

Minutes. Meeting April 29, 2024 Online.

## **Scottish Parliament Cross Party Group on Chronic Pain**

MSPS : Miles Briggs, Fergus Ewing, Monica Lennon, Rhoda Grant, Jeremy Balfour.

Miles Briggs chairing

Andrew Searil, Andrene Maxwell, Margaret Coats, Ian Semmons, Lisa Megginson, Dorothy-Grace Elder, Kirstin Laing, Ewan Kennedy, David Caulfield, Michelle Wilson, Natalie Frankesh, Ken White, Dr Emma France, Hazel Borland, Victoria Abbott-Fleming, Paulo Quadros , Dr Jacqueline Mardon, Alex Thorburn, Julie Mackenzie, Catherine Hughes, Anne Hughes, Lee Mackie, Hussein Patwa, George Welsh, Kirsteen Campbell, Brian Whitters, John Thomson, Andrew Laing, Peter Mortimer, Gilly Dow, Sharon Turnbull, Soryia Siddique, Sidra Batool, Jacqui Tweddle, Amber Welsh, Mary Craig, Liz Barrie, Ania Withania Zwozdiak, Alex Stobart, Dr Patrick Trust, T. McCready, Alison Carey, Lucas Nicholson. 49 total

Organisations include: Action on Pain UK, Genetic Alliance UK, More than Fibro,

Fibromyalgia Assoc. UK, Stirling University, Burning Nights charity, Children's Health Scotland, North Highland Women's Hub, Centre for Integrative Care, Endo Borders,

**Membership keeps increasing:** Miles Briggs, chairing welcomed all. He said that we're delighted to welcome esteemed charities Burning Nights which aids Complex Regional Pain Syndrome, represented tonight by their chair and founder Victoria Abbott-Fleming, Children's Health Scotland. Ehlers-Danlos Support UK's Scottish help and Genetic Alliance UK, who represent rare, genetic and undiagnosed conditions which often cause chronic pain.

He thanked Rona Mackay MSP who was standing down after years as a convener, due to her work as chief whip with the SNP group.

MSP Christine Grahame, SNP had agreed to be a new supporter member.

**Secrecy from officials** Voluntary Secretary Dorothy-Grace Elder reported that there continued to be no proper information for patients

from the Pain Management Task Force after two years without any patients being allowed to take part in discussions. Around 20 officials were discussing privately the future of patient services.

One patient is now due to be appointed – Hussein Patwa had been chosen by officials and she thought him an excellent person but just one- maybe two- patient appointments after two years was not acceptable.

A strong discussion ensued over the secretary's research showing that a report commissioned by Clinical Priorities officials had claimed that some with chronic pain should be labelled "no impact" . Three learned bodies, including NICE, had written stating that this was not a recognised category with chronic pain.

The report cost the public purse £40,000. FOI showed that private researchers were used but they had reported being unable to find any with "no impact" But why three were later produced- and only from Inverness – was not explained.

Fergus Ewing MSP for Inverness and Nairn, Ian Semmons, chair of the charity Action on Pain and members of the group requested urgent action.

The meeting agreed that MSPs should write to Health Secretary Neil Gray and head of the Civil Service John-Paul Marks to explain the whole situation.

### **CHILDREN AND YOUNG PEOPLE IN PAIN: new research.**

Stirling University research found that "In the UK, few specialist services exist for managing children's chronic pain, and current services are inadequate."

**Dr Emma F. France, Associate Professor at Stirling University's Faculty of Health Sciences and sport gave a very illuminating talk, details of which have already been circulated to the group.**

We knew adult services are very short on help, but child pain services are way beneath that.

Few realise that between 20% and 35% of children and youths suffer non cancerous long term pain.

### **NHS HIGHLAND PAIN SERVICES**

The battle continues to protect one of our top pain services. With the Board refusing infusions and injections to new patients and a limited

number continuing only temporarily, patients are subjected to the stress of not knowing when their service would be harmed further. Fergus Ewing and some other Highland MSPs, have joined our cause and we arranged a “Highland” meeting.

**Endometriosis** : North Highland Women’s Health Hub

[n.highlandwwg@gmail.com](mailto:n.highlandwwg@gmail.com) had challenged the system for women in NHS Highland, One woman said: “It is now a year’s wait to see the consultant. I was offered self-management but it’s myself that runs SM in Highland!” Highland women reached out to ministers about pain management and the gynaecology service but feel “massively let down” and very disappointed in lack of activity around the issue. Women’s health is not progressing.

**MESH VICTIMS**: Mesh survivor Lisa told how a Government group on patient safety turned into “something too secretive”.

"They invited some patients to join but we had months of no information. It all got quite sinister, and quite cloak and dagger. I found it all too secretive and left.” There seemed to be two parts to the group – one for certain people and the other for the rest, including patients. Patients had not asked for the Alliance to represent mesh victims. (Mesh sufferers had long rejected a report by the Health and Social Care Alliance, a Government funded charity which got £5 million this year)

## **IDEAS FROM PATIENTS**

Hussein Patwa suggested a look at how to help pain sufferers at work.

Catherine Hughes said: “I’d like to see chronic Urinary Tract Infection (UTI )as a topic. It can be life threatening from sepsis risk and chronic UTI can be linked to endometriosis & several other conditions.”

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From the rare, genetic and undiagnosed conditions patient rep:- I just wanted to highlight that much of what we've heard tonight is replicated in the experiences shared by families affected by rare, genetic and undiagnosed conditions many of which involve chronic pain”.

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