

## CROSS-PARTY GROUP ANNUAL RETURN OCTOBER 2019

<b>NAME OF CROSS-PARTY GROUP</b>
Cross-Party Group on Chronic Pain
<b>DATE GROUP ESTABLISHED</b> (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.)
October 2016
<b>DATE OF MOST RECENT AGM</b>
9 <sup>th</sup> October 2019
<b>DATE OF PRECEDING AGM</b> [this date is required to aid clerks in verifying that the most recent AGM has taken place within 12 months of the previous AGM]
31st October 2018
<b>DATE ANNUAL RETURN SUBMITTED</b>
1 <sup>st</sup> November 2019
<b>GROUP MEETINGS AND ACTIVITIES</b>  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.
<b>MEETING: April 24, 2019:</b> chaired by Rona Mackay MSP.  Minutes of meeting of October 28 2018 approved.

Jeane Freeman, health secretary, had agreed to speak since January 2019 but her office cancelled five days before the April 24 meeting, stating they'd forgotten that she had asked them to change to October 9. The meeting expressed concern for mesh and chronic pain sufferers, some booked for round trips of hundreds of miles who paid personally for a hotel overnight, being unable for a same day return.

### **ARE CHRONIC PAIN PATIENTS AND CLINICS BEING SIDE-LINED AGAIN?**

There was astonishment that chronic pain clinics were given just £27,000 out of £855 million from the Scottish Govt to cut waiting times. The voluntary secretary had, at the CPG's request, spent two days at the new Access Collaborative "design" workshops on chronic pain. These were organised by the DHI/Glasgow School of Art, which did not claim knowledge of chronic pain and said they were "advised" by Government officials from the Clinical Priorities Unit. The CPG objected to being asked not to mention waiting times statistics. When a patient group wrote a blog giving one statistic - on 40 week waits for new patients – the patient was asked to remove the one fact. The CPG protested over the draft report excluding even the number of clinic patients, claiming these were "small" without mentioning tens of thousands.

The meeting passed a resolution stating they had no confidence in the National Advisory Committee on Chronic Pain and the Clinical Priorities Unit being assigned by Government to aid the implementation of Collaborative plans in view of years of lack of progress.

### **MESH SUFFERERS**

Mesh patients said that the Scottish end was delaying and obstructing the offer by Dr Dionysios Veronikis, who has world class experience of full mesh removals, to come to Scotland from Missouri to share his knowledge with Scottish surgeons and help patients. This is a remarkable offer, patients said. Patients had hoped to discuss with the health secretary but she did not attend. One patient, Claire Daisley, said that in Scotland she would shortly have her bowel and bladder removed. Although she had been informed that mesh had been removed, she believed some of it was still there and was the cause of continuing excruciating pain. She did not want to lose vital organs if remaining mesh was to blame.

### **WAITING TIMES -INFO FROM INFORMATION SERVICES DIVISION (ISD)**

Scott Heald, Head of Profession for Statistics and Fiona MacKenzie, Manager, Service Access, invited the CPG on chronic pain to be represented on ISD's Governance Group. Members welcomed this inclusiveness from ISD and CPG patient FR volunteered. The meeting learned that the Dundee University dataset work on chronic pain has now been transferred to ISD to complete, who will receive fees. Members queried why as much as £257,000 had already gone to Dundee University to study only three board areas, while pain clinics got only £27,000 for their clinical work. But the ISD representatives were not involved with such decisions. ISD had not been informed of the project originally. ISD now has to roll out the project to all Scotland.

**DATA GATHERING CUTTING TIME FOR PATIENTS?** Discussion moved to the time taken away from patients while clinicians fill in more forms. Ian Semmons, chair of Action on Pain, related that a pain physiotherapist he knows spends one day a month recording statistics. He could see how disruptive data collection can be in a clinical setting, unless it is vital data, which he did not think the original Dundee work was.

**CONCERN OVER LACK OF OUTSIDE VIEWS.** The CPG voiced concern that the Dundee project was another example of moves on chronic pain being limited to a small circle. The contract was awarded by a Scottish Government grant, so did not require to be put out to tender. Three persons involved with the dept at Dundee University which received £275,000 are on the Scottish Government's National Advisory Committee.

