

## CROSS-PARTY GROUP ANNUAL RETURN

### NAME OF CROSS-PARTY GROUP

Cross-Party Group on Chronic Pain

**DATE GROUP ESTABLISHED** (the date of establishment is the date in this parliamentary session that the Group held its initial meeting, where the office bearers were elected and not the date that the Group was accorded recognition. All Groups should hold their AGMs on, or before, the anniversary of this date.)

**September 2011**

### DATE OF MOST RECENT AGM

**May 20, 2015**

**DATE OF PRECEDING AGM** [this date is required to aid clerks in verifying that the most recent AGM has taken place within 12 months of the previous AGM]

**June 25, 2014**

### DATE ANNUAL RETURN SUBMITTED

**June 19, 2015**

### GROUP MEETINGS AND ACTIVITIES

Please provide details of each meeting of the Group including the date of the meeting, a brief description of the main subjects discussed and the MSP and non-MSP attendance figures.

Details of any other activities, such as visits undertaken by the Group or papers/report published by the Group should also be provided.

It's been another hard working year for the Group. As volunteers, we've had to cope with problems which should have been tackled by official bodies paid to do so. On the plus side, the CPG found that previous Health Secretary Alex Neil and his deputy Michael Matheson went out of their way to listen to our patients and doctors and act when problems were presented & we've been supported throughout Parliament.

Highlights of the past year include six months of voluntary work for some of us on the threat to the Centre for Integrative Care in Glasgow, an unique hospital aiding chronic pain. This included a petition to the Scottish Parliament by patient Catherine Hughes, which took three months to be accepted but she got a good hearing on June 9, 2015 when she eventually reached the MSPs on the Public Petitions Committee. Lanarkshire MSP Elaine Smith spoke strongly, backing the petition. CPG member Irene Logan of Fibromyalgia Friends Scotland submitted key evidence. Mrs Jane Hawking, ex wife of Professor Stephen Hawking, is among health campaigners in support.

In December 2014, Catherine also gained a promise from Health Secretary Shona Robison that she would visit the CIC “early in the New Year”; this changed to June Unfortunately after Lanarkshire’s Board started barring new patients on April 1. However, the visit did take place in June from Ms Robison and Maureen Watt. .

Patients approach the CPG having failed to get action elsewhere. We took on the cause of Lanarkshire pain patients who were 2 - 14 weeks over their six weekly infusions of Lignocaine, returning them to unbearable pain levels. The public health minister Maureen Watt and civil servant Elizabeth Porterfield acted on CPG highlighting of these delays, due to Lanarkshire’s short staffing. The patients are now promised six weekly treatments – but what about those who didn’t reach the CPG?

The CPG’s regular complaints about shortages at Scottish pain clinics continue and a Ministerial Group has been set up to gain action. We continue to gain new members.

#### **MEETING JUNE 25, 2014 and AGM chaired by Jackie Baillie MSP**

Speaker: Prof. Blair Smith, new clinical lead on chronic pain.

Attendance: 2 MSPs, 25 non MSPs, 8 apologies.

Blair recalled that he joined the CPG and supported our aims from early days, remembering that he had supplied research to help the first debate on chronic pain held in February 2002 by Dorothy-Grace Elder, then an MSP, which had 130,000 responses and, Blair said, started focus on chronic pain.

He was happy to see that a key CPG aim he supported, creating the first Scottish Residential Centre, had now been accepted by the Scottish Government. Blair confirmed his role would involve helping the new residential service when he could.

The meeting expressed concern that Blair was appointed for only half a day a week. The Government’s National Steering Group now had a coordinator for two days but the meeting protested that the Steering Group still wasn’t tackling shortages at clinics. Blair said that, like the CPG, he had also believed this was a priority.

#### **SECRECY**

Several members said a major problem was that there was little transparency about the Steering Group and it was extremely difficult to find out what they, or the Service Improvement Groups (SIGs) were doing. No minutes of the Steering Group had been published since December 2013 to date (June 25), but there had been two

subsequent meetings in February and May 2014. Also, ten out of 14 of the Service Improvement Groups had still not made public their plans to improve services.

