

Meeting of the Cross Party Group on Lung Health

19 Sep 2017 5.30pm-7pm

CR4 Scottish Parliament

MINUTES

Attendance

MSPs

Emma Harper MSP (Convener)

Alexander Stewart MSP

Members

Irene Johnstone	British Lung Foundation (Scotland)
Claire Shanks	British Lung Foundation (Scotland)
Alison Sweeney	British Lung Foundation (Scotland)
Katherine Byrne	Chest Heart & Stroke Scotland (CHSS)
Jill Adams	Chest Heart & Stroke Scotland (CHSS)
Lorna Stevenson	Chest Heart & Stroke Scotland (CHSS)
Phyllis Murphie	National Advisory Group for Respiratory Managed Clinical Networks
Linda McLeod	Breathe Easy Clackmannanshire (BLF Scotland)
Andrew Deans	Royal Infirmary Edinburgh
Mostyn Tuckwell	Breathtakers: Action for Bronchiectasis (CHSS)
Gordon Thomson	Braveheart Association
Elaine McKay	NHS Greater Glasgow & Clyde
Alan Kirk	Golden Jubilee National Hospital
Caroline Murray	Airsonett UK Ltd
Margaret Stevenson	NHS Fife
Tom Fardon	NHS Tayside / STS / NAG
James Paton	NHS GGCHB
Yvonne Hughes	Cystic Fibrosis Trust
Anne Crilly	BREATH / UWS
Steve Jones	Action Pulmonary Fibrosis
Phyllis Craig	Clydeside Action Against Asbestos

Guests

Dr George Chalmers	Consultant Respiratory Physician, Glasgow Royal Infirmary
Annette Smith	Clydeside Action Against Asbestos

Apologies

Fergus Donachie
Agnes Whyte
Allison Brisbane
Julie MacDougall
Krisnah Poinasamy
Gourab Choudhury
James Wildgoose
Michelle Duffy
Jane Ferguson

John Lockart

1. New members

- **Colin Brett** - sits on the COPD managed clinical network at NHS Dumfries and Galloway
- **Steve Jones** - Trustee at Action Pulmonary Fibrosis
- **Anne Crilly** - member of the BREATH project
- **Margaret Stevenson** - respiratory nurse consultant

2. Minutes of last meeting, 30th May 2017

- 2.1 One amendment to the minutes was noted - "Irene Harper" corrected on page 6 to "Irene Johnstone".
- 2.2 Minutes ratified.

3. Update on progress since last meeting

3.1 Irene Johnstone updated members on some key developments in air quality. BLF Scotland submitted a response to the Environment, Climate Change and Land Reform Committee's inquiry into air quality. The Scottish Government's new Programme for Government includes further commitments to improving air quality and Transport Scotland has launched a public consultation on Low Emission Zones. All welcome developments but the BLF and CPG members need to keep pushing for greater and measured public health outcomes.

3.2 Emma Harper informed members that Parliamentary Questions and Answers had been shared by the Secretariat and encouraged members to forward any possible questions to Claire Shanks (BLF Scotland) or Kath Byrne (CHSS).

4. Topic Discussion: Coordination and Consistency of Service Provision

The Convener introduced the meeting's two speakers, and highlighted the CPG's ambition to improve Scotland's lung health through raising political awareness and by promoting a strategic approach to tackling the agenda.

At the inaugural meeting in November members highlighted the importance of national action to tackle local variation in practice and the need for better coordination of research into lung disease. There are challenges because of the relatively small scale of some diseases and a coordinated network is needed which identifies where expertise is sited. This is particularly so if the disease is much more complex to diagnose and manage.

This meeting falls during **Idiopathic Pulmonary Fibrosis Week (IPF)**. IPF is an incurable lung condition with no known causes or cure and Scotland has the one of the highest incidence in the UK.

This month the British Lung Foundation will publish their report, *A Map for Better Care*, calling for improved services for people with Interstitial Lung Disease (ILD), the umbrella term for over 200 conditions of which IPF is one.

Dr George Chalmers works in the Glasgow Royal Infirmary, is Co-Chair of the Scottish ILD Group and is a leading clinician in ILD/IPF services in Scotland. Mr Mostyn Tuckwell is from Chest Heart & Stroke Scotland's Action for Bronchiectasis support group. Figures from the BLF Battle for Breath report suggest the number of people living with bronchiectasis is possibly four times higher than had been previously thought.