### **CENTRE FOR INTEGRATIVE CARE (CIC)**

The Parliament's Health & Sport Committee asked our CPG and the CPG for Arthritis and Musculoskeletal Conditions for patient and professional views over the CIC, the loss of beds and stoppage of Scotland-wide access, despite protests from patients. This is the follow up to the petition by Catherine Hughes. Her health is increasingly poor and she is unable to access past care she received as inpatient access is now barred. Members thought the hospital might have been lost entirely without Catherine's campaigning for 15 years.

**Action:** Due to Catherine's illness, the voluntary secretary has agreed to gather views from the two CPGs, research round Scotland and write a Report for the health committee. This will take several weeks of voluntary work.

### **MIGRAINE**

The CPG agreed to spread the word that over one million in Scotland suffer the pain of migraine. Yet there were only three specialist treatment centres covering Scotland. The voluntary secretary recently attended a special meeting at Holyrood organised by Alex Neil MSP and migraine sufferers to update the CPG.

**ATTENDANCE** Three MSPs, 40 non MSPs.

### **MEETING AND AGM, October 9, 2019, chaired by Rona Mackay MSP**

Again, the health secretary cancelled five days before this meeting, on a date she had chosen. This was the second time this year and there was patient anger. A mesh patient had travelled from Dunoon. Two UK charity heads had come from Norfolk and London. But this time public health minister Joe Fitzpatrick deputised. The parliament was sitting very late, patients had to wait over two hours before MSPs were free. But four attended plus the public health minister Joe Fitzpatrick. The AGM endorsed the following MSPs being elected co

conveners – Elaine Smith, Miles Briggs, Rona Mackay, Monica Lennon, Anas Sarwar. DG Elder was re-elected voluntary secretary.

The minutes of April 24 and of our previous AGM on October 31 2018 were approved.

Patients protested to the minister about the health secretary failing to appear. Scottish Mesh Survivors had made considerable and painful efforts to attend once again and decried being let down for the second time.

### **43,000 hidden patients.**

The meeting was angry that officials had decided to prioritise primary care, not waiting times at pain clinics, as advance promises showed. Officials had claimed that the number of patients attending CP clinics was “small”. But the CPG secretary revealed Freedom of Information statements by boards which showed the following:

\*Officials omitted to count over 43,000 patient visits to clinics. Therefore, how could that decision to downplay clinics be correct? They ignored 43,000 return patients, who add to the 20,000 new patients annually. A total of 63,000 patients should never be called a “small number” to be ignored. The figures were obtained under FOI legislation – 13 boards except NHS Fife complied. For years, the public had been told that officials couldn’t produce return patient numbers – or staffing numbers at clinics. The secretary obtained both under FOI legislation.

\*FOI also disclosed a history of lack of aid for clinics – one pain service hadn’t had a budget increase in 9.5 years, since it started. Another received no budget increase for six years, etc all happening as patient numbers rose.

\*FOI disclosed that few health boards had given chronic pain clinics any share of the SG millions available to cut waiting times despite the long waits caused by short staffing.

There was detailed discussion and upset that the Government’s Advisory Committee and the Clinical Priorities Unit had shown showed no action. The meeting agreed that, apart from their vote of no confidence on April 24 in the National Advisory Committee on Chronic Pain and the Clinical Priorities Unit, this was reinforced and they wanted no involvement of these agencies in the Access Collaborative plans.

Patients urgently wanted an end to return patients having no limit to the time they wait - people became return patients after the first visit. As some could wait 18 months between treatments needed six monthly, patients requested the time limit given by a clinician should be made official.

The Minister promised to study what he had been informed and see what could be done. The meeting did not finish until 10.25 pm. The chair thanked all, especially patients, for enduring sitting for so long.

**ATTENDANCE:** Five MSPs, 41 non MSPs.

## **WORKLOAD OF THE CPG BETWEEN MEETINGS**

Members attended over 15 informative meetings on many aspects of health affecting our interests, including health board meetings.

A detailed report requested by the Health & Sport Committee was accomplished voluntarily regarding the CIC hospital Involving contact with dozens of patients and agencies. This led to successful decisions.

A detailed investigation of waiting times for return patients was accomplished, with this voluntary CPG listing information which paid officials had not produced.

The CPG was represented when the UK Statistics Regulator visited Holyrood – the Regulator’s support for the CPG in its battle against lack of transparency is now a case history used by the Office for National Statistics.

