted an award, just our heartfelt thanks and appreciation.

Well done to both girls for a superb event.

MIKE POLLOCK AWARD 2020

Last year, the Board of Trustees chose Corin Ridout to receive this award.

In the past, Corin has raised lots of funds and awareness for us on behalf of his brother Glen, a cluster headache sufferer. These events included the London Marathon, Ride London and Swim Serpentine. Sadly, Glen passed away not long before last year's virtual London Marathon but Corin was determined to carry on in Glen's memory. We felt that this was a wonderful example of going the extra mile that we've always associated with the Mike Pollock award and that he was a very deserving recipient.

Heartfelt thanks to you, Corin, to your family for the continuing support of the charity and to everyone who made such generous donations to this event. We would also like to extend many thanks to Corin's employers, BUPA Care Home Oak Lodge, for their support once again with their match funding of £250, boosting the amount raised in Glen's memory to an amazing £1670 for OUCH

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!

AMAZON SMILE

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

amazonsmile
You shop. Amazon gives.

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.

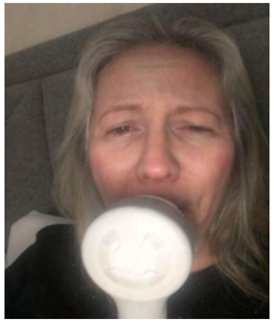
So far we've raised almost £250 through AmazonSmile. It's very quick to register, so please consider signing up today. Then just remember to start your shop at:

smile.amazon.co.uk

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".

My Experience with the ONSI (Occipital Nerve Stimulation Implant) by Clare Tucker



Before being offered the ONSI operation I had suffered with refractory chronic cluster headaches for 6 years. I had tried every preventative medication available and invasive procedures such as the SPG. I relied on three monthly multi cranial nerve blocks, which was a huge round day trip every time we went and gave me limited periods of pain relief and of course oxygen and sumatriptan injections.

I wouldn't go as far as saying that the ONSi is a cure for cluster headaches but I would say for me it has worked and I have got my life back.

Before having the operation I had finally accepted that I was chronic and I had learned to live with it and find the positives in my life and enjoy what pain free time I did get. So when I was offered the ONSi I took it.

Of course I felt trepidation because I know some people who having had the operation had experienced difficulties with it such as infections and it not working, there were of course photos to go with the posts, which almost put me off.

Luckily I have a friend for whom the operation was a success. I have never forgotten when she told me that it had given her her life back. Those words were my drive and the courage to go for it.

I think it would be a good idea to set up a questions and answers section in OUCH for anyone who has been offered the op and would like to find out more about the overall experience of it and the must have advice tips for after care.

There is a procedure to go through before being signed off as suitable for this procedure, one of which is a two week assessment with a psychiatrist. This is to find out whether you are able to deal with the emotional trauma of the operation not working.

It is made very clear that it isn't a cure and that sometimes it doesn't work or because the body rejects the battery as a foreign object.

The psychiatrist had a long talk with me and carried out an assessment. He confirmed that I was indeed a suitable person for the procedure and that he felt I didn't need any further sessions.

I was happy with that but in hindsight I wouldn't accept that again. I would strongly advise anyone going for the ONSi to have the full amount of pre operation support available as I don't think that I would have been prepared very well if it had failed. I strongly believe that having a full range of coping mechanisms and strategies would be needed if this were the case.

The team at St Thomas and Guys Hospital were absolutely brilliant and I can never thank them enough for what they have done for me but I have agreed to volunteer for new and exciting research into the cause of cluster headaches. I have given one lumbar punch pre op and will be going for another one soon. They are looking for changes in spinal fluid both before and after the procedure.

Happily I am 5 months post operation and have had zero cluster attacks. I can honestly say, like my friend before me, I have got my life back.

I have been on 2 staycations with my girlfriends. I have been away with my hubby and even started kayaking and to top that I have a new full time job.

