

Cross-Party Group on Lung Health

Grŵp Trawsbleidiol ar Iechyd yr Ysgyfaint

Minutes from 13 June 2023

Attendees

MSs

John Griffiths MS (supported by Owen Thomas)
Altaf Hussain MS

Non MSs (23)

Joseph Carter - Asthma + Lung UK Cymru (Secretariat)
Alice Spencer
Bernardine Rees
Catherine Chiu
Chris Davies
Chrissie Gallimore
Dee Montague
Josephine Cock
Julie Mayes
Jonathan Morgan
Lyn Lording
Megan Lewis
Neil Harris
Pam Lloyd
Philip Webb
Rebecca Heathcote
Stephanie Philips
Steven Adair
Valerie Ann Tweedie
Val Maidment
Verdun Moore
Victoria Hunt

1. John Griffiths MS - Welcome and introductions

John Griffiths MS started the meeting and thanked everyone for attending. asked if any MSs or support staff wanted to introduce themselves.

John Griffiths MS explained that there were two presenters today, **Catherine Chiu** and **Joseph Carter**. He encouraged people to put any questions they had in the chat.

2. John Griffiths MS - Apologies

The following MSs have sent their apologies:

Natasha Asghar MS
Cefin Campbell MS
Tom Giffard MS
Sian Gwenllian MS
Mark Isherwood MS
Samuel Kurtz MS
Darren Millar MS
Rhianon Passmore MS
Carolyn Thomas MS
Sioned Williams MS

3. John Griffiths MS - Minutes of the last meeting

None of the MS present were at the previous meeting, so the minutes couldn't be signed off. **Joseph Carter** will speak to the MSs who attended to get them signed off.

Action: Joseph Carter to liaise with MSs to sign off the minutes.

* Mike Hedges MS and Huw Irranca-Davies MS were happy to sign the February 2023 minutes off as a true and accurate record.

4. Joseph Carter - Matters arising

The following actions had been agreed at the previous meeting

- **Action: Joseph Carter** to liaise with **Altaf Hussain MS**
 - Completed
- **Action: Joseph** said he would take all the concerns raised to a meeting with the Health Minister on 20 March 2023
 - Completed

5. AGM - Election of Chair and Secretariat of the CPG

Nominations were received from **John Griffiths MS** as Chair and Asthma + Lung UK Cymru as Secretariat.

Chair - **Altaf Hussain MS** proposed **John Griffiths MS** as chair, and he accepted.
Secretariat - **Altaf Hussain MS** proposed Asthma + Lung UK Cymru, whilst **John Griffiths MS** seconded it.

Actions - Joseph Carter to submit AGM paperwork to the Table Office

6. Catherine Chiu, Asthma + Lung UK - Women with asthma

John Griffiths MS introduced Catherine Chiu and thanked her for presenting.

Catherine started her presentation by explaining what hormones were and what they did.

For anyone who's taken biology GCSE, you'll be familiar with the idea of chemical messengers but it really is the best way to describe what hormones do. Hormones are produced in various organs around the body, for example insulin which regulates sugar levels, is produced in the liver.

Hormones then travel via our blood stream all over the body, getting cells ready to do whatever it is they need to do.

In our case, sex hormones, are produced in the ovaries and testes and busy about regulating all sorts of things to do with reproduction - for women specifically, these are things like kick starting puberty, regulating menstrual cycles, getting ready for and guiding the body through the pregnancy or menopause. That's what they're job is, but over the last few years, we - as in scientists, researchers, and the real life women with asthma - have noticed that they seem to be going above and beyond their job description and are getting involved with our breathing. Or at the very least are linked with the way our lungs function.

Sex hormones, particularly oestrogen, are involved in airway inflammation. We understand that oestrogen increases inflammation and testosterone decreases inflammation - it's a lot more complicated than this but this see saw effect is a good one to remember for now. Specifically, we know that oestrogen is fiddling around with our smooth muscles in our airways (the muscles are the things that control movement), we're just not sure what yet.

