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Peter Bryce
Pulmonary Fibrosis Trust
c/o EBS Ltd
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Dear Peter

PETE THE PUFFLING'S BRAVE ADVENTURE

I am writing to introduce myself to you and to inform you of the book that I have co-written with another lady whose family members have been impacted by Pulmonary Fibrosis.

Firstly, my name is Clare Donohoe, and I am a mum of two children, Hannah and Ryan, and wife to Tom. Tom was unfortunately diagnosed with idiopathic pulmonary fibrosis in 2019, age 43. Our daughter was 15 at the time, and our son was six years old.

As I am sure is the case with many families, receiving a diagnosis of Pulmonary Fibrosis is devastating. Tom and I went through many emotions, shock, sadness, disbelief, despair. It was difficult for us to understand the gravity of the situation, never mind explain it to family, friends, colleagues, and indeed our children.

Tom was told last February that he is in the terminal stage of this disease and is currently on the list for a double lung transplant. He is on oxygen 24/7 and his daily living is severely affected. We are acutely aware that there is no guarantee that Tom will get this life saving surgery on time, as you know, the disease can deteriorate rapidly before a match is offered. Consequently, I have recently accepted voluntary redundancy (I am only 52) from my job as a Business Lecturer in a local college, to dedicate myself to supporting and caring for my husband.

So this leads me on to the children's book – 'Pete the Puffling's Brave Adventure'. Last year, I was asked to give a presentation to respiratory nurses at Queen's University, Belfast, on

behalf of our charity. Many of the photographs of fundraising activities contained pictures of our young son, and one of the nurses asked what support was there for children. The answer was a resounding 'none'. So I committed there and then to writing a children's book to raise awareness of the disease and to help families have the conversation with their children and grandchildren to help them understand.

I collaborated with Janet Bamford, Tom McMillan's Neice, who have several family members who have passed away with PF and, some, who are still living with PF, and we, along with Kevin McHugh a local Fermanagh Artist, have produced what we believe to be a world first children's book to help children understand what PF is and what role they can play to help family members who have been diagnosed. It truly is sensitively written. As Dr Nazia Chaudhuri (Dr, MB ChB (Hons) BSc (Hons) PhD FRCP) put it 'This book beautifully and sensitively raises awareness amongst young readers about Pulmonary Fibrosis.' Actor Julie Hesmondhalgh our patron has said 'It is never easy to tell a child that a loved one is seriously ill. This beautifully written and illustrated book helps to navigate those difficult conversations.'

We have big plans for 'Pete the Puffling' and his 'Grandpa Percy'. In addition to having the book translated into different languages, we are hoping to make it available in audio format, and eventually we will make it into a play to bring into primary schools. There are also plans for a sequel to the book to help children understand organ donation, and the lung transplantation journey (that we are hopefully embarking on), and potentially, the grieving process, as no doubt, for many families, childhood trauma can occur with the loss of those dear to them.

I recently spoke with one of our patients in our support group and asked him how the conversation about this disease was handled in his family. The response was that he has 9 grandchildren, and "it's never been spoken of, they just see the oxygen cylinders and paraphernalia". This is so sad, but typical in so many families, as unlike with a diagnosis of other more commonly recognisable diseases, it is difficult to explain this unknown disease to people in general, let alone to children.

The feedback that we have received so far since we launched the book in Enniskillen on 15 June 2024, has been phenomenal. We are tremendously proud of how the book has come together and how it is raising awareness not only amongst children, but also in wider community.

As we are all only too acutely aware, this disease knows no borders or boundaries, therefore, we would love to share the book with as many people as possible across the UK and beyond. If it can help one family to have the conversation with their children/grandchildren, then it will have achieved it's objective. I know that Tom McMillan has sent you a copy, so I hope that you agree with the sentiments.

Should you wish to share with PF Trust members, I have attached an advertisement to the email that could be used.

If you have any questions or queries, please do not hesitate to contact me. My address is above, and we can also organise a Zoom call should you wish to meet to discuss this further.

Many thanks Peter. Looking forward to hearing from you.

Yours sincerely



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