I have been taking as many photographs as I can when I'm out and about enjoying myself. New memories are being made and I hope that more people are offered this opportunity.

Clare, 3rd from left, with her pals. Having fun again.

and now back at work

TONY ROCKS by Tony Barker

I have had SUNCT and CH since 2014. I had MVD (Microvascular Decompression) done in 2017 and DBS in 2018, and awaiting ONSI as well. I had to give up my amazing hobby of skydiving when it all started but now I really love to paint/draw when I am feeling ok. Sometimes it may take days or weeks to finish a project due to the unpredictable nature of the beast, but it's always worth it to see the end result and the happy recipient.

I have been painting pebbles for quite some time, probably about 5 years or so now. I started out doing them to hide out in public places for people to find, after finding a painted rock myself, and reading on the back the name of a rock group on Facebook. Anyway, when COVID and the first lock down became a thing, my days of going out hiding rocks were temporarily numbered. I didn't want to be potentially leaving rocks out with my 'germs' on them for others to pick up. However, I still carried on painting rocks now and then, and ended up with a big cupboard full of painted rocks! I put up some photos on the various rock groups I belong to on Facebook, and then started getting people actually request designs! For me, someone who was kicked out of art GCSE level at school because I was so terrible at it, this was a big boost for me! I often sit quietly and just paint one pebble for an hour or two, and I find it very calming, it really gives me a break from all the stresses of daily life and from my CH most of the time too. Anyway, here's a few of my most recent rocks… see if you can spot the one I've done for Darren with his 'Ouch-mobile' Land Rover.

This one is currently living in my mum and dad's lovely garden.

And this one too. These bigger ones took me about 2 weeks with all the layers to complete.

More of TONY'S Magnificent ROCKS

The Toy story ones were for a young lad who has autism. I didn't know him, but his mum contacted me after seeing my designs on Facebook and asked if I'd be able to do a Toy story themed one, and I enjoyed doing it so much I ended up doing 5!

My tribute to Prince Philip, The Duke of Edinburgh.

The ones I did for the learning difficulties primary school were these 'number rocks' and a few extras I did which I figured they could use at story time.

This Teletubbies slab was a birthday present for a family member's baby.

Darren's Land rover.

I have a Facebook page simply called 'Tony Rocks' in case anyone would like to make any requests or see any of my previous projects. It's not just rocks now ironically. I have also painted a couple of canvases and some drawings / paintings on paper for requests from people. Also, I never ask for any money for any of my work, but will gratefully receive any, if it is offered, just to buy new paints etc.

I think everyone will agree that Tony sure does rock!

Darren's Travels August 2019 by Darren Hamilton

We can't put a picture of Darren's landrover in Tony's article without some of Darren's travels to follow it.

At Darren's request, we're leaving all the spellings just as he wrote them because he very much wants to highlight dyslexia. Darren may be dyslexic but he is a wordsmith of the highest order. Long may this caring clusterhead keep on writing!

Darren travels the length and breadth of the UK to meet and support other sufferers. He's very well known in the CH community and everyone loves to read the Darren's-eye-view of his clustery world!