- Asthma affects women more, and in worse ways, than men
- More women than men have asthma
- Women are less likely to recover completely from asthma
- They experience more attacks - women aged 20 to 50 are 3x more likely to be hospitalised
- They're more likely to die - almost twice as likely to die

Asthma + Lung UK are investing £1.2 million trying to better understand women with asthma.

They have funded two categories of project.

Unlocking answers

- What are our genetics doing? We already have the answers in unconnected data sets. Professor Timothy Hinks, Oxford
- What's oestrogen doing in our small airways? Professor Mona Bafadhel, KCL
- How do exogenous sex hormones affect asthma? Syed Ahmar Shah, Edinburgh

Testing solutions

- Can medicine used to treat diabetes be repurposed to treat asthma? Dr Chloe Bloom, Imperial
- How linked are our body clocks and asthma, and does the time you take your asthma medicine matter? Dr Hannah Durrington, Manchester
- Can dietary supplements prevent asthma attacks by guarding against viruses? Dr Cornelia Blume, Southampton

7. Alice Spencer - the patient perspective

John Griffiths MS introduced **Alice Spencer** and thanked her for sharing story.

Alice explained that she was 46 years old, lives in Cardiff and is the main carer for her daughter.

She was diagnosed with asthma in her 30s. There was a family history of asthma and she thought she'd be able to manage it through exercise, but this proved challenging as she had exercise induced asthma.

She went to the GP but was only given a salbutamol inhaler. This wasn't enough so she was prescribed a brown inhaler as well, but this made symptoms worse, so she didn't use it. Alice's asthma remained poorly managed, she kept coughing, wheezing and it was poorly controlled for a couple of years. She thought this was what life with asthma was going to be like.

In 2016, she fell pregnant and her symptoms disappeared. She saw an Anaesthetist and he asked about her asthma. She hadn't thought about it and had wondered if it was cured. After the birth of her daughter it came back worse than before. Her daughter has cystic fibrosis and her care need took priority and as a result Alice's asthma deteriorated, she didn't have the time to exercise and manage it. When her daughter was a toddler, Alice visited her GP who tried her on a different inhaler (Fostair - twice a day) and she now knows her triggers - pollen, stress, changes in air pressure, humidity and any viruses. Being a carer with asthma and having someone else's needs to put first is really challenging.

At 44 she was diagnosed as She has been diagnosed with perimenopause. Her asthma worsened and she developed migraines. Both were linked to her monthly cycle. She was prescribed HRT but this made her migraines worse.

John Griffiths MS invited people to ask questions of **Catherine** or **Alice**.

Dee Montague suggested that the evidence around asthma in women should be shared with Welsh Government as part of the Quality Statement for women and girl's health. She asked about patient involvement in designing the research.

Catherine explained that researchers need to show that they have involved service users in developing their research questions before they can be considered for

funding. She said that the Asthma + Lung UK Respiratory Insight service can help with this.

Meg Lewis talked about her own condition Hypersensitivity Pneumonitis. She has started to notice her symptoms seem to change depending on her monthly cycle. She has started to develop migraines from her medication and has been told not to get pregnant as the medication could harm the foetus.

Catherine said that oestrogen affects lung inflammation so it is likely to impact on other lung conditions as well. There was already some evidence to link asthma to oestrogen so the project started here first, but we hope to use it to springboard into other lung conditions.

Philip Webb wanted to flag to the group the work Respiratory Innovation Wales are doing on indoor air quality. He said the data indicates that chronic exposure to low levels of gases and particulates is the root cause of respiratory health and wellness. They are working with a number of collaborators on changing this from both a population level through SMARTER, intelligent and net zero build environments (homes, public spaces and places of work) and looking at the link between particulates gasses and respiratory health and wellness.

Catherine said that air pollution is impacting all of us, causing some lung conditions and worsening others.

Dee said that **Philip's** point fits in with the social model of disability, which Welsh Government have committed to implementing throughout public services as a result of the Locked Out report (impact of covid on disabled people). Clean air could mean fewer people are disabled.