4.1 Dr George Chalmers - IPF services in Scotland

- When diagnosed, many patients are relieved not to have cancer, but that's before they come to understand the severity of IPF.
- IPF falls under the umbrella of interstitial lung disease (ILD), and results in continuous scarring (fibrosis) of the lungs. IPF accounts for around 40% of all ILD cases.
- Non-fibrotic ILDs can usually be reversed by removing the cause or agent, eg. Something in the workplace. Fibrotic ILDs cannot be reversed. People can often feel fine and experience minimal symptoms for some time until they get an infection - this usually leads to patients experiencing worse lung capacity and requiring oxygen treatment.
- It's a rare disease but numbers are great enough for it to be "not really that rare".
- There are roughly 500 deaths per year in Scotland. Survivability is worse than most cancers, with mean survival rate of 2-5 years, less than 15% of patients living for 10 years after diagnosis.
- There is a real increase in the number of cases of IPF in Scotland, but the reasons are not entirely known. An ageing population can explain it only in part.
- One of the key challenges in ILD/IPF is diagnosis - it's a rare disease and the symptoms of breathlessness and cough are common.
- Getting access to specialist services for an accurate diagnosis is difficult. Currently a "coalition of the willing" in Scotland trying to provide a specialist service but it needs formalising and strengthening - Health boards needs to require more training. Also "desperately lacking" input from radiology.
- There is currently a degree of support from health boards, the government and from external organisations like the BLF which provide very good patient information, education, support, advocacy etc. But more needs done.
- There are only three ILD Nurse Specialists in Scotland and we desperately need more as they are incredibly valuable and essential to service provision.
- Access to drugs and oxygen treatment is challenging and varied.
- NICE Quality Standards for IPF mean that all health boards have access to an ILD multidisciplinary team (MDT), but this can be very limited, perhaps only once a month.
- Pulmonary rehabilitation works best for people who are at their worst, but many aren't getting to PR.
- Palliative care planning for IPF is really lacking. Less than 15% of patients are referred to palliative care, whilst many are only receiving any end-of-life discussions within the last 3 days of life. Despite wishes to die at home, 60-80% of people are dying in hospital.

- Dr Chalmers wants to see Scottish Government support for -
 - Specialist/MDT process
 - admin support
 - Specialist Radiology time
 - ILD Nurse Specialist training & appointments
 - ILD Specific Pulmonary Rehabilitation
 - Palliative Care Services

4.2 Mostyn Tuckwell, Breathakers Action for Bronchiectasis support group (CHSS) - Living with bronchiectasis

- Mostyn Tuckwell asked members to think of an important date and remember it until the end of his presentation.
- Bronchiectasis is less well known than some lung disease like COPD and asthma, and is often confused with bronchitis.
- Bronchiectasis causes a build-up of mucus and phlegm in the airways, which leads to difficulty breathing and infection.
- Mostyn was a “typical case” - it was after a series of increasingly debilitating chest infections that he was diagnosed. This came as a shock as he had always lived a healthy and active lifestyle.
- There is no cure for bronchiectasis but people can live active lives if with the help of exercise, pulmonary rehabilitation, medicine and, Mostyn would argue, a positive outlook. Mostyn has seen the benefits of PR for people with bronchiectasis and wants far more people to get access to it.
- The Breathakers support group was set up with support from Chest Heart & Stroke Scotland, for both people with bronchiectasis and their families. On top of the regular meetings, the group hosts many different events, quizzes, social outings etc.
- The group meets in a hospital, which means that there is plenty of medical advice to hand. The group holds meetings on clinic days, which means that members are available to speak to anyone who might have just received a diagnosis.
- The Breathakers launched a website in January 2016 which features patient stories, meeting updates and NHS-approved information on the disease, such as information on chest clearance and exacerbations. They also want to design an information booklet.
- The group also set up a clinic table which provides advice and support to people receiving a diagnosis at RIE.
- Mostyn closed by reminding CPG members that he had asked them to think of an important date. This is because for most people who receive a bronchiectasis diagnosis, that date becomes the most important to them.

4.4 Questions and discussion points

- Linda McLeod asked some questions on behalf of some absent Breathe Easy support group members, including a non-smoking member who was diagnosed with emphysema and then IPF, and another member who had queries around medicines and exercise for bronchiectasis. Dr Chalmers said the emphysema diagnosis was potentially a misdiagnosis considering the person did not smoke - highlighting again the difficulties in diagnosing lung conditions.