hi all, another cluster bus road trip, this ones a long one, aug the 6th saw me loading up with every thing i think id need, camping gear cooking stuff and dog stuff plus the 3large o2 and 4portable o2 just in case, suffering cronic cluster headaches we cant go any where with out our o2, and a whole load of suma injections of course, still after all my road trips nerves and fears of haveing attacks in public still bother me lot, and suffers so easyly become house bound loseing any past life thay onec had to relentless pain and fear, ive had thousands of attacks in my bedroon, liveing room ect, safe at home missing out on the world , so haveing passed my test buying the landy, kitting out to my needs and the hound, i still suffer as much but atleast i have attacks in the most beutiful places, and live my life my way, setting of from farnbrough to hull to start my trip, 250, and fish and chip with my mum, well i can go through yorkshire with out calling in, in the morning I called in on Geneva another ch suffer and a lovely lady, always good to catch up when im in hull, i follow the humber to easeington on through withernsea, hornsea, bridlington and scarbrough, but left my camra at my mums bugger, Whitby we went donw on the beach had a brew in the back of the landy and followed the coast up to sundrland where I called in to see Dorothy from ouch we had coffee in her garden boomer had big fuss, Dorothy has given so much to help others while suffering her self its nice to give her a hug from us all to say thank you, the afternoon sunshine and the open road calling we say fair wells, o and I found my camra in the fridge result, through Newcastle and called in on new bigging by the sea, because it sounded intresting and it was great beach boomer loved it, hes not seen the sea befor so had great time caseing the waves in the warn sun, back on the road north passed banbrough castle and on to holy island for the night, well so I planned, 10.30ish im all settled and the bloody car park monks in a pick up found me in the dunes and turffed me off again, im determined to stay a night there one day, so with the hump I head north along the coast following the a1 through Edinburgh over the forth bridge as the rain came down it was a soggy Scottish welcome, as it was gone midnight I was looking for some where to stop for the night got lost in perth, I should have given scott bruce a shout, will next time, I ended up on the old milerty road, through thick forest and a lay by to park up for the nigh, tiredness and eye strain took it toll by giving me an attack from hell, o2 suma and rest, in the morning I woke to a snack van parked next to me, well that's coffee an bacon sarnie sorted, carrying on stopping at braemar castle for a brew in the rain, over cock bridge just for fun, feeling exhausted and ruff from last night I find some where to rest sort my head, found a nice pickinc area, but was bedevilled by midges till I got the burner going, by tenish the rain stopped the wind dropped and all the stars came out, I wouldent want to be any where else at that moment, in the morning the midges got revenge when I took my spade to do what bears do in the woods to have all exposed flesh bitten shitless, ive never pooed so fast, back on the road on to Nairn where my son got marryed to his now lovely wife, I also found a load of fatwood in the hotel grounds, me and boomer stayed in a guest house where every one made big fuss of him, still heading north hugging the east coast through wick, to duncansby head and camped in john of groats for the night, a chance to try my new frame for the tarp, it worked well, I cut up that fatwood smelled lovely and fired up a treat, fire lit feet up clear calm night and relax, I just realised im the most northly cluster head in the uk, foned my mum to let her know how the trips going as I do, she loves traveling as much as I do, tomorrows a new adventure,

me and Dorothy, ouch admin, and a frend.

With Darren's permission I'm adding these lovely words he typed while we chatted on messenger. (Dorothy)

“Some times kind words count more than a mountain climbed,, and theres meny kind words given from all the chers to each other, im sure mike (Ref to the late Mike Pollock) would agree, just 2 words to save a life, "I care" smiles are free, x”.

OUR FANTASTIC FUNDRAISERS

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

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

Let's all look forward to better days ahead.

……

In the past, OUCH and its fundraisers have been using Virgin Money Giving to promote challenges and to receive donations. However, this service will be unavailable after the end of November - but OUCH has a new way for you to do this, directly through our website. Fundraisers will be able to create their Personal Campaign Page using a link we provide.

The fundraiser will be able to fill in the details of their fundraising activity including their info, story, fundraising target, optional progress thermometer, honour roll, text, images, etc. Once completed, it then needs to be approved by an OUCH admin before it becomes active. Supporters can then donate directly via this page in a similar way to Virgin Money Giving!

Contact: info@ouchuk.org to get your link and fundraising pack.

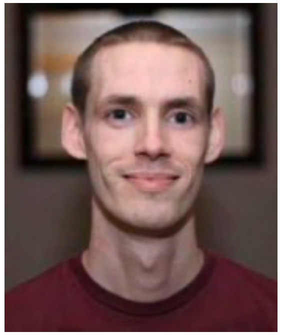
Thank you!

