

Long Covid CPG Meeting

8th September 2001 5pm-6pm

Minute

Present

MSPs

Jackie Baillie
Paul O'Kane
Alex Cole Hamilton
Jim Fairlie
Beatrice Wishart
Sandesh Gulhane

Invited guests

Helen Goss - Long Covid Kids
Sheban Begum - Long Covid Scotland
Connor Walker – Long Covid Scotland
Lesley McNivan Long Covid UK

Non-MSP Group Members

Paul O'Kane
David Blane
Kate McLachlane
Stuart McIver
Gail Carson
Susan Hedgely
Samantha Tully
Sheena Alalami
Dorothy Grace Elder
Paula Lally
Jennifer Syme
Esperanza Miyake
Sarah Boyack
Katherine Byrne
Beatrice Wishart
Jane Ormerod
Jasmine Mailley
Prof. Kay Cooper
Sarah Marshall
Sheeran Smith
Dr Tracy Ibbotson

Shaun Qureshi
Amy Small
Brian Whittle
Moira Newiss
Andrew Langford
Eddie Duncan
Freja Lundberg
Nicholas Sculthorpe
Christina Moriarty
Morag Connell
Jackie Baxter
Emma Davies
Barbara Melville
Miranda Curry
Leanne Mitchell
Cass macDonald
Lesley Walker
Ben Finch
Maria Timoney
Jenny O'Boyle
Rob Gowans
Ramsay Meldrum
Elizabeth Ritchie
Helen Gibson
Helen McCabe
Alison Love
Kyla Johnson
Callum O'Dwyer
Chris White
Kevin Bell
Richard Fernandez
Sarah Jayne Marshall

Apologies

Pam Duncan Glancy

Agenda item 1 Welcome

Jackie Baillie welcomes all attendees and discusses the fact that the next pandemic will be Long Covid
Chris White from Long Covid Scotland welcomes and explains the process of setting up the CPG

Agenda item 2 Electing Office Bearers

Jackie Baillie, Alex Cole Hamilton and Sandesh Gulhane are nominated by Beatrice Wishart to be co-convenors of the CPG. Paul O'Kane seconds this nomination

Long Covid Scotland is nominated as both secretariat and treasurer. Jackie Baillie formally nominates LCS for both and Sandesh Gulhane seconds.

Agenda item 3 Hearing from those living with Long Covid

First speaker – Helen Goss from Long Covid Kids

- Helen's daughter Anna has LC and is 8 years old. She has been ill for 17 months and is still too unwell to go to school.
- She is on a huge amount medication and has brain inflammation from LC. She can't see her friends and she is unrecognisable as the child that she used to be.
- Scottish and UK Govt messaging is that kids don't get Covid and if they do, then it is mild.
- It took 8 months to see a paediatrician. It took 12 months before she got a proper diagnostic test and only finally got medication last month after finally going private.
- Her NHS Diagnosis is chronic fatigue syndrome and PANS.
- This is one of thousands of stories and the current number of Covid cases in young people means there will be thousands more.
- In the last week in Scotland, there were over 2,000 cases every single day in under 19s. In the first three weeks of school from 16 August to 5 September, there was 38,177 cases of Covid in 0-19 years in Scotland. 1% will be hospitalised. 14% will suffer LC. 0.01-0.3% could die from this which means 3-11 children.

Second speaker – Sheban Begum

- Sheban used to work for a charity based in Edinburgh for 19 years and worked to promote the rights of disabled people.
- She became unwell in January 2020 and was told that it was a chest infection but had all the symptoms of COVID-19. Between February and April 2020 was given 3 courses of anti-biotics
- On GPs advice she took off more annual leave but nothing could make a difference. She was told that she had post viral fatigue. GP finally admitted that she probably had COVID-19
- Went on extended sick leave in October 2020
- In Jan 2021 she felt a shift in relationship with employer, her pay was halved, and she was referred to an OT.
- She was dismissed on the grounds of ill health and is now in the middle of an appeal. Her TU sees this as disability discrimination
- The use of usual sickness/absence policies are not fit for purpose for people with LC
- Many people are experiencing discrimination and judgement. Some employers are questioning the GP's diagnosis
- Employers are pushing people into poverty. The Scottish Govt. are letting thousands of people down. The SG must put financial support in place for people with LC

Third speaker – Conor Walker

- Used to work 40 hours a week and swam 2km a day before work/used to row as part of a team and cycled
- Initial symptoms were considered mild but ended up developing pneumonia
- Healthcare workers have been fantastic and have also received the short end of the stick. This isn't about people with lived experience vs. health care workers, they deserve resources together
- Conor is now officially disabled. Navigating the healthcare system are tools of exhaustion. He says that the NHS is a nightmare to navigate when healthy, never mind when you are sick.
- He is a civil servant and is now going into debt every month trying to access care
- There are over 160 symptoms of LC. Needs to be a concerted effort to bring together specialisms. Scotland is the only country within the 4 nations which doesn't have LC clinics

Fourth Speaker – Lesley MacNiven

- This is a human rights issue. There are significant systemic challenges with LC. It is an opportunity to analyse where existing systems are dysfunctional
- LCS assumed that the SG would be receptive of the work of LCS but they haven't been.
- Met with Jeane Freeman who gave the impression that she would help LC sufferers
- LC sufferers were told to stay home unless your lips turned blue
- Many people had to write final letters to their loved ones and the only advice was that you will be better in 10 days
- The pandemic has created a radical grassroots patient led campaign group. There are 40,000 people in the Long Covid UK support group

Agenda item 4 General Discussion

Alex Cole Hamilton

- Alex is proud have been elected as co-convenor.
- Believes that what tonight is devastating.
- Pledges that the MSPs on this call believe LC patients, will take them seriously and fight for the care pathway that they need

Sandesh Gulhane

- Wrote a paper in June after speaking to 3rd sector orgs and patients on Long Covid.
- Believes that can't treat LC under the current models of care pathways that we have. If we can get the clinics and begin to move forward then we can begin to treat this, but we shouldn't wait for perfection, there is lots that can be done now

Cass MacDonald

- Cass is an LC sufferer and has been on her own throughout this and had to be really reliant on asking people for help. She has been in and out of work since April 2020 and has a number of neurological issues and bad tremors
- Cass believes that LC must be recognised as a disability

Amy Small

- Amy is a GP and LC sufferer. She met with Jeane Freeman at Christmas as part of a group of doctors who have LC. GPs feel helpless about what to do next. She has looked at LC services around the UK to see best practise. Hertfordshire is a great model. Lothian will only fund a specific service if they can prove it is saving money. There is no funding mechanism for moving funds from secondary care to primary care. Until money comes from the govt. then there will be no services.

Jim Fairlie

- Believes that there have been powerful testimonials tonight and is very emotional about how badly this is effecting people. Jim is on the Covid recovery committee and will raise LC with colleagues. Everyone has his absolute support to get all the help that they can

Agenda item 5 Closing remarks

Jackie Baillie There have been hugely powerful testimonies but LC patients don't need praise, they need action

One action point to be taken forward is that a letter is sent from the CPG to the Cabinet Secretary requesting a meeting. He must hear from LC sufferers

- Aims and objectives will be agreed by the office bearers. Secretariat
- All members agree with the above action points

Chris White Thanks to MSPs and all those who spoke. Meeting is closed