



Pain UK

An alliance providing a voice for people in pain

c/o SSS
41 North Road
London
N7 9DP

020 7870 5683
info@painuk.org
www.painuk.org

Registered charity number 1145561

Date: 18 October 2012

Pain UK Annual Report

This is the first annual report of the Trustees of Pain UK.

Aims

Pain UK was established on 1 November 2011 and received charitable status in January 2012 (registered charity number 1145561). Its objectives, as stated in the constitution, are:

- To relieve the suffering of pain, in particular by bringing together voluntary organisations established for the relief of pain sufferers in a common effort to improve their care, treatment and management
- To advance the education of the general public on the causes, effects, treatment and management of pain; and
- To promote social inclusion for the public benefit among people living with pain who may be socially excluded from society, or parts of society, as a result of poor management of their condition and the physical, psychological and social issues that can ensue.

In pursuit of this, Pain UK has set itself four key objectives:

- To improve the efficiency and effectiveness of member charities, thus enabling them to advance the education of the public, reduce social exclusion and improve quality of life for people in pain
- To educate the public and those who work with people in pain so that they come to understand that pain is an important issue in its own right, deserving of more effort to improve care, treatment and management of pain
- To highlight support for people in pain where it exists, thus helping to improve their care, treatment and management
- To raise awareness of the need for additional forms of support where none exists

In year one, the overarching priority has been to understand the strengths and weaknesses of member charities and those they support. Pain UK has also prioritised creation of a visual identity and establishment of a website bringing all the members together. We have also engaged in some awareness raising work and worked with partner organisations on particular issues. These will be described later in the report.



Our first AGM

Ordinarily, Trustees must hold an Annual General Meeting (AGM) within 15 months of the start of the previous operating year (which, in our case, runs from 1 November to 31 October). However, in the first year, the Trustees are obliged to hold the AGM within 12 months of the date on which the charity was established. At that time, the Trustees must also step down and, if they wish, put themselves forward for re-election.

Trustees are usually required to present annual accounts and these have to be independently produced if the charity's income exceeds £25,000. However, our constitution makes it clear that we do not have to do so at the first AGM as we will not yet have completed twelve months in operation. Usually, charities are at least fifteen months old before it becomes possible to close the year one books.

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Trustee business:

During Pain UK's first year the following Trustees were elected or co-opted:

At the inaugural meeting of Pain UK held on 1/12/2011:

- Sean McDougall (Chair)
- Christine Hughes (Secretary)
- Susan Haydon (Treasurer)
- Marian Nicholson
- Tricia King
- Sue Clayton
- Judy Birch (resigned 1 February 2012)
- Ros Meek (resigned 31 March 2012)

In September 2012:

- John Richardson (co-opted) and appointed as Treasurer, succeeding Susan Haydon.

During the year there were nine meetings of the Board of Trustees. In addition, a number of sub-committees were established, including Branding, Membership and Policy. The Executive met monthly as a minimum.

Advisory Board:

Pain UK has begun the process of creating an Advisory Board of experts from different sectors. Members of the Advisory Board have no rights in relation to Pain UK. At the present time, its members are:

- Martin Johnson (RCGP Chronic Pain Clinical Champion)
- Ros Meek (Founder Trustee of Pain UK before she left ARMA to become Government Affairs Manager, Medtronic Foundation)



- Steve Gilbert (National Lead Clinician for Chronic Pain in Scotland)
- Jean Gaffin (highly experienced charity CEO and founder of the Chronic Pain Policy Coalition).

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There has been one meeting of the Advisory Board, on 4th July. There was general agreement that the Board should be used on an ad-hoc basis, normally by phone call to an individual on a particular issue, with a formal meeting annually. The gaps in the Advisory Board were recognised both in terms of its geographic reach and skill spread and we are looking to fill these.

Main Activities of the Charity

Following the inaugural meeting our first task was to set up the board and elect officials, register as a charity, open a bank account, secure funding and to prioritise the initial workload: a number of subcommittees were set up to facilitate this.

There were early changes to the board due to work commitments, both Ros Meek and Judy Birch finding it necessary to stand down, Ros joined the Advisory Board and Judy became our representative at Pain Alliance Europe.

By March we had achieved all of our initial objectives and had received pledges for a total of £25,000 in funding as follows:

- Gruenthal (£10,000)
- Pfizer (£10,000)
- NAPP (£5000)

The final instalment of this funding was received in August 2012. Pain UK wishes to place on record its thanks to these three companies for the support they have provided and for showing faith in the charity as it was being established.