## **MSP MEMBERS OF THE GROUP**

Please provide names and party designation of all MSP members of the Group.

Elaine Smith, Lab;  
Rona Mackay, SNP;  
Miles Briggs, Con;  
Anas Sarwar, Lab;  
Alex Neil, SNP;  
Willie Rennie, Lib Dem;  
Donald Cameron, Con;  
Jackie Baillie, Lab;  
Bill Kidd, SNP;  
Tom Mason, Con.  
Monica Lennon 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  
Prof Martyn Steultjens  
John Thomson

	Anne Murray
	Lord George Foulkes
	Dr Colin Rae
	Margaret McInnes
	Councillor Frank McAveety
	Karen Neil
	Claire Daisley
	Elaine Holmes,
	Olive McIlroy
	Nancy Honeyball
	Rob Friel
	Robert Dickson
	Frances Boyle
	A Floyd,
	Katharine Kilgour
	Fiona Collins
	David Caulfield
	Rob McDowall.
	George Welsh
	Catherine Hughes
	Ooi Thye Chong
	Prof Jim McEwen
	Bailie Josephine Docherty
	Maire Whitehead
	Dr David Weeks
	Bill Sinclair
	Claire Schiavone
	Laura Clark
	Maureen McAllister
	Anne Hughes
	Margaret Coats
	Tasneem Nadeem
	Mohammed Nadeem
	Akhtar Javaid
	Lara Grant
	Margaret Searle
	Lyssa Clayton

	Helen Campbell
	Ian Brogan
	Anne Simpson
	Margaret Wyllie
	Karen Hooton
	Dr Sheila Inglis
	Jim Eadie
	Marion Scott
	Irene O'Neill
	John Mutch
	Kathleen Powderly
	Marian Kenny
	Dr Patrick Trust
	Dr Andreas Kelch,
	Nicola Mills
	Alan Watt
	Linda Mawson
	Frank Mawson
	Pete McCarron
	Lesley Riddoch
	Michael Grieve
	Jim Scanlon
	Martha Heaney
	Jean Rafferty
	Anne Cassels
	Christine Martin
	Jacque Forde
	Irene Logan
	Arlene Byrne
	Linda Tierney
	Fiona Robinson
	Geraldine McGuigan
	Janice Connelly
	John Lawrence
	Prof Blair Smith
	Dr Martin Johnson
	Dr Helen Jackson

	<p>Dr Michael Basler  Dr Mike Serpell  Dr Sabu James  Liz Barrie  Gordon Barrie  Anne Hughes  Dr Pat Roche  Alasdair Barron  Heather Cameron  Paulo Quadros  Kenny Boyle  Phil Atkinson  Helen McCluskey  Lloyd Mawson</p>
Organisations	<p>The Health &amp; Social Care Alliance Scotland  Action on Pain UK  Chartered Society of Physiotherapy Scotland  Royal College of Physicians &amp; Surgeons of Glasgow  Scottish Mesh Survivors campaign  Community Pharmacy Scotland  Complementary &amp; Natural Healthcare Council UK  Fibromyalgia Friends Scotland  FFU-Scotland (Fibromyalgia)  BMA  Independent Federation of Nurses in Scotland  “Affa Sair” Moray campaign group  Versus Arthritis, Scotland &amp; UK  Cope Scotland  RCN  Grunenthal  Healthcare Improvement Scotland  Leuchie House chronic conditions respite centre  National Osteoporosis Society  NHS Ayrshire &amp; Arran  NHS GGC</p>

	<p>NHS Highland  NHS Lothian  NHS Tayside  NHS Lanarkshire  Pain Association Scotland  Royal College of General Practitioners  Royal Pharmaceutical Society  Scottish Massage Therapists Association  Intlife  Scottish Neurological Society  Marfan Association  ASH Scotland  Femme Fatigue,  Glasgow Caledonian University  Equality Council</p>
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**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	<p>Co convener MSPs:</p> <p>Elaine Smith,  Rona Mackay,  Miles Briggs,  Anas Sarwar  Monica Lennon</p>

Secretary	Voluntary 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).

### SUBSCRIPTION CHARGED BY THE GROUP

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

n/a

### CONVENER CONTACT DETAILS

Name	Elaine Smith MSP
Parliamentary address	M1.21 Scottish Parliament
Telephone number	Ext: 85824 Regional Office 01236 423555