

# 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
  - 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

# COUCH IN NUMBERS





**65,000** 

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

800

**OUCH** members

9,700
Followers of the OUCH Facebook

>800k

Views per year on the OUCH Facebook forum

Attendees at the annual conference

350
Calls to the Advice
Line per year

forum

Referrals for CH sufferers to the National Migraine Centre per year

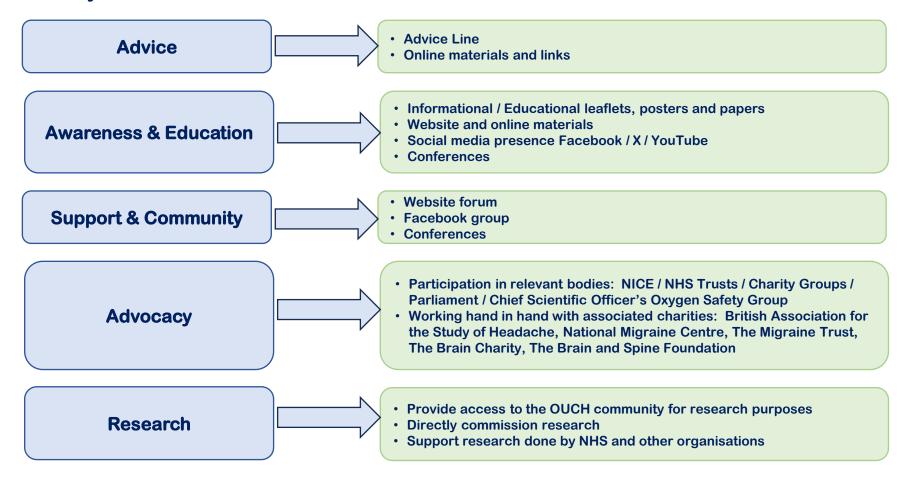
## What does OUCH do? ()UCH





#### **Our Key Areas of Work**

#### **How We Deliver**



### **Current Initiatives**

treatments

**Extending advice line** 

cover to weekends





#### The objective/problem we are trying to solve

· To provide definitive medical evidence that demand valves should be

Oxygen Treatment Demand Valve Trial	<ul> <li>Medics and sufferers believe demand valves are better than full-rebreather masks - quicker benefit, safer and cheaper</li> <li>However, many health authorities still do not prescribe them due to "lack of evidence" (Dr Diana Wei)</li> </ul>
Making it easier to donate Brains for research	Research on brain anatomy working with the Dutch Brian 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	<ul> <li>Work to understand travel and the biology of cluster headache</li> <li>Compiling and analysing diary studies before, during and after travel</li> </ul>
Tracking your attacks with a Cluster Headache App	<ul> <li>Allows more efficient diagnosis</li> <li>Records the effectiveness of treatments</li> <li>Provides a database for ongoing research (Darshan Ramanagoudra )</li> </ul>
Discovering new	 Partnering with Lundbeck (brain disease focused pharma company) to

quicker response time

investigate chemical in the blood and saliva

Recruiting more advice line volunteers to enable more coverage and



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.

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#### **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

<sup>\*</sup> 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 <a href="mailto:easympass-eas