



# **2021 Annual Review**

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**Pain UK CIO, registered charity 1145561**



# Chair's Report / 1

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

By then end of our year in October 2021, we had 37 member charities. We also have over 1,200 individuals who have joined Pain UK.

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. We recruited three new trustees who have helped extensively with running the charity. Pain UK trustees meet monthly on Zoom and have worked with a number of stakeholders to discuss and find pathways to continue promoting the issues of living with pain across Britain.

We ran a training day for trustees from our member charities this year. Helen Harvey of H3 Solicitors gave comprehensive training to those attending on zoom, and all the trustees of Pain UK attended.



# Chair's Report / 2

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This year, we have re-registered Pain UK with the Charity Commission as a charitable incorporated association (CIO no. 1191657). This was after taking legal advice and looking at the risks and benefits of the different models.

Pain UK also began to think about research, and funded the UK Lived Experience of Pain Project. More later!

In September 2021, for Pain Awareness month, Antony Chuter was featured in the pull out magazine that was distributed with Guardian and at targeted industry events.

Pain UK continues to be a place where people who live with or 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.

Pain UK also gets emails straight 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.



# 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.
- Pain UK is aiming to publish a paper in a respected peer reviewed journal in 2022 along with a report for government and decision makers in health, social care, housing, employers and will be published in 2022.



# Website Data Report /1

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The total page views were 72,712 (up 6.65% on last year).

The overall trend was up slightly (6.65%) in page views. The amount of time spent on the site per session was broadly the same as last year as were the number of exits.

The most popular pages were:

1. The home page (19% of all visits) - up 43%
2. Fibromyalgia Action (8.5% of all visits)
3. Member charities' page (7%) - down 0.5%
4. Help and Support (3.3%) - down 9.5%
5. FAQs (2.5%) - up 2%

Overall the members section had 38,217 page views 53% of all visits (down 4.8% on last year).

The most popular charity member pages were:

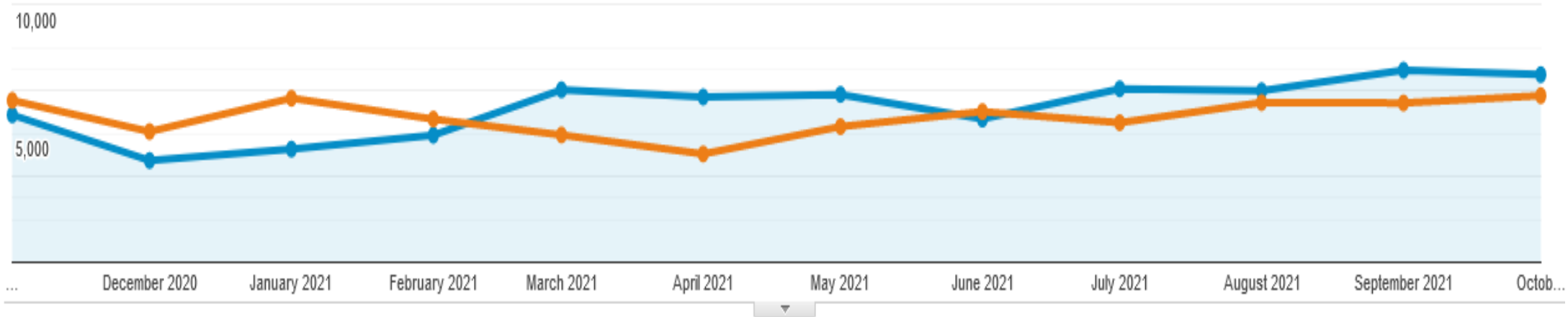
1. Fibromyalgia Action (6,146 - 17% - down 3%)
2. Herpes Viruses Association (2,161 - 6% - up 55%)
3. Endometriosis UK (1,476 - 4% - down 3%)
4. Pain Association Scotland (1,463 - 4% - up 41%)
5. National Rheumatoid Arthritis Society (1,372 - 3.8% - down 10%)

**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

Nov 1, 2020 - Oct 31, 2021: ● Pageviews  
Nov 1, 2019 - Oct 31, 2020: ● Pageviews



Pageviews  
**6.65%**  
72,211 vs 67,710

Unique Pageviews  
**6.82%**  
58,858 vs 55,099

Avg. Time on Page  
**-0.08%**  
00:01:25 vs 00:01:25

Bounce Rate  
**0.16%**  
52.61% vs 52.52%

% Exit  
**-0.28%**  
50.99% vs 51.14%



# Treasurer's Report /1

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The Financial Report for the accounting year end October 2021 was prepared with the support of **Castle view accounting**.