- Dr Fardon runs the bronchiectasis service in NHS Tayside along with Professor James Chalmers - one of only three in the UK, with the other two in Papworth and Brompton. He said there has been a real “guidelines vacuum” for years regarding bronchiectasis. The service started in 2009 and has around 800 people using it in the Tayside area alone. Dr Fardon reiterated that the best treatment for bronchiectasis was exercise and pulmonary rehabilitation, and that he would like to the amount of PR available in Scotland (for all lung conditions) to treble.
- Steve Jones was an IPF patient for 8 years and had a successful lung transplant. He said there is a lack of PF support groups in Scotland (currently only 3) and that the value of support groups cannot be underestimated.
- Emma Harper reminded members that NHS Borders is without any PR services, which is not good enough. She echoed the sentiment about support groups; having visited several support groups she has seen the value and benefit to people for herself.
- Several members spoke of the benefit of support groups. Phyllis Craig told members that Clydeside Action on Asbestos now has 10 support groups, which include referrals to PR. Gordon Thomson said the Braveheart Association has a non-disease specific support group system that also has many benefits for patients.
- There was praise from several members for the clinic table developed by the Breathtakers. Dr Fardon has said that this model was copied in Dundee and patients have said it’s a fantastic resource - there is an “appetite” amongst patients to learn about their condition. Mostyn Tuckwell said it’s a simple idea that could be potentially rolled out across Scotland.
- Dr James Paton spoke on paediatric services. He says that bronchiectasis affects children as well as adults, and there is a growing clinic for children with non-cystic fibrosis bronchiectasis. He hopes that earlier diagnosis of bronchiectasis in children should help alleviate some problems in adulthood, but there is currently no equivalent service for adults. Dr Fardon agreed that transitioning from children to adult services is difficult due to gaps, which again highlights the need for a national co-ordinated MDT for bronchiectasis.
- Elaine Mckay says PR uptake needs to increase, but there also needs to some form of follow-on programme or service in place. NHS GGC is doing quite well in this regard. Linda Mcleod said her Breathe Easy support group has recently got council money to set up a Tai Chi group for members.
- Several members engaged in a discussion on data and how more and better use of data could help with many of the aforementioned problems. Dr Chalmers said the system currently being used in Glasgow is a private paid-for service, which will at some point come to an end - there needs to be a replacement. We cannot wait for patient’s to demand services - “provide it and they will come.”
- Dr Paton said there is currently no registry data for non-CF bronchiectasis in children. Dr Chalmers said there is almost zero compliance across Scotland for recording PF data. Dr Fardon said there are some “political reasons” that people in Scotland aren’t inputting data into the BTS registry. Steve Jones said there is no UK registry for PF.
- Andrew Deans said there is no registry data for IPF that results from alpha-1-antitrypsin deficiency. There is currently a 22-year gap in life expectancy between the UK and USA for this disease (UK being worse), and he believes poor data gathering is a factor in this.
- Frustration was voiced by members at the financial cost of getting data from Information Services Division (ISD) Scotland.

- Kath Byrne reminded members of the recent report from SPRAG on PR, which evidenced what we have known about the poor and varied uptake of PR across Scotland.
- Irene Johnstone spoke about an IPF Meet the Expert event hosted that day by BLF Scotland, with patients highlighting the inconsistency not only in access to PR and support groups, but also with access to drugs, diagnosis etc. It requires a true MDT approach to fixing the problem. Dr Chalmers said one of the real problems for IPF patients is travel, so local teams are needed in order to reach patients.
- Dr Fardon questioned whether PF patients should have a specific and separate PR service. Dr Chalmers said that patients often want to know that a service is relevant to them, which was echoed by Andrew Deans who said the evidence, whilst limited at just five papers on PF PR, concludes that PF patients have a high drop-out rate because they want a specific service.

5. Next Steps

- I. The Secretariat and members will identify any further Parliamentary Questions which could be raised, and where clarification is needed on previous answers received.
- II. Considering the fact some lung diseases are rare, such as IPF, Emma Harper suggested that CPG members look into linking up / reaching out to the CPG on rare diseases.
- III. Phyllis Murphie and Irene Johnstone said that momentum needs to be kept up on getting tangible evidence from the Scottish Government that it is committed to implementing the Respiratory Quality Improvement Plan. Emma Harper has already written to the Cabinet Secretary asking for an update on the plan. She will share this response with members when it comes.
- IV. Emma Harper reminded members that a debate to mark World COPD Day will be taking place in the Parliament on Tuesday 14th November, and encouraged everyone in the CPG to ask their local MSP to engage in the debate as this was an opportunity to lobby Scottish Government on many of the issues that have been raised at CPG meetings.
- V. BLF Scotland has secured funding from Dolby Vivisol for the evening reception on 15th November. As such, Emma Harper and the joint Secretariat will begin planning for the event in earnest, welcoming ideas from members. Andrew Deans raised a possible opportunity to have a “COPD simulator” at the event - the joint Secretariat will follow-up with him on this.

6. Proposal for meeting schedule and topic discussions

The next meeting of the CPG will be the AGM, which needs to be completed before December 2017. This will be a purely procedural meeting - details to be confirmed by the joint Secretariat.

The next proper meeting of the CPG will be on **6th February 2018**, looking at data and informatics.

Meeting closed.