Jackie Baillie MSP said lack of information from the Steering Group was “long standing and unacceptable”. She was particularly concerned to discover if the local SIGs would deal with the priority issue of long waiting lists at pain clinics.

Several patients have already lodged complaints over the failure of SIGs or Edinburgh officials to respond when they tried to volunteer as patient representatives for SIGs or the Steering Group. But a health professional outlined a similar experience and had become so concerned she travelled from Aberdeen to inform of facing “remarkable secretiveness” after asking about the Grampian SIG. Grampian was of particular concern to the HIS report, which stated that it had, at 31 weeks, the longest waiting times for first appointments in Scotland. She’d had “seven wasted months, including being passed from pillar to post, with no one willing to provide ordinary information”

**AGM:** Jackie Baillie MSP and John Wilson MSP were re-elected as co-conveners. Jackson Carlaw MSP had just ended his term, was thanked warmly and would remain a member.

Dorothy-Grace Elder was elected Voluntary Secretary.

The minutes of the April 1st meeting were approved, also the minutes of the previous AGM of May 29, 2013.

#### **MEETING, NOVEMBER 12, 2014**

##### **Chaired by John Wilson, MSP**

attendance: Six MSPs – John Wilson (chairing), Jackie Baillie, Bill Kidd, John Finnie, Alex Fergusson, Fiona McLeod.

Non MSPs: 34 Apologies: 10

Members welcomed a review of CPGs by the Standards Committee, which highlighted our CPG for achievements in campaigning for patients, including the successful campaign to gain Scotland’s first residential service for chronic pain patients. Out of 89 CPGs, ours was one of ten mentioned for achievements.

**SPEAKER:** Dr Mike Winter, Medical Director of the National Services Division, reported that the specially renovated building for the new residential service, at the Gartnavel, Glasgow, site, should open in January 2015 and should gain permanent premises possibly in 2017 at Gartnavel.

**SPEAKER:** CPG member Prof. Martijn Steultjens, professor of musculoskeletal health at Glasgow Caledonian University reported on meetings initiated by Scottish health ministers with CPG members at which Health Secretary Alex Neil and Public Health Minister Michael Matheson invited CPG views on what most needs to be done to improve services. CPG members pressed the issue of day clinic shortages and cutting waiting lists and were assured these were a Government priority. We asked for regular figures on waiting lists and shortages. It was pointed out that the Steering Group, set up in 2009, had grown to over fifty members but had not tackled the patient priority of day clinic shortages, nor was there a sign that the 14 Service Improvement Groups round Scotland would do so.

Prof Steultjens reported that the Govt has now decided to appoint a new Ministerial Steering Group, to take charge and deal with the clinics and boards. The present Steering Group is to be re named the National Chronic Pain Improvement Group and will report to the Ministerial Group.

### SERIOUS DELAYS IN TREATING LANARKSHIRE PAIN PATIENTS

The gravity of shortages at pain clinics was illustrated by three Lanarkshire pain patients appealing in person to the CPG for help, having tried every official avenue for many months, without success.

The three cited delays of between two weeks and 14 weeks on receiving Lignocaine infusions, needed every six weeks. Otherwise, they returned to “unbearable” pain levels wrecking their lives and threatening their jobs.. These infusions had “changed their lives completely”, freeing them from pain- but only if treated on time. All three women, aged early 30s to mid 40s, blamed serious staff shortages in Lanarkshire clinics. It had taken good work by the Lanarkshire pain team to discover the right treatment but now this was under threat through short staffing though the pain team tried everything to cope. One described her pain level as “like having a red hot poker thrust into my kidneys every few minutes”. A fourth Lanarkshire patient made the same case by letter. The CPG expressed shock and promised to pursue. The Conveners, plus Professors Steultjens and Eden and DG Elder, hon. secretary, wrote to the public Health Minister and Ms Elizabeth Porterfield, head of Strategic Planning/Clinical Priorities promised to pursue. Alex Neil, as a Lanarkshire MSP, was alerted and attended a meeting with the patients and Lanarkshire officials.