Branding

The Trustees felt that creating a clear recognisable logo that worked in all settings was essential if Pain UK was to be taken seriously and the branding sub-committee led by Sean McDougall set about developing this. The new logo was launched in April, swiftly followed by headed paper, business cards, a website and, soon, banners. The branding has been very positively received and has given us a clear identity.

Membership

We started with seven founder members and the membership sub-committee led by Marian Nicholson and Chris Hughes set a target of 30 members in our first year. By September we had 23 full members and also have 7 Associate members. We are continuing to identify and



recruit new charities both big and small. Members have been kept informed of our progress by regular newsletters.

Pain UK has recently surveyed all its members and completed what we believe to be the first 'insider' study of the strengths and weaknesses of UK pain charities. The information gleaned from our survey will help develop our business plan.

International Organisations

In March we joined Pain Alliance Europe (PAE) and the International Association of Patient Organisations (IAPO)

Support

Trustees did almost all of the work in year one, and it was September 2012 before we secured full time administrative support via a full time six-month secondment from BT. This has enabled us to us move beyond research and preparation into delivery. In August, we appointed a freelance fundraiser who will be using the survey as the basis for a number of applications, each intended to help us help our member charities. The arrival of full time administrative support also enabled us to commission a professional journalist who has been translating our research findings into text for our new website.

Website

A new website was one of our major targets, and although we quickly set up a temporary site so that we had a web presence, we recognised that it would take longer to establish a site that had the same visual appeal and credibility as those of organisations that we work with and seek to influence.

A test site was developed in May and it has a number of characteristics:

- It is based on Wordpress, a free content management system that underpins approximately 50 million websites at this time
- It has a 'responsive' template – that is, it automatically reorganises how information is displayed according to the size of the screen being used by the viewer
- It is dynamic – meaning that it automatically updates itself as new articles are published, and it can present the results of searches in a format that looks like a web page.
- All pages on the site are optimised for search engines, meaning that they are deliberately designed to find their way to the top of searches on Google and Yahoo without being sponsored. In this way, we hope to help people in pain find their way to support very quickly, and with the fewest possible number of clicks.

The website was launched at the AGM with core content and special pages written for each of our founder members. Our other members will be added to the site by Christmas.

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Policy

This sub committee gave careful thought to where we should put our effort at this time of great change in the NHS, and how we could best work with other interested parties to increase our spread. There have been some notable successes: Tricia King became our representative on PIN the NICE patient organisation. Sue Clayton was appointed as the patient representative on the Specialist Pain Care Guidelines Commissioning Group. Martin Johnson of the RCGP invited Pain UK to be part of the working group on creating a measurement tool for problematic pain.

Promotion and Representation

One of the issues that matters most to our member charities is representation at events. Pain UK has been very active in this regard:

- distributing member leaflets at events such as the British Pain Society annual scientific meeting and RCGP conferences on pain management
- attending events such as the Northern Ireland Pain Summit and the launch of the Pain Summit Report at the House of Commons
- speaking at events such as the European-wide Societal Impact of Pain conference
- attending conferences organised by NICE and the Royal Pharmaceutical Society
- participating in training, with a view to passing the knowledge on to members
- joining steering groups, including the Chronic Pain Policy Coalition Affiliates Meetings and the RCGP Stakeholder group meetings throughout the year.

Pain UK has also responded to two consultations:

- a NICE Neuropathic Pain clinical guideline draft scope consultation
- a Department of Work and Pensions independent review of the Work Capacity Assessment

Press Coverage.

We have made our first forays into press campaigning, with a half-page profile of one of our Trustees in the Daily Telegraph and an opinion piece in the Huffington Post. A news piece which appeared in the Mature Times was followed up in the Daily Mirror. An article on the charity also appeared in the British Pain Society's Pain News, and on the Clinical Leaders website.

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Pain Award

In April the Trustee board decided to set up an annual award to honour individuals who have significantly contributed to defeating pain. The Chronic Pain Policy Coalition and the British Pain Society have both agreed to work with us on the Pain Champion Award. The CPPC has also agreed that the award can be presented at their parliamentary reception in the New Year.

Finances

As mentioned above, Pain UK received £25,000 in seed-funding from Grunenthal, Pfizer and NAPP. Our priorities in year one were to:

- Discover whether or not there was a need for the charity
- Establish a visual identity
- Equip the charity with core requirements such as headed paper, staff and a budget

Having done so, as of 18 October 2012 the charity has reserves of £19,502.19

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