

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.)
October 26, 2016
DATE OF MOST RECENT AGM
October 31, 2018
DATE ANNUAL RETURN SUBMITTED
November 28, 2018
DATE OF PRECEDING AGM [this date is required to aid clerks in verifying that the most recent AGM has taken place within 11-13 months of the previous AGM]
October 4, 2017
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.
Meeting March 14, 2018: chaired by Miles Briggs MSP. Seven MSPs and 34 non MSPs attended. (41 total). Waiting times suicide risk: chronic pain waits in Grampian increased to 40 weeks for new patients on the 18 week maximum, in an area where uncounseled return patients report suicidal impulses on their even longer waits. But a Lanarkshire return

patient present said she had attempted suicide this month and been taken to A& E because of up to 18 months waits due to staff shortages on treatment due six monthly. NHS Lanarkshire sees all NEW patients in time..

Waiting times for return patients- first information. Speakers Scott Heald, Head of Profession for statistics at ISD and Fiona MacKenzie, Service Access & Waiting Times Manager, expressed deep concern and hoped their work – the first to focus on return patient facts – would help.

ISD discovered that 974 “first return” patients were added to the returns waiting lists in nine months of 2017. The meeting agreed that 974 indicated how large the other long term numbers may be, which ISD is next investigating.

The meeting passed a motion supporting ISD’s work in tackling “the reality of pressure on pain clinics and bringing to light hitherto ‘invisible patients’”

Women in pain: Contributors from the campaign to ban mesh, started in Scotland and now international, included founders Elaine Holmes and Olive McIlroy who detailed lives wrecked by mesh. Their journalist champion Marion Scott said these brave women had alerted the world to what is possibly the biggest modern health scandal, involving hundreds of thousands.

Speakers against poor treatment of thyroid sufferers (95% female) were Elaine Smith MSP and Lorraine Cleaver. They charged that conditions with mainly women sufferers had a history of old attitudes.

NHS Centre for Integrative Care

Patient campaigner Catherine Hughes accused the Scottish Health Council’s public consultations of being ineffectual. The Council recommended that closure of the ward (80% female patients) at the CIC was “minor”, despite patient protests. Closure barred decades of patient demand from all over Scotland.

Support for our Group’s work from the Scottish Parliament’s Presiding Officer.

The meeting welcomed a letter of support from PO Ken Macintosh over our campaigns for patients, stating “Your CPG on chronic pain has long been one of the most productive of all the groups.”

Meeting June 20 2018: chaired by Rona Mackay MSP. Four MSPs and 40 non MSPs. (44 total) Ms Mackay thanked many for travelling far to CPG meetings -from Aberdeenshire, Fife, Dunoon, Glasgow, Lanarkshire, Renfrew, Ayrshire and Borders as well as Edinburgh.

How much will go to chronic pain services out of £51.6 million extra in 2017/18 to cut waiting times?

19 new chronic pain patients in Scotland died on the long waiting lists in one quarter. These were “prioritised” new patients – uncounted return patients wait longer. Yet when Boards shared an extra £51.6 million this past year to improve waiting times of choice, CPG research discovered chronic pain facilities got a total of only £333,000 out of £51.6 million. Only six out of 14 boards gave anything.

Members believed patients being unable to have severe pain tackled in time was a Human Rights issue – CPG to pursue.

Secretiveness in health: When co convener Miles Briggs MSP wrote to 14 Board CEOs asking simply how much of waiting times extra money they gave to CP services, some took over three months to reply and some responses were so obscure they had to be queried four and five times..

Suicide risk caused by excessive waiting times.

A return patient who had twice attempted suicide reported reluctantly going private “in desperation” to avoid 18 month waits. The patient couldn’t afford this. And opposed on principle. But asked “What about others?”

Mesh Injured Women. The Scottish Mesh Survivors’ fight for “no more whitewash”, is now backed by 101 MSPs.

But Mesh women campaigners present said they were “still not getting the truth” to prevent other lives being ruined.

Chronic Pain and Physiotherapy. Physiotherapists Emma Mair and Dan Thompson of NHS Ayrshire & Arran were thanked for an illuminating presentation on how physiotherapy was tailored to individual needs.

