



# **2023 Annual Review**

**Pain UK CIO, registered charity 1145561**



# Chair's Report / 1

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I will start by thanking all our members, both charities and individuals, who work to help people living in and with pain. I would like to thank all our donors who have financially helped Pain UK over the past year. We are a low-cost charity and these gifts of time and money go a long way and make our continued work possible.

By the end of our year in October 2022, we had 42 member charities. We also have over 1,300+ individuals who have joined Pain UK. There is more about our members on later slides. Pain UK answers emails from people living with from a wide range of problems associated with chronic pain. Since Pain UK cannot help individual patients, we direct such enquires to the appropriate charity member(s).

Pain UK continues to be a place where people who live with or are in pain can find others, and where they can be connected with the member charities. We are proud to support some of the most vulnerable people in the UK as well as champion the work done by our member charities.



## Chair's Report / 2

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Last year, Pain UK became a charitable incorporated association. Since then, the board has been creating all the necessary documents for the smooth running of the charity. Most important of these have been the strategy and policy documents for the new version of the charity. This involved an extra meeting of the board devoted just to this topic. We have set up a Clinical Advisory Board, led by our new trustee Dr Joel Brown who is a GP.

We have recruited more trustees to fill the places left by two trustees who had to resign. We had applications from many excellent people with lots of fantastic expertise.

We ran a training day on governance for representatives from our member charities and all the Pain UK trustees. Helen Harvey of H3 Solicitors gave comprehensive training to those attending on Zoom.

I have been kept busy with meeting, almost every week, the UKLEPP steering committee (see slide 3). Other meetings have been at the Office Independent Adjudicator for Higher Education:



## Chair's Report / 3

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We help adjudicators to understand pain and the needs of university students living in pain regarding such things as building access, time allowances for exams, help with IT equipment, furniture and much more.

This year, most meetings have been virtual, such as the quarterly meetings of the new Parliamentary Pain Campaign Group. I was able to attend, in person, a roundtable at Portcullis House hosted by one of our members- the Migraine Trust on the topic of migraines. The ABPI (Association of British Pharmaceutical Industry) held a patient organisations forum at their headquarters.

I would like to thank our volunteers and, of course, the other trustees of Pain UK. This is a charity that runs on nothing but goodwill and kindness and we have to be thankful that among our volunteers and trustees we have that in spades.

In particular, I thank Jessica Potts, who took over from me as chair at the end of this financial year (31<sup>st</sup> October 2022). During the year, Jess and I had many meetings and she shadowed me so that the handover went very smoothly.



# The UK Lived Experience of Pain Project

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Working over the last year and crossing into 2022, Pain UK started to fund a research project, funded in part by a generous unrestricted grant from industry: The UK Lived Experience of Pain Project (UKLEPP).

- Pain UK established an external steering group for this project, chaired by Fiona Hodson, President of Chronic Pain Australia and past President of The Australian Pain Society
- The researcher that Pain UK commissioned, Renée Blomkvist, has been funded to conduct a rigorous systematic literature review of all relevant studies regarding the lived experience of pain for people in the UK, and to create a survey based on the data from the review.
- The survey was circulated to our individual members, as well as the charity members for distribution to their members. The survey received over 1000 responses. This is the first stage and when Pain UK has the funding, we plan to commission further work, analysing the results of the survey and carrying out focus groups in each of the 4 nations of the UK.
- To continue this work, we need to raise £20,000 and there is a Crowdfunder running with an aim of raising some of this sum. The sum of £162 has been organically raised so far with no paid advertising/organised campaign.
- Pain UK aims to publish a paper in the British Journal of Pain, a respected peer-reviewed journal, as soon as the project is completed. We will then produce a report of the findings for government, employers and decision makers in health, social care, and housing to raise awareness around what it is truly like to live with long-term pain.



# Website Data Report /1

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The overall trend was up significantly (up 68.96%) in page views. Page exits were down 9%.

Whereas the amount of time spent on the site per session was broadly the same as last year.