(Result later: all four patients promised treatment on time and thanked the CPG but remained concerned to know if other Lignocaine patients who hadn't complained to the CPG are being helped)

MSP REQUEST: Alex Fergusson MSP spoke and urged that ME and Chronic Fatigue Syndrome patients suffering chronic pain be included in the CPG's work, especially as the separate ME Group had folded. He was assured that the Group represented all suffering CP.

CAM ALTERNATIVE TREATMENTS FOR PAIN . The meeting agreed to requests from members that complementary treatments on the NHS should be a future subject. Paulo Quadros proposed that the CPG support chronic pain patients' equal rights to access through the NHS, if they wish.

RETIRING CO CONVENERS Jackie Baillie and John Wilson were ending their terms of CPG office and were applauded for their years of service but will remain members. Jackie Baillie was thanked for her many years of questions to Parliament, and her unfailing support for the CPG and patients every time extra help was needed and John particularly for his support at the Public Petitions committee.

NEW CO CONVENERS The meeting elected Bill Kidd MSP, John Finnie MSP, Neil Findlay MSP as new co conveners and welcomed them. Dorothy-Grace Elder was elected as voluntary secretary and the previous secretary, Jacquie Forde, was

thanked for her good work.

MINUTES The minutes of the Nov. 12 meeting were approved unanimously.

## **MEETING FEBRUARY 24, 2015**

**Chaired by Bill Kidd, MSP.**

Attendance: Six MSPs: Co conveners Bill Kidd, SNP (chairing) ; Neil Findlay Lab, Jim Hume, Lib Dem, Jenny Marra, Lab, Annabel Goldie Con, Jamie McGrigor, Con.

Non MSPs: 34 Apologies: 9.

**SPEAKERS:** Outlining the work of The Centre for Integrative Care, (CIC) formerly known as Glasgow Homeopathic Hospital:

Dr Jacqueline Mardon, clinic lead at the CIC and Dr David Reilly, Consultant in Integrative Care, outlined specialisation in chronic conditions, including Chronic Pain, Fibromyalgia, Multiple Sclerosis, Arthritis, ME, Parkinson's, Crohn's and Motor Neurone Disease. Dr Mardon explained the modern hospital was custom built in 1999 to create beautiful, peaceful surroundings, including landscaped gardens. Dr Reilly spoke of the Wellness Enhancement Learning (WEL) programme he runs in Scotland as part of a need to change NHS approach over "the epidemics of long term conditions" now apparent.

Controversy over Health Board withdrawals closing two clinics and access to the CIC.

Catherine Hughes and other CIC patients and supporters were vocal in condemnation of three Boards removing patients against their wishes because some Boards are against homeopathy, although the CIC uses other conventional methods. Ms Hughes pointed out that patients were being ignored entirely by Boards, citing that NHS Lanarkshire discarded an 80.6% overwhelming majority urging continuation of access. This meant the views of 4,800 people and 98 patients' organisations were ignored in a decision by only nine Board members. She said that the Board's decision to close two Lanarkshire CIC outreach clinics and access to the Glasgow hospital was "totally undemocratic". Several MSPs questioned this Board decision, and the meeting was told that Ian Welsh, CEO of the Alliance for Health & Social Care, Scotland, which represents over 900 organisations and individuals aiding chronic conditions, protested to the Health Secretary on February 17. Liberal Democrat Health spokesman Jim Hume MSP pledged that, like Mr Welsh, he would also write, requesting a moratorium and consideration of national funding to protect the hospital as a "national resource". But it is now reduced to only four boards sending patients regularly.

(The two CIC doctors did not join in the Group's discussion on this controversy because discussing individual health boards' actions is apparently not allowed by officials. Some CPG members voiced concern over this.)

The meeting passed the following motion unanimously: proposed by patient member Catherine Hughes. Seconded: John Thomson.

