



**CLUSTER  
HEADACHE**  
**2025 CONFERENCE**  
**Sunday 8<sup>TH</sup> JUNE 2025**



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

**A Brief Overview**

**Professor Peter Goadsby, Patron and Chair of Trustees**

**Dale Nolan, Trustee and Treasurer**

# Our Objectives



**OUCH is the only  
UK charity  
focused on  
Cluster Headache  
and related  
conditions**

## **Objectives and Activities (From our Annual Report and the Charities Commission website)**

**The charity aims to benefit the public by its objects and activities namely by:**

- 1. relieving the distress of people suffering from cluster headaches particularly, but not exclusively, by
  - a. providing support and information for sufferers and their families**
  - b. liaising with the medical profession to improve diagnosis and treatment****
- 2. conducting and supporting research into cluster headaches and disseminating the results of such research for the public**

# OUCH<sup>UK</sup>

## IN NUMBERS



**65,000**

estimated Cluster Headache  
sufferers in the uk (1 in a 1,000)

**800**

**OUCH<sup>UK</sup>**  
members

**9,700**

 Followers of the  
OUCH Facebook  
forum

**>800k**

Views per year  
on the OUCH  
Facebook forum

**100**

Attendees at the  
annual conference

**350**

Calls to the Advice  
Line per year

**>500**

Referrals for CH  
sufferers to the  
National Migraine  
Centre per year

# What does OUCH do?



## Our Key Areas of Work

## How We Deliver

### Advice

- Advice Line
- Online materials and links

### Awareness & Education

- Informational / Educational leaflets, posters and papers
- Website and online materials
- Social media presence Facebook / X / YouTube
- Conferences

### Support & Community

- Website forum
- Facebook group
- Conferences

### Advocacy

- Participation in relevant bodies: NICE / NHS Trusts / Charity Groups / Parliament / Chief Scientific Officer's Oxygen Safety Group
- Working hand in hand with associated charities: British Association for the Study of Headache, National Migraine Centre, The Migraine Trust, The Brain Charity, The Brain and Spine Foundation

### Research

- Provide access to the OUCH community for research purposes
- Directly commission research
- Support research done by NHS and other organisations

# Current Initiatives



## The objective/problem we are trying to solve

### Oxygen Treatment Demand Valve Trial

- To provide definitive medical evidence that demand valves should be prescribed for CH oxygen treatment
  - Medics and sufferers believe demand valves are better than full-rebreather masks - quicker benefit, safer and cheaper
  - However, many health authorities still do not prescribe them due to “lack of evidence” (Dr Diana Wei)

### Making it easier to donate Brains for research

- Research on brain anatomy working with the Dutch Brain Bank (Isobel West)

### Analysing Problems with Physician Interactions

- Using the Help Line call information to understand issues in management (Dr Ravi)

### Analysing Cluster Headache during Travel

- Work to understand travel and the biology of cluster headache
- Compiling and analysing diary studies before, during and after travel

### Tracking your attacks with a Cluster Headache App

- Allows more efficient diagnosis
- Records the effectiveness of treatments
- Provides a database for ongoing research (Darshan Ramanagoudra )

### Discovering new treatments

- Partnering with Lundbeck (brain disease focused pharma company) to investigate chemical in the blood and saliva

### Extending advice line cover to weekends

- Recruiting more advice line volunteers to enable more coverage and quicker response time



YOUR CHARITY NEEDS  
**YOU**

*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.*

# CLUSTER HEADACHE 2025 CONFERENCE Sunday 8<sup>TH</sup> JUNE 2025



## HOW TO DONATE

Via our website:

<https://ouchuk.org/donate>



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](https://easydonate.org)