The most popular pages were:

1. Hidradenitis Suppurativa Trust  
21,191 visitors (1,001 last year - up 2000%)
2. The home page  
17,429 visitors (13,829 last year - up 26%)
3. Fibromyalgia Action  
9,415 visitors (6,115 last year- up 54%)
4. Help and Support  
6,617 visitors (4,522 last year - up 46%)
5. Member Charities Page  
4,273 visitors (2,538 last year -up 68.3%)

Overall the members section had 70,825 page views 58% of all visits (up 85.3% on last year).

The most popular charity member pages were:

1. Hidradenitis Suppurativa  
(21,211 – 32% - up 2000%)
2. Fibromyalgia Action  
(9,461 – 14.3% - up 53.9%)
3. Endometriosis UK  
(2,531 – 3.8% - up 71.5%)
4. CRPS UK  
(2,451 – 3.8% - up 385.4%)
5. Herpes Viruses Association  
(2,393 – 3.6% - up 10.7%)

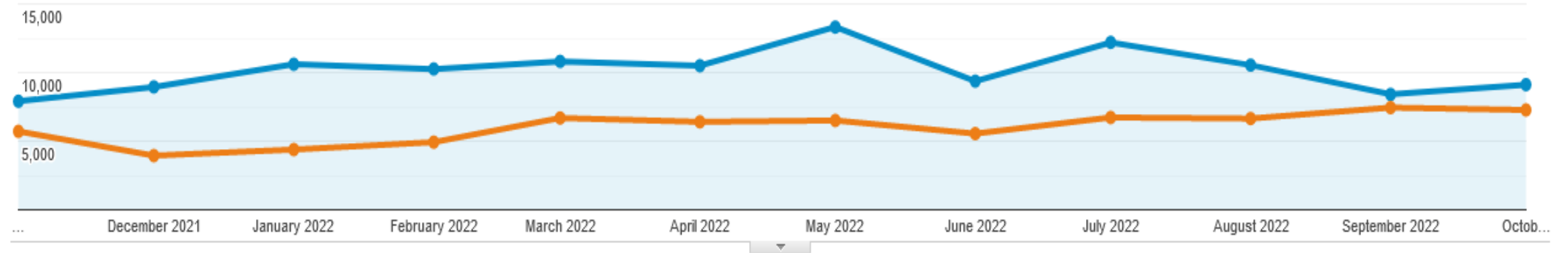
**We invite member charities to populate the FAQs page and send us information to add the Support Groups page listing these.**



# Website Data Report / 2

1 Nov 2021 - 31 Oct 2022: ● Page Views

1 Nov 2020 - 31 Oct 2021: ● Page Views



Page Views

68.96%

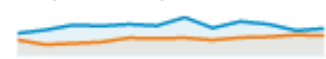
122,005 vs 72,211



Unique Page Views

77.10%

104,236 vs 58,858



Avg. Time on Page

0.75%

00:01:26 vs 00:01:25



Bounce Rate

5.84%

55.68% vs 52.61%



% Exit

9.00%

55.58% vs 50.99%





# Treasurer's Report /1

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The Financial Report for the accounting year end October 2022 was prepared with the support of Castle view accounting.

## **Income:**

Donations were received through Just Giving, Much Loved, Giving Comm Ltd, Amazon Smile, or individual donations. Pain UK ended the year with reserves of £16,946.

## **Outgoings:**

This year outgoings amounted to £6,946

A major expense in 2022, was contracting an experience researcher to continue work on for the 'UK lived experience of pain project'. The funds for this come from a grant given by Pfizer in 2020.

Another annual charge is for the upkeep of our website, which is maintained by an agency Doive Designs (<https://www.doivedesigns.co.uk/>) It ensures the website is kept up to date, which is of benefit to our member charities and to our target audience.

We pay a yearly indemnity insurance premium, membership of the Fundraising Regulator and a subscription to SurveyMonkey.





# Treasurer's Report /2

## Income in last two years:

	2022	2021
Donations	£5,488	£6,606

Pain UK ended the year with reserves of £16,946.