"To request that the Cabinet Secretary for Health and Wellbeing and the Public

Health Minister intervene urgently on behalf of Lanarkshire patients of the Centre for Integrative Care and two outreach clinics in Carlisle and Coatbridge” (full text in minutes)

**SPEAKER:** Patients’ Rights to Complementary & Alternative therapies (CAM) on the NHS. Paulo Quadros spoke of years of difficulty for patients in accessing alternative therapies on the NHS despite some CAM treatments being approved by the SIGN guidelines on Chronic Pain in 2013. A packed agenda was short of time and a discussion could be held in future.

**LANARKSHIRE LIGNOCAINE PATIENTS:** Three patients attended again, thanking the CPG for taking up their case over Lignocaine infusions being delayed 2 – 14 weeks beyond their six-week period at conventional treatment clinics in Lanarkshire due to staff shortages.

The patients are now being promised they’ll receive treatment every six weeks but it was agreed that vigilance will still be needed.

Minutes of November 12 2014 passed unanimously.

## **MEETING, MAY 20, 2015 and AGM**

**Chaired by John Finnie, MSP.**

Attendance: 3 MSPs: Maureen Watt, SNP, John Finnie, (Chairing) Independent & Green Group, Bill Kidd, SNP.

Non MSPs 38. Apologies: 12

**SPEECH AND Q & A SESSION WITH THE PUBLIC HEALTH MINISTER.** Maureen Watt MSP, who replaced Michael Matheson after he was promoted to the cabinet in November, offered to meet the CPG and much of the meeting involved her statements during and after Ms Watt’s appearance. She assured the CPG that her Government continued to stress the importance of chronic pain issues. Members asked numerous questions and challenged on the future of the Centre for Integrative Care (NHS CIC) which specialises in chronic conditions, including chronic pain. Ms Watt said the Government had no intention of closing the hospital. Members challenged, saying the hospital was now down to only four boards out of 14 sending patients regularly, with Highland, Lothian and currently Lanarkshire withdrawing and requested Government intervention. Patients’ protests were being ignored, despite 80.6% of public & patients voting for continuation in Lanarkshire. Ms Watt said such matters were up to Boards and she couldn’t intervene. Members disagreed strongly. But she was due to visit the hospital soon. Ms Watt said the Scottish Government was considering a new wing being built at the CIC to take the permanent home of the first Scottish Residential Service in about two years time. If this happened, she said, both the CIC and the Residential Service would be more secure. Members agreed but said no building work was happening, tenders weren’t out and that the hospital could suffer more run down in the two years.

Elizabeth Porterfield of Clinical Priorities said Ms Watt is responding to a CPG

request for waiting list figures at all Scottish chronic pain clinics; these should be published in November.

Ms Watt complimented the Group on being very active for patients and attracting large attendance and was thanked for her visit.

Catherine Hughes, a CIC patient, said afterwards that she was taking a petition aimed at protecting the CIC, to the Parliament.

**SPEAKER:** Claire Schiavone, a young member of Arthritis Care, outlined the extreme difficulties people with chronic pain can endure through benefits assessments and how many have waited without money for months.

**NEW SUB GROUPS:** The meeting considered a proposal from Paulo Quadros that two sub groups be set up on major issues: benefits cutbacks as they affect people with chronic pain and another group to deal with access to Complementary and Alternative Medicine on the NHS. The meeting agreed to a CAM and CIC sub group being set up, to also be vigilant over the Centre for Integrative Care. People wishing to join these two subs should notify names to the honorary secretary who will send to the co conveners.

**AGM:** Co conveners re-elected unanimously: Bill Kidd, SNP, Neil Findlay, Lab, John Finnie Independent & Green Group. Hon Secretary Dorothy-Grace Elder re-elected unanimously.

Minutes of meeting on February 24 2015 approved unanimously; also minutes of previous AGM June 25, 2014.

Bill Kidd, SNP

Neil Findlay, Lab

John Finnie Independent and Green Group

Jackie Baillie, Lab

Jim Hume, Lib Dem

Malcolm Chisholm, Lab

John Wilson, Independent & Green Group

Richard Simpson, Lab

Jackson Carlaw, Con

Michael McMahon, Lab.

