Cross-Party Group Minutes

Meeting Minutes:

Cross Party Group Title:	CPG on Long Covid
Date of Meeting:	26/01/2022
Location:	Zoom

In attendance:

Name:	Title:
Rhun ap Iorwerth MS (Co-Chair)	Member of the Senedd
Hefin David MS (Co-Chair)	Member of the Senedd
Sarah Murphy MS	Member of the Senedd
Heledd Roberts	Office of Rhun ap Iorwerth MS
Alex Still	Office of Hefin David MS
Ken Moon	Office of Heledd Fychan MS
Georgia Walby	Long Covid Wales
Dr Ian Frayling	Long Covid Wales
Sian Griffiths	Long Covid Wales
Edward Sliz	
Dr Helen Davies	Respiratory Consultant at Llandough Hospital, Cardiff & Vale Health Board.
Sharon Dutton	Office of Dr Helen Davies
Mark Smith	Wales Online
Theresa Howe	
Dee	FTWW
Julie James	
Dale Thomas	
Rhiannon Moore	
Helen James	
Emma Kavanagh	
Will Ayes	
Lee David Bowen	
Leanne Jagne	
Meena Upadhyaya	
Kat	
Eleri Morgan	
Katie Goddard	

Gail Kris Helen Marchant J Mclellan G Williams Chloe James Geraint Jones Elena Collins	RCGP
Joanne E	

Apologies:

Name:	Title:

Summary of Meeting:

Speaker: Dr Helen Davies, Respiratory Consultant at Llandough Hospital, Cardiff & Vale Health Board.

Dr Davies has seen over 300 Long Covid Patients. She told us that there are approximately 76,000 long covid sufferers in Wales and that this is probably an underestimate. Of these, 73% are female (reason unknown) and the average age is 49. A quarter of long covid sufferers have never tested positive due to tests not being available to them. However, in these cases a clinical diagnosis should be accepted as an alternative.

Initial findings of 100 patients in a trial run in Cardiff & Oxford shows that 25% of people have been unable to return full time to work and a further 33% are on amended duties.

Dr Davies gave us an update on the research programmes that are currently running and/or recruiting in Wales. Anyone wanting to take part in the long covid research programmes should contact Dr Davies's secretary Sharon Dutton at Llandough Hospital (available through the main hospital switchboard). At the end of the talk Georgia Walby thanked Dr Davies for all her work with long covid sufferers and explained what a huge relief it has been for patients to be seen by a doctor who has experience of long covid and is familiar with the issues caused by this new illness.

Georgia gave an update from Long Covid Wales:

The Petitions Committee has responded to our reply to the Welsh Government (Give us One Stop Shop Clinics for Long Covid in Wales petition). The Petitions Committee has agreed to write to the Health Minister asking how services are being shaped and how patient voices are being heard on this matter.

In response to the First Minister's recent comments, Georgia confirmed that our members at Long Covid Wales are in large numbers being forced to use private healthcare due to the long waiting lists and lack of referrals available on the NHS for long covid and that the GP referral route is still proving extremely problematic for many of our members.

Leanne Jagne gave an update to the meeting: Leanne's daughter is 17 years old and living in the Cwm Taff Healthboard area. She is currently off school and bed bound with long covid and has been refused a referral to see Dr Davies and the Cwm Taff Health Board will not fund it. Leanne has also asked her GP to refer her daughter to the local Long Covid service but the GP has said she must wait until she is 18 as it's a service for adults only. There is no long covid service for children.