

Meeting & AGM November 20, 2024: Four MSPs: Miles Briggs, Monica Lennon, Fergus Ewing, Foysol Choudhury. 35 Non MSPs. 39 total

Conveners elected: Miles Briggs, Clare Adamson. Voluntary Secretary: Dorothy-Grace Elder.

TALK Disabled People demand Justice: Dr Rianna Price of Inclusion Scotland outlined why three charities-Inclusion Scotland, Glasgow Disability Alliance and Disability Equality Scotland -resigned from a Scottish Government advisory group, calling it “a sham process”.

The three said they’d “worked tirelessly” with the Scottish Government for the past 20 months to develop “a bold, action-focused Disability Equality Plan to improve lives. But it ended in collapse of all promises and ambition – leaving us struggling to defend our involvement to our members, in what has turned out to be a sham process. ” CPG members claimed the same happening with pain and long covid.

Voluntary Secretary Report: Secrecy continues on flawed report on pain.

Health secretary Neil Gray and JP Marks, current head of the Scottish Civil Service, did not reply to letters from two of our MSPs, which patients requested they write at our April meeting. Gray and Marks also ignored a request to meet MSPs. Our MSPs’ letter concerned serious flaws in a Scottish Government report on chronic pain which cost public purse £40,000. **Nearly two years of questions have been ignored on this report.** What’s going on?.

Patients pointed out the report, commissioned and supervised by Clinical Priorities officials working for ministers, lessened severe pain suffering impact, contrasting with all other reports. It even produced a category of “no impact” on some with chronic pain which experts say they don’t use.

Clinical Priorities officials replaced diagnosed patient volunteers with paid social media and commercial recruitment at £200 each for 16 people . Why will no-one answer? MSPs and secretary to try again – openness was promised at Holyrood but delivery awaited.

More Secrecy : Why is revealing the fate of all Scotland's specialist chronic pain services now delayed until 2026 by ministers ,meaning four years of officials' talks 2022-26? At the same time, around NINE conditions, including chronic pain, are being involved in another consultation which may delay until 2026 we're not told why, how, any details. It's also been claimed this might be almost all long term conditions. We ask but aren't told.

Patients regarded fear of cuts to specialist NHS services “an approaching storm” affecting thousands in every area and, overall, Scotland's 800,000 chronic pain sufferers and their families.

UPDATES

More than fibro Sharon Turnbull is a young mother from Coatbridge who founded the group “more than Fibro”, despite her own suffering. She has attracted many thousands of members for this least helped all-body pain condition.

Fibromyalgia Action UK has its HQ in Paisley and their speaker was Hazel Borland, a very supportive regular attender of our group who, with Des Quinn, runs the charity UK HQ from Paisley. Like Sharon, Hazel and Des have fibromyalgia.

Centre for Integrative Care - Dr Patrick Trust reported continuing lack of help for the Centre, despite its remarkable record of almost 100% patient support. Its value to his patients, before he retired as a GP, “was tremendous”.

NHS Highland - there's good news short-term - but not long term. MSPs Fergus Ewing, Rhoda Grant, Miles Briggs, Monica Lennon and our voluntary secretary, intervened to stop some key pain treatments being cut this autumn in Highland. But the reprieve is only temporary. Vigilance from volunteers is essential.

The plan still is that the Edinburgh-arranged "Task Force" of about 20 officials will recommend for all Scotland in 2026 on what should happen to pain patient treatments.

Lanarkshire is now back to three year waits between return specialist treatments- for what should be 6 monthly relief, reports a CPG patient's experience.

Even with NEW patients, usually seen faster, Public Health Scotland highlights increasing waits in NHS Ayrshire & Arran, Dumfries & Galloway, Grampian, Lanarkshire and Tayside . Staffing shortages is the main factor (for years). Meanwhile, the Western Isles and Orkney are still without specialist help. Borders had to help NHS Western Isles online! Now stopped after a few months as Borders are also short on staff. The pain crisis throughout Scotland started long before covid.