**NON-MSP MEMBERS OF THE GROUP**

For organisational members please provide only the name of the organisation, it is not necessary to provide the name(s) of individuals who may represent the organisation at meetings of the Group.

Individuals	Dorothy Grace Elder (Hon. Sec) Martin Tighe Lord George Foulkes Dr Colin Rae Margaret McInnes Councillor Frank McAveety Linda Mawson Frank Mawson Pete McCarron Lesley Riddoch, Michael Grieve John Thomso Jim Scanlon Martha Heaney Jean Rafferty Anne Cassels Anne Murray Christine Martin Dr Sabu James Professor Martin Steultjens Prof. Blair Smith, Jacquie Forde Irene Logan Pat Onions Arlene Byrne Linda Tierney Fiona Robinson Geraldine McGuigan Janice Connelly John Lawrence Dr Fiona McLeod Dr Martin Johnson Dr Helen Jackson Dr Gordon McGinn Dr Michael Basler Dr Mike Serpell Ros Meek Janette Barrie Anne Hughes Dr Pat Roche Alasdair Barron Heather Cameron Paulo Quadros Kenny Boyle Phil Atkinson, Helen McLuskey
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	<p> Catherine Hughes  Julie Mcanulty  Ooi Thye Chong  Professor Tim Eden  Prof Jim McEwen  Baillie Josephine Docherty  Maire Whitehead  Dr David Weeks  Bill Sinclair  Claire Schiavone  Laura Clark  Margaret Coats  Tasneem Nadeem  Mohammed Nadeem  Akhtar Javaid  Lara Grant  Margaret Searle  Lyssa Clayton  Helen Campbell </p>
Organisations	<p> “Affa Sair” Moray campaign group  Action on Pain  Arthritis Care  BMA  Chartered Society of Physiotherapy Scotland  Community Pharmacy Scotland  Complementary &amp; Natural Healthcare Council  Fibromyalgia Friends, Scotland  Gruenthal  Healthcare Improvement Scotland  Int Life  Leuchie House chronic conditions respite centre  National Osteoporosis Society  NHS Ayrshire &amp; Arran  NHS GGC  NHS Highland  NHS Lothian  NHS Tayside  Pain Association  Pain Concern  RCN  Reckitt Benckiser  Royal College of General Practitioners  Royal Pharmaceutical Society  Scottish Massage Therapists Association  Scottish Neurological Society  The Health &amp; Social Care Alliance, Scotland </p>

## GROUP OFFICE BEARERS

Please provide names for all office bearers. The minimum requirement is that two of the office bearers are MSPs and one of these is Convener – beyond this it is a matter for the Group to decide upon the office bearers it wishes to have. It is permissible to have more than one individual elected to each office, for example, co-conveners or multiple deputy conveners.

Convener	Co-conveners: Bill Kidd, SNP; John Finnie, Ind & Green Group, Neil Findlay, Lab.
Deputy Convener	n/a
Secretary	Honorary Secretary: Dorothy-Grace Elder
Treasurer	n/a

## FINANCIAL BENEFITS OR OTHER BENEFITS RECEIVED BY THE GROUP

Please provide details of any financial or material benefit(s) received from a single source in a calendar year which has a value, either singly or cumulatively, of more than £500. This includes donations, gifts, hospitality or visits and material assistance such as secretariat support.

Details of material support should include the name of the individual providing support, the value of this support over the year, an estimate of the time spent providing this support and the name of the organisation that this individual is employed by / affiliated to in providing this support.

Groups should provide details of the date on which the benefit was received, the value of the benefit and a brief description of the benefit.

If the Group is not disclosing any financial information please tick the box to confirm that the Group has considered the support received, but concluded it totalled under the threshold for disclosure (£500).

n/a No sponsorship sought, no subscriptions.

## SUBSCRIPTION CHARGED BY THE GROUP

Please provide details of the amount charged and the purpose for which the subscription is intended to be used.

none

**CONVENER CONTACT DETAILS**

Name	Co convener Bill Kidd MSP
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Parliamentary address	Scottish Parliament, EH99 1SP
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