Meeting & AGM October 31, 2018: chaired by Miles Briggs MSP. Three MSPs, 24 non MSPs. The date clashed with many events. The chair welcomed all, including Ian Semmons, patient founder of Action on Pain who travelled from Norfolk.

AGM: Present MSP co conveners Elaine Smith, Rona Mackay, Miles Briggs, and Anas Sarwar were re-elected unanimously, as was voluntary secretary Dorothy-Grace Elder.

Almost four out of five chronic pain patients contact unscheduled care & emergency services. ISD new figures prove the strain on return patients, the NHS, emergency services and out of hours GPs over the suffering of long-term pain patients.

ISD discovered that 36,877 out of 47,933 chronic pain patients needed to contact ‘at least one’ unscheduled care service – ambulance, GP out of hours, emergency departments, NHS 24, emergency admissions. That’s in a three-year period (April 2015 to March 2018) ISD wrote:

“That means nearly four out of five accessed at least one of the unscheduled care services”.

Scottish Mesh Survivors : Women campaigners were applauded for their campaign resulting in the new health secretary intervening against mesh. But Jeane Freeman pointed out that regulating mesh products was not devolved. She has written to the London regulator, MHRA, expressing her “dismay and concern” over reports that they approved mesh devices on “the flimsiest evidence” The campaign continues over women who state their lives were ruined,

Respite help for chronic pain: who cares? CPG member Mairi O’Keefe, CEO of Leuchie House, spoke on her retirement this week after 15 years of remarkable work. Leuchie House faced closure by the MS Society but Mairi, then manager, refused. The meeting applauded her work in rallying all Scotland, including the Parliament, in a huge campaign which turned Leuchie into a model respite centre for many painful conditions. Her plea was for “more Leuchies” in Scotland beyond East Lothian.

Fibromyalgia: more help needed. Fibro patients reported waiting times delays regularly. So devastating is this all over pain condition from day to day that six Patients had to cancel on the night. MSPs to lodge Parliamentary questions on waits.

Other CPG work : all year, group members research and gather facts and tackle individual patient pleas for help. (The secretary can spend months on a key injustice to an individual). Members also attend relevant meetings – e.g. on suicide prevention, and participate in meetings called by the Alliance. We have pursued the human rights issue over chronic pain excessive waiting times with the Scottish Commission on Human Rights and contacted mental health organisations to urge that suicide risk with severe pain should be included in the Scottish Government’s Suicide Prevention strategy. The Group’s MSPs ask scores of Parliamentary Questions, all taking considerable time. The Secretary has been at two Stirling meetings of the new Collaborative which was set up to cut waiting times for several conditions. We await action.

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.

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

	Linda Mawson
	Frank Mawson
	Pete McCarron
	Lesley Riddoch
	Michael Grieve
	Jim Scanlon
	Martha Heaney
	Jean Rafferty
	Anne Cassels
	Christine Martin
	Jacquie Forde
	Irene Logan
	Arlene Byrne
	Linda Tierney
	Fiona Robinson
	Geraldine McGuigan
	Janice Connelly
	John Lawrence
	Prof Blair Smith
	Dr Martin Johnson
	Dr Helen Jackson
	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

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

	<p> 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. </p>
Organisations	<p> The Health & Social Care Alliance Scotland Action on Pain UK Chartered Society of Physiotherapy Scotland Royal College of Physicians & Surgeons of Glasgow Scottish Mesh Survivors campaign Community Pharmacy Scotland Complementary & 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 & UK Cope Scotland RCN Grunenthal Healthcare Improvement Scotland Leuchie House chronic conditions respite centre National Osteoporosis Society NHS Ayrshire & Arran NHS GGC </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
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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	Co convener MSPs: Elaine Smith, Rona Mackay, Miles Briggs, Anas Sarwar.
Deputy Convener	N/A
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).

The secretary donates all work voluntarily as an individual. No funders.

SUBSCRIPTION CHARGED BY THE GROUP

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

No subscription.

CONVENER CONTACT DETAILS

Name	Elaine Smith MSP
Parliamentary address	Scottish Parliament office M1 21
Telephone number	0131 348 5824