

PUBLIC PETITION NO.

PE01714

Name of petitioner

James MacLachlan, Ivy Dodds, Jean Watson

Petition title

Interstitial Lung Disease and Home Management

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to provide funding to raise awareness of Interstitial Lung Disease and home management.

Action taken to resolve issues of concern before submitting the petition

Discussed at meeting with local MSP, Jackson Carlaw

Petition background information

Interstitial Lung Disease (ILD) or Diffuse Parenchymal Lung Disease (DPLD) is a substantial group of lung diseases affecting the interstitium. The lung scarring that occurs can't be reversed. In other words, oxygen cannot be transferred from the lungs to the bloodstream. Result, increasing breathlessness as the disease progresses. ILD is an incurable, debilitating and distressing lung disease. Only new drugs and management can maintain a quality of life once the disease is stabilised or progresses. Early diagnosis is therefore essential. A number of disorders and the signs and symptoms of a wide range of medical conditions can mimic ILD. This makes ILD difficult to diagnose. Sufferers usually first become aware of shortness of breath with slight exercise or on walking up an incline which necessitates rest stops for recovery. This breathlessness, often with a dry cough, begins to become more troublesome and a GP appointment is sought.

Here is the first problem. A lack of awareness.

Statistics extracted from the British Thoracic Society Interstitial Lung Disease Registry Programme Annual Report 2015/16 show that the elapsed time from initial onset of breathlessness to presentation is—

46% waited over 2 years.

25% waited 1 to 2 years

20% waited 1 to 2 years.
20% waited 6 to 12 months.
8% waited less than 6 months.

This shows that 70% of sufferers delayed presentation either due to “it will go away”, ignorance of ILD or it is age related. The average age for diagnosis is 65 to 80. Hence why it is referred to as “an old person’s disease”. If it was due to ignorance this is most likely due to The Scottish Government’s failure to raise awareness of ILD. How many members of the public know what ILD is compared to asthma, COPD, lung cancer or pneumonia?

As the prognosis and quality of life for ILD is on par with many of the above why does ILD not receive the same government support and awareness? No media exposure. No poster programme, No targeted exposure by well known faces. No awareness programme. With the provision of home and portable oxygen many sufferers are no longer confined to home but have a mobility only subject to their oxygen requirement and any other medical condition. An awareness programme would highlight that a quality of life is expected after diagnosis. With the exception of some industrial and workplace environments, ILD is a disease of unknown origin and is in effect non-preventable. This precludes any alterations to lifestyles being touted to avoid it being contracted. The Petition therefore calls on the Parliament to urge the Government to raise awareness of ILD. This could be done by—

A) Initiate the reporting and recording of all incidences of ILD in all Government Health Surveys, trends and projections. Respiratory disease is more than asthma or COPD.

B) Initiate the funding of a public awareness programme for ILD including GP training (see “first problem” above).

C) Initiate the funding to GPs to conduct a chest examination on all patients over the age of 60. If heard, the distinctive “crackle” of ILD will assist in deciding if further investigation is necessary. The examination to be immaterial on the complaint presented.

The second problem is home management and how it is provided across Scotland.

As can be seen from introduction ILD is an insidious, incurable, progressive disease. Its progression is mitigated by medication and improved management. Once stabilised, management is usually at patient’s home. The main effect of ILD is as stated breathlessness. Breathlessness is both debilitating and distressing and the availability of mobile / home oxygen is essential.

Home management also relieves pressure on the NHS by freeing up beds, resulting in untold savings to the NHS. Home management for ILD patients is reliant on the support from family, friends, charitable organisations, local authorities and Government. Government provides funds to the sufferer through benefit entitlement but also and importantly through local authorities.

Support from family, friends and charities saves Government and local authorities millions of pounds per annum. However, all local authorities do not apply, either due to their own dictats or lack of funds, a uniform service. We think this could be addressed by the Scottish Government establishing a cohesive national management policy for all local authorities to adhere to, so that benefits are not determined by a boundary line. ILD and other similar home managed patients often require stair lifts, walk in showers, additional toilet facilities, grab handles and further health and safety items that a home survey would highlight. Again, targeted and ring-fenced funds need to be made available from Scottish Government.

This petition calls on the Scottish Parliament to urge the Scottish Government to raise awareness of Interstitial Lung Disease and Home Management by initiating the funds and required procedures.

Unique web address

<https://www.parliament.scot/GettingInvolved/Petitions/PE01714>

Related information for petition

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YES

How many signatures have you collected so far?

0

Closing date for collecting signatures online

07 / 01 / 2019

Comments to stimulate online discussion

- What is your awareness or experience of Interstitial Lung Disease?
- Have you experienced any difficulties or delays in diagnosis and any follow-up investigations?
- What is your experience of home management for ILD in your area?