

---

## **Asbestos Victims Support Groups' Forum UK**

Graham Dring (Chair)                      Joanne Gordon (Secretary)  
GMAVSG, Windrush Millennium Centre

70 Alexandra Road, Moss Side Manchester, M16 7WD

Tel: 0161 636 7555    E Mail: [asbestos.mcr@gmail.com](mailto:asbestos.mcr@gmail.com)

---

George Freeman MP

25 March 2016

Parliamentary Under Secretary of State for Life Sciences  
Richmond House  
79 Whitehall  
London SW1A 2NS

Cc Lord Prior of Brampton, Parliamentary Under-Secretary of State for NHS  
Productivity, Department of Health [lords@dh.gsi.gov.uk](mailto:lords@dh.gsi.gov.uk)  
Professor Dame Sally Davies, Chief Medical Officer, Department of Health  
[CMOweb@dh.gsi.gov.uk](mailto:CMOweb@dh.gsi.gov.uk)

Dear Mr Freeman

I am writing on behalf of the Asbestos Victims Support Groups' Forum UK (the Forum). We represent charities and not for profit groups throughout the UK who work directly with and on behalf of victims of mesothelioma and other asbestos-related diseases.

Each year we help thousands of such people claim the benefits and compensation they are entitled to, run support groups for people living with mesothelioma and for bereaved family members and campaign on issues affecting all asbestos victims.

We have campaigned for many years for improved funding for mesothelioma research and our groups have raised hundreds of thousands of pounds for this cause in sponsorship donations raised at our annual Action Mesothelioma Day events.

So we were both surprised and delighted to hear the news that a sum of £5 million had been allocated to mesothelioma research in the Budget with the aim of establishing a National Mesothelioma Centre. This is a significant sum of money, especially compared to the amounts that have been allocated to mesothelioma research in the past.

However, we were concerned to learn that a decision seems to have been made to allocate this funding to a consortium led by Imperial College, without other researchers and organisations being given the opportunity to present the case for alternative proposals. Imperial College has many fine qualities I am sure but as far as we are aware has no track record or published output in the field of mesothelioma research.

### **Asbestos Support Groups' Forum UK**

Asbestos Action Tayside; Asbestos Support West Midlands; Bradford Asbestos Victim Support Group; Cheshire Asbestos Victims Support Group; Clydebank Asbestos Group; Derbyshire Asbestos Support Team; Greater Manchester Asbestos Victims Support Group; Hampshire Asbestos Support & Awareness Group; Merseyside Asbestos Victims Support Group;; North East Asbestos Support & Awareness Group; Sheffield And Rotherham Asbestos Group

The idea of a national centre of excellence has great merit. We desperately need a co-ordinated and collaborative strategy for mesothelioma research in this country if we want to give any hope to mesothelioma victims in the future. And we desperately need not only more research funding, but sustainable funding for the future that will ensure continuous improvements in treatment and hopefully even a cure for this neglected disease

But there is no need to reinvent the wheel. The UK has some of the leading international researchers and institutions who have been, and still are, producing cutting edge research and clinical treatment on mesothelioma over many years, a fact recognised by the International Mesothelioma Interest Group biennial conference being hosted in the UK this year. It beggars belief that not only are none of these researchers considered worthy of consideration in the allocation of these newly announced funds, but that none of them were even consulted about how this money could best be used nor how a national centre of excellence could work.

I would urge you to give all the key players in mesothelioma research the opportunity to submit bids for funding and plans for a national research centre through an open bidding process and allow time for proposals to be prepared. Any national centre and strategy for future research must be built on collaborative work that utilises the existing wealth of experience and the good work being conducted around the UK already. And collaboration must be a part of the decision making and discussions about the best way forward from the outset, not something tacked on after all the key decisions have been made.

We have the opportunity to make significant advances in research in the UK if the right decisions are made and this £5 million is used wisely. The best way to ensure the right decisions are made are to talk to those who know most about this disease and enable them to participate fully in discussions about the best way forward and allow them to submit their own proposals. It will be a criminal waste of talent and expertise if this is not done. And central to any decisions made must be consideration of the best interests of mesothelioma patients throughout the UK, not what best serves the interests of any institutions or organisations.

I would urge you not to make any hasty decision on this issue and allow time for proper consultation and participation from other researchers and organisations who have worked for many years in this field. I would be grateful for a response to the comments raised in our letter.

Yours sincerely

Graham Dring  
Chair

**Asbestos Support Groups' Forum UK**

Asbestos Action Tayside; Asbestos Support West Midlands; Bradford Asbestos Victim Support Group; Cheshire Asbestos Victims Support Group; Clydebank Asbestos Group; Derbyshire Asbestos Support Team; Greater Manchester Asbestos Victims Support Group; Hampshire Asbestos Support & Awareness Group; Merseyside Asbestos Victims Support Group;; North East Asbestos Support & Awareness Group;; Sheffield And Rotherham Asbestos Group