MORWENNA BERTH-JONES 10K BEDDINGTON PARK NOVEMBER 2020

Morwenna achieved her very first 10K run – well done and thank you!

MATT GOODRUM HEAD SHAVE. JANUARY 2021

This was a good one – Matt even provided a video of it! What a great sport. His mum, Karen Garrett, is a long-time CH sufferer with a very supportive family!



PAULINA STAGG GOING SOBER FOR OUCH (UK) MARCH 2021

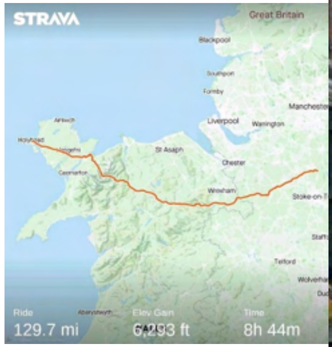
Paulina went sober for a month in March to raise funds, awareness and to show her support for husband Rob, a CH sufferer. Above and beyond Paulina!

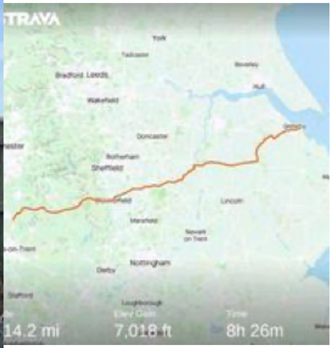
DARREN LAMB PETERBOROUGH MARATHON. MAY 2021

Thank you to Darren Lamb for enduring this marathon for us. Darren is a CH sufferer of 15 years, who completed this marathon in May. Well done, Darren! Another super supporter!

FRED AND WAYNE'S COAST TO COAST CHALLENGE - SUPPORTING OUCH (UK) AND BRITISH DIVERS MARINE LIFE RESCUE. JUNE 2021

Fred George and his friend Wayne cycled coast to coast in June to support two charities. Sadly, both Fred's wife and daughter are cluster headache sufferers. Wayne's charity helps stranded and injured marine life such as seals, dolphins and whales. We were all able to follow training and then each day of the challenge on Fred & Wayne's Epic C2C page on acebook. Two days, 244 miles and 13200 ft of climbing. Awesome - and they even had their own teeshirts made!





TOM O'RIORDAN – COTSWOLD WAY CHALLENGE JUNE 2021

Tom ran the Cotswold Way Trail – 53 Kms (33 miles) and 1630 metres (5347 feet) as his best friend, Simon, suffers from cluster headaches. Tom completed the run in just over 8 hours! He said the heat and the hills were energy zappers but he did it! Well done, Tom. Great job!

BRIAN CLARK - A MARATHON WITH A DIFFERENCE - IN AID OF OUCH (UK) AND THE SCOTTISH ASSOCIATION FOR MENTAL HEALTH. JULY 2021

Brian is trustee Jason's dad and has suffered with CH for more than 20 years. He completed a 20.2K marathon kayak from Portencross to Little Cumbrae South, up the west side over to Bute, back over to Little Cumbrae North, over to Millport, Cumbrae, back over to the West side of Little Cumbrae and back home to Portencross. This, with his paddle the previous day from Lunderston bay (17.5k) completed Brian's marathon with a difference. What an achievement from this cluster warrior.

OCTANAUTS SWIMMING TEAMS JULY – SEPTEMBER FUNDRAISING AND AWARENESS DRIVE

OCTANAUTS
SWIM SCHOOL

Elina Regan is a cluster headache sufferer and her son's swimming school, Octanauts Ltd, have been amazing in their support of Elina and understanding of her condition. Elina was delighted when they declared OUCH (UK) as their designated charity for the quarter, which continued up until the end of September. Thank you Octanauts and all involved! We loved the thought of the swimming teams raising funds for us. Some of them only teeny tiny ones. Wonderful.