Lyn Lording said she was only diagnosed with asthma when she was 62, post menopausal and had respiratory failure. She asked whether we could do more to raise awareness with GPs. Catherine agreed we needed to do more and hoped the results of the new research would help to raise awareness.

Action - Joseph Carter to draft a letter for John Griffiths MS to send to the Minister for Health and Services on women with asthma

Action - Joseph Carter to circulate the women with asthma presentation with the minutes

8. Joseph Carter - Senedd lung health debate

Due to time, Joseph Carter did not give his presentation at the meeting, but a summary is included here and the presentation will be circulated with the minutes.

On 17 May 2023, Members of the Senedd debated a Plaid Cymru motion on lung health. The motion read:

To propose that the Senedd:

1. Notes:

- a) that 1 in 5 people live with a lung condition in Wales;
- b) that Wales has the highest level of respiratory deaths in western Europe;
- c) that respiratory services have not recovered post-pandemic, with waiting lists for pulmonary rehabilitation being as high as three years in some parts of Wales;
- d) that the Welsh Government has developed a new quality statement but there is no implementation plan.

2. Calls upon the Welsh Government to develop an improvement plan for respiratory disease to transform improve the lives of people living with lung conditions.

There was a good discussion from across the political spectrum.

Rhun ap Iorwerth MS described the lung disease as a public crisis and called for Welsh Government to take action to reduce respiratory deaths. He said less than 10% in BCUHB are receiving the five fundamentals of basic COPD care, and he argued that the Quality Statement would be ineffective without an implementation plan.

Russell George MS called on the Welsh Government to make lung health a priority. With over 74,000 people living with COPD, he said this was the equivalent to a whole constituency, to illustrate the scale of the problem. He said people were forced to use their savings due to waiting lists.

Mabon ap Gwynfor MS talked about his own experience of having asthma, air pollution and housing. He called on the Welsh Government to do more to tackle air pollution which cause and worsen lung conditions. He said that children who live in houses with mould and damp are up to three times more likely to suffer from constant coughing or wheezing than those who live in dry ones.

John Griffiths MS spoke about the importance of preventing lung disease. He welcomed the Environment Bill but called for more funding. John said the most deprived parts of Wales still have smoking rates of over 21% and said we must do more to support them.

Jenny Rathbone MS spoke briefly about the dangers of idling vehicles generating dangerous amounts of air pollution and causing lung conditions. She said the local authorities have power to tackle this problem now and could be doing more.

Sioned William MS talked about her grandmother dying of asthma before she was born. She talked about the greater proportion of women with asthma and not enough research being done to understand the role of hormones. In Aberavon, Sioned said 75 per cent of surgeries and 11 per cent of schools are in areas that breach the WHO limits for NO₂.

Dr Altaf Hussain MS said that South Wales West sees some of the highest rates of respiratory deaths in the United Kingdom and western Europe. It is therefore vital that we put in place an improvement plan for respiratory diseases and do all we can to tackle our horrendous record on respiratory deaths.

Responding to the debate, **Eluned Morgan MS** said poor respiratory disease outcomes reflect historic high smoking rates air pollution and industry. She talked about the success of the respiratory apps and argued that the new NHS Wales Executive and the Quality Statement would lead to change.

The motion was defeated, with 24 MSs in favour and 25 MSs against.

Action - Joseph Carter to circulate the lung health debate presentation with the minutes

9. **Joseph Carter** - Next meeting and the work ahead

John Griffiths MS asked **Joseph Carter** to talk about the future meetings. **Joseph** thanked everyone for their contributions and for making the time to come and confirmed that the next meeting would be on 12 September 2023. They were considering options for speakers including Respiratory Innovation Wales on indoor air pollution.

10. **John Griffiths MS** - Any other business

John Griffiths MS asked if anyone had any other business. They didn't, so he thanked everyone for attending and brought the meeting to a close.