Cross-Party Group on Lung Health
Grŵp Trawsbleidiol ar Iechyd yr Ysgyfaint

24 September 2024

Attendees

Chair: John Griffiths (Aelod o'r Senedd | Member of the Senedd)

MS Attendees

Mike Hedges MS

Non MS Attendees

Alice Spencer
Dr Anthony Gibson (NHS Executive)
Bec Miller (secretariat, Asthma + Lung UK)
Cheryl Samuel
Jackie Radford
Jane Douglas
Joanne Oliver (NHS Executive)
Joanne Popham
Jonathan Morgan
Josephine Cock
Joseph Carter (Asthma + Lung UK)
Kristina Kunsteinaite
Leigh Mair
Lis Murray (Action on Pulmonary Fibrosis)
Louise Elliott (ASH Wales)
Meg Lewis (Action on Pulmonary Fibrosis)
Mike Armitage
Owen Thomas (MS support staff)
Pam Lloyd (Betsi Cadwaladr University Health Board)
Rebecca Heathcoate
Rhodri Curtis
Ryland Doyle

Steve Jones (Action on Pulmonary Fibrosis)
Susan Lang
Val Maidment

1. Welcome and Introduction

John Griffiths MS opened the meeting, welcoming all attendees. Due to time constraints, attendees did not introduce themselves, but **John Griffiths MS** invited MSs and staff to make their presence known in the chat.

He requested participants to mute their microphones unless speaking and to submit questions via the chat function. He also noted that the meeting was being recorded.

2. Previous minutes and matters arising

The minutes of the previous meeting were approved. There were two matters arising from the previous meeting:

- **Action 1:** A letter was sent to the Cabinet Secretary regarding survey findings, though no response has been received. **Joseph Carter** stated that the secretariat would follow this up.
- **Action 2: Anna Francis** was to email Josephine Cock regarding wood smoke and asthma. This action was completed.

3. Discussion on Pulmonary Fibrosis

Presentation by Lisa Murray (Policy and Public Affairs Officer, Action on Pulmonary Fibrosis)

Lisa Murray provided an overview of pulmonary fibrosis and the significant challenges patients face. She emphasized the need for better awareness and advocacy, saying: *"One of the biggest issues we face is the delay in diagnosis. It can take up to two years for some patients to get a clear diagnosis, which significantly impacts their health and quality of life."*

She spoke about the role of Action on Pulmonary Fibrosis in supporting those affected by the condition: *"At Action on Pulmonary Fibrosis, we are committed* *to raising awareness, improving access to treatment, and supporting research that can lead to better outcomes for patients."*

Lisa concluded by stressing the importance of continued advocacy and collaboration: *"We need to keep pushing for better resources, better care pathways, and greater understanding of this disease, both among healthcare professionals and the public."*

Lisa's presentation will be made available with these minutes.

Presentation by Meg Lewis (Patient Volunteer, Action on Pulmonary Fibrosis)

Meg Lewis shared her personal experiences living with pulmonary fibrosis. Reflecting on the emotional journey of receiving her diagnosis, she said: *"When I was first diagnosed, it was overwhelming. I didn't know where to turn or what to expect. It felt like I was stepping into the unknown."*

Meg also discussed the day-to-day challenges of managing the condition and how vital support networks have been: *"What's helped me the most is the community I've found through Action on Pulmonary Fibrosis. Knowing that there are others who understand what I'm going through makes all the difference."*

She ended by emphasizing the importance of support and raising awareness: *"People need to know they're not alone. Support is out there, and we need to make sure every patient has access to the information and resources they need."*

Questions following the presentations

Pam Lloyd commented to reassure the group that, while there are no specialist ILD nurses in Betsi Cadwaladr Health Board, patients are cared for by respiratory nurses and are now managed in Wales without being outsourced to England- though the affiliation with Aintree Hospital continues.

Steve Jones, a trustee of APF and lung transplant recipient, commented on how debilitating breathlessness can be. He explained that planning for end of life care, for those who cannot have a lung transplant, is poor. He recommended utilsing APFs support groups.

Meg responded to Pam's comment by explaining that NHS staff in Wales are doing a great job however resources and training for a rarer condition like ILD does not appear to be there, in her experience. She also highlighted some of the logistical issues of having a lung transplant and the unlikelihood of finding a viable organ. **Meg** mentioned that the general public lacks awareness of the reality of having a lung transplant. She commented that she has not found the mental health support, as a person awaiting a transplant, to be adequate.

Lisa Murray emphasised the need for dedicated ILD time for respiratory teams and explained that APF are launching a toolkit for healthcare professionals which will help to support them.

4. Next Steps and Close

The meeting concluded with a brief discussion on the next steps regarding the actions mentioned and ongoing efforts to address lung health issues, particularly around pulmonary fibrosis. The group emphasized the need for continued advocacy and support for those affected by the condition.

John Griffiths MS thanked everyone for their contributions and closed the meeting.