JENNY AND IAN NICHOLLS' SPECTACULAR COFFEE MORNING! SEPTEMBER 2021

Here's Jenny's overview of the event:

My husband didn't know my Father without headaches. He didn't remember the carefree man that was enjoying the career of his choice, raising a young family and enjoying life before he was struck down at a young age with the burden of Cluster Headaches. Cluster headaches weren't known about when my Dad was diagnosed but it was something that eventually we all came to know about. Cluster Headaches were a shadow over my dad's life until he died, comparatively early, at the age of 70, when I believe he just gave up waiting for the next attack to come. He sadly lived his life just waiting for that to happen. I remember at his funeral thinking that at least he could sleep peacefully now without being woken by another attack. That was almost 5 years ago.

Cluster Headaches came back into our lives earlier this year when a good friend of ours lost his fight against Cluster Headaches. He had suffered all his life (certainly from being a young child) and, having reached retirement age should've been able to continue enjoying the years ahead of him, with his wife and their growing family. Tragically, it wasn't to be.

Over the last 10 years Ian and I have held an annual coffee morning. We held these initially for a large cancer support charity. We have always been astounded by the amount who arrive at our coffee mornings and have generously donated to this large charity, but we decided that it was time to spread the love to the smaller charities.

OUCH (UK) immediately came to mind. So, we tentatively put the date, 25th September in the diary, hoping for no more lockdowns or restrictions.   All week the weather was glorious, bright autumnal sunshine but, on Saturday morning - it was cloudy! Fortunately, the cloud meant it was comparatively warm weather and one by one, many of our good friends, business acquaintances and colleagues arrived and gave generously to OUCH (UK). Our coffee mornings have developed into a breakfast morning with Ian barbequing sausages and bacon followed by copious amounts of generously donated, tantalising cakes and the odd 'creation' by me (there's always the fear there won't be enough cake!). We sit and drink coffee, chew the cud, obviously (this year) moan about COVID, lockdowns and life in general but this year we also talked about the condition that we all know as Cluster Headaches. At one point I stood back and took in the fact that people were talking about the headaches my Dad had - I had seen that before. There were obviously the 'yes, I get migraines and have to lay down' conversations and the 'have you tried this and that' etc but we were armed with literature, freebies and information to put people on track, to help them really understand the concept of what the condition Cluster Headache can be about.

Ian and I are thrilled that we have managed to raise just over £1100 with some money still trickling in. Ian works for a large corporate mobile telephone company, and they will match our fundraising efforts to a maximum of £1000 so we are hopeful that we have been able to raise around £2000 for Ouch (UK).

I am so pleased that there are charities to support sufferers living with Cluster Headaches. My Dad knew about OUCH (UK) but was probably beyond helping by that point. Our good friend didn't know about OUCH (UK) and I wonder if his life might have been different had he known that there was support out there, that there are people living like he did, who understand the pain he was living through and most importantly who care. We have been proud to support Ouch (UK) and thank them for their support. We hope this donation is of use to them and that it might help them reach out to someone needing help.

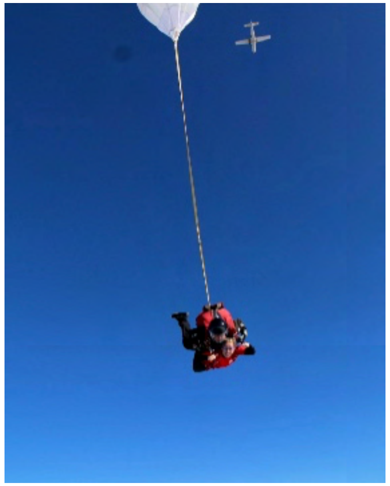
Jenny and Ian Nicholls.

THANK YOU Jenny, Ian and friends for choosing to support us this year – the funds will help us enormously.