## **Income:**

Additional donations were received through Just Giving, Much Loved, Giving Comm Ltd, Amazon Smile, or individual donations. Pain UK ended the year with reserves **of £18,874**.

## **Outgoings:**

This year we have reduced our spending by using virtual meetings rather than physical ones.

A major annual expense throughout 2021, was paying for a contractor to undertake research for the 'living with pain project'. Pain UK have used the grant given by Pfizer in 2020.

A major annual expense is the upkeep of our website, which is maintained by an outside agency 'Doive.' This means the website is kept up to date and this is of benefit to our target audience.

We pay a yearly indemnity insurance premium and a subscription to SurveyMonkey.



# Treasurer's Report /2

## Income in last two years:

	2020	2021
Donations	£21,211	£6,606

Pain UK ended the year with reserves of £18,874

## Breakdown of expenses in last two years:

	2020	2021
Travel and subsistence	£283	£15.24
Exhibition costs	-	-
Accounts	£240	£450
Legal and professional	£2,959	£2,428.40
Annual General Meeting	-	-
Insurance	£529	£318.40
SurveyMonkey costs	£408	£408
Website maintenance	£1,020	£1,019
Computer equipment	-	-
Printing, postage, stationery	£8	£7.54
Training	-	-
Other costs	-	-
	£5,447	£4,647





# Membership Report /1

Membership rises year on year. 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.

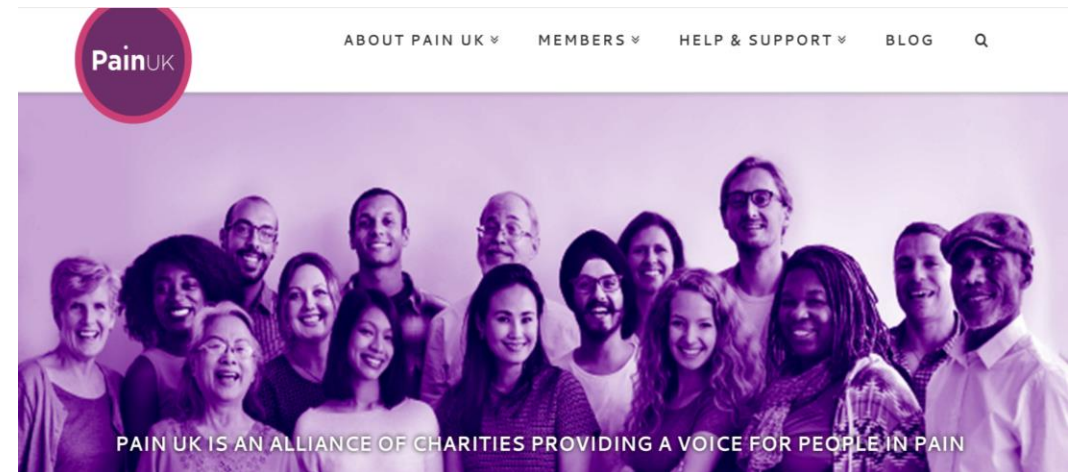
The three new charities this year are:

- Chronically Awesome "to support chronic illness warriors with reliable information, guidance and discussion to help them become more resilient in mind and body – stronger, fitter, healthier, happier."
- Sarcoidosis UK – exists to fund research and to support and inform people with this condition
- Pancreatitis Supporters Network – for people with pancreatitis their families and the professionals in this field.

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. Over the year we sent out:

- 3 emails which included surveys to be circulated to their members, invitations for various forms of free/low cost training on aspects of running charities, etc.

We do not forward any advertising materials.





# Membership Report /2

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We contact our individual members by MailChimp and via our Facebook pages. Researchers, PhD students at universities our membership to be a valuable way of recruiting subjects. For example, one researcher sent us a 'thank you' email as she had achieved a response from 800 people which was marvellously beyond her expectations.

This year we have added over 60 posts to our two Facebook pages. Many of these were invitations to people to take part in studies, as long as these are not from profit-making organisation. These are often aimed at reader sub-sections, i.e. specific age groups. At the end of the year we had Facebook followers on these pages:

- Pain UK: 3,000+ members
- Pain UK Public Group: 280+ members

Three emails were targeted directly to the 1200+ individuals. These covered several items such as webinars about pain, surveys and many on-line research projects which were recruiting volunteers to fill in their questionnaires.

Pain UK is a member of Pain Alliance Europe, (PAE). Several charity members of Pain UK are members and a Pain UK trustee is on the PAE board. 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**

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