## Breakdown of expenses in last two years:

Year ending 31 <sup>st</sup> October:	2022 £	2021 £
Travel and subsistence		15
Accounts	600	450
Legal and professional	475	2428
Charitable activities	5700	-
Charity training	460	
Insurance		318
SurveyMonkey cost		408
Website maintenance	730	1019
Printing, postage, stationery		8
UKLEPP		7200
Bank charges	51	
Fundraising regulator subscription	50	
TOTAL	8166	11847



# Membership Report /1

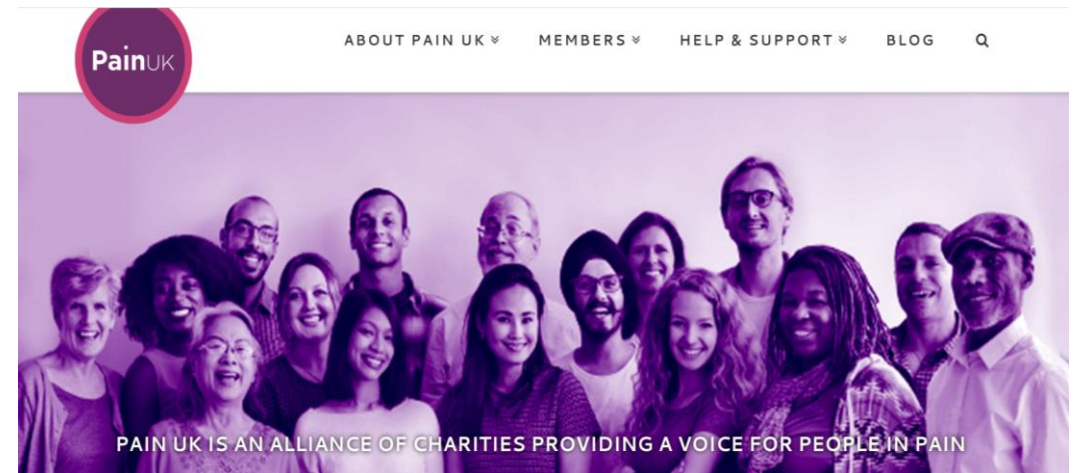
Membership rises year on year. We now have 42 charity members. Our website activity report shows that we are performing our function of signposting people with concerns about pain to the charities that can help them.

The four new charities this year are (listed in order of their joining):

- **The IBS Network**
- **Crohns and Colitis UK**

Both of these work for people with digestive and bowel problems which affect over 500,000 people in the UK. These charities are working to improve the lives of people suffering in silence due to the stigma and misunderstanding surrounding these diseases.

- **GUTS UK** is the charity for the digestive system from top to tail... all 25ft of it!
- **The Patients Association:** a patient charity campaigning for improvements in health and social care for patients. It works with patients directly to offer help and advice.





# Membership Report /2

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The trustees keep in touch with many different organisations, which together offer a wide range of services, and opportunities for charities and their members which are circulated.

We contact our individual members by MailChimp and via our Facebook pages. This year we made 115 posts on our two Facebook pages. Many of these are invitations from researchers, PhD students at universities, etc., for people to take part in studies. We do not post anything from profit-making organisation. These researchers have expressed their appreciation for this valuable way of recruiting subjects. Our followers enjoy getting their voices and opinions heard, judging by the number of 'engaged' comments that Facebook shows.

At the end of the year we had Facebook followers on these pages:

- Pain UK: 1400+ members
- Pain UK Public Group: 500+ members. which is almost double last year's figure.

We set up an Instagram page, #PAINUKCIO, in July 2022. We posted several times a week and it has acquired a good following. The growth of the Instagram page has been organic with no paid promotion.

Pain UK is a member of Pain Alliance Europe, (PAE) and one of our trustees is on the board. Several charity members of Pain UK are members. This is an umbrella charity for organisations helping chronic pain patients across Europe - not just the EU.



# Thank You

**Pain UK CIO, registered charity 1145561**

**Trustees: Antony Chuter, Marian Nicholson, Jessica Sarah Potts,  
Jason Bingham, Dr Joel Brown, Rebecca Pollard.**

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