CHLOE AND CLARE EVENS – SKY DIVE – 27TH AUGUST 2021

16 year old Chloe Evens and her mum, Clare, jumped out of a plane for the cause! Clare suffers from CH and wanted to raise awareness of the condition while raising funds for OUCH. She also wanted to show that the beast doesn't stop sufferers from doing amazing things and she certainly proved her point! What a fantastic display of awareness this was.

Love it!



BEN AND SALLY'S GREAT NORTH RUN - SEPTEMBER 2021

and BEN'S SPARTAN CHALLENGE - OCTOBER 2021

Ben Doyle and his mum, Sally, raised £386.25 from their Great North Run. The money raised is shared between OUCH (UK) and the Bobby Moore Fund, a very worthy cause. Sally has also made a very generous £100 personal donation to OUCH! Thank you so much for this, Ben and Sally!

Ben will also be running, wading, climbing and jumping through the 10k 25 Spartan obstacle course on 10th October - and leaping through fire at the end! WOW! Awesome!

TRACY WAKEFIELD GREAT NORTH RUN – SEPTEMBER 2021

Tracy never seems to tire of wearing out shoes for OUCH (UK). Yet another Great North Run completed by her in her quest to raise as much awareness as possible for the cause. Thank you once again, Tracy!

SARAH WHITE. VIRTUAL LONDON MARATHON. 3RD OCTOBER 2021

Sarah's story.

My story is common amongst sufferers, in fact many have waited much longer to receive help than I have.

I have been suffering for at least 17 years, I've missed birthdays and anniversaries, I've had countless days off work, I've had wisdom teeth removed, tried hundreds of different types of medications and been misdiagnosed so many times. I've been poked and prodded, had scans and hospital stays. And I'm not ashamed to admit that during attacks I've also felt that life isn't worth living, whilst struggling to cope with the pain.

During an episode in 2019 OUCH (UK) gave me the support and guidance I needed to get my diagnosis, they ensured I had enough information to provide my GP so I wouldn't get fobbed off again. I was finally given everything possible to help me survive my most recent episode episode (June/July this year) and I cannot explain how much difference this has made to my life.

I'm sharing my story to raise awareness (and money), to give hope to others that may be suffering.

There is a light at the end of the tunnel, don't give up.

Sarah has raised £437.95 so far. Well done, Sarah and many thanks to you!

FUNDRAISING 2020/2021

LISA'S BANCHORY BEAST CHALLENGE. 25th September 2021

By Lisa Munro

A bit like when you are not in cycle, you forget how grueling something can be.

Having done this challenge twice before, I had underestimated what was ahead of me. I had teamed up with my daughter Abbi (16), and my friend Scott who is in his 70's in order to raise some money and awareness for OUCH (UK).

Having not done any training for the event, we walked, chatted and laughed along the way whilst jumping over hay bales, climbing steep and rough terrain, wading through the most vile smelling bog, submerged in a loch and back into mud and clay again before going through the water for a final time. This was a huge test for us all, but we did it (very slow) – but WE DID IT!!

With an initial target of £500, I am delighted to announce that we have raised £1320.90 (£500 of which was an amazing contribution from a friend), and have been able to raise some awareness with my new work colleagues.

This will be a challenge that I will undertake again (but with training) next time!

WHAT A GREAT CHALLENGE AND WHAT A BATTERING YOU TOOK FOR US! WELL DONE TO YOU ALL AND MANY THANKS.
Hope the bruises are getting better!

FUNDRAISING 2020/2021 and beyond

So far in 2021 we've had some amazing fundraising events and more to come soon but we'll save the upcoming challenges for the next Chit Chat.

A massive thanks to every single brave and dedicated fundraiser and we can't thank the very generous donors enough. The charity couldn't survive without our fundraisers, member subscriptions and donations. We are very grateful to you all.

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

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

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

"Cartoons drawn and kindly donated to OUCH by Jamie Charteris, a fellow CH sufferer. Thank you Jamie!"

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

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The Organisation for the Understanding of Cluster Headaches
www.ouchuk.org

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