

# Insider

*Living well with Pulmonary Fibrosis*

- ◆ Focus on nutrition
- ◆ What we've learned from life with pulmonary fibrosis
- ◆ Clinical trials
- ◆ Fundraising

Spring / Summer 2022



Tom and Una from Northern Ireland



**Action for  
Pulmonary Fibrosis**

[www.actionpf.org](http://www.actionpf.org)

# What's inside...

Welcome to our new look Insider. You'll recognise some of the usual sections, but with a renewed focus on quality of life with pulmonary fibrosis (PF). Each bi-annual issue will have two contributors. We're delighted to welcome Tom and Ras to our Summer edition.

## Meet our contributors:



**Rasleen (Ras) Kahai** is a cardiorespiratory dietitian at the Royal Brompton & Harefield hospitals. Ras works with patients with all respiratory conditions. She's passionate about respiratory nutrition and has recently started a forum to bring together respiratory dietitians across the country.



**Tom McMillan** from Northern Ireland cares for his wife Una who has idiopathic pulmonary fibrosis (IPF). As Chairman of the Northern Trust Pulmonary Fibrosis Support Group Tom dedicates much of his time to improving the lives of others living with pulmonary fibrosis.



Message from our Chair [Page 3](#)



What we've learned from life with PF [Page 6 & 7](#)



Research: clinical trials [Page 9](#)



Spotlight on Tom's campaigning [Page 11](#)



Wellbeing: focus on nutrition [Page 4 & 5](#)



60 seconds with our new president Professor Jenkins [Page 8](#)



Fundraising highlights [Page 10](#)



Meet our support team [Page 12](#)

## Message from our Chair



**This is the first issue of our 'new look' Insider magazine, which firmly puts the spotlight on 'living well with PF'. Everyone's experience of living with PF is different but Action for Pulmonary Fibrosis (APF) wants to help patients living with PF to focus on what they can do now not on those things they can no longer do.**

I lived with IPF for eight years before my lung transplant. As my disease got worse, I remember how frustrated I felt when even walking on the flat became difficult. For me, the solution was to get an e-bike, which meant I still managed to exercise but I could let the battery take the strain when I got breathless. I am still a keen e-biker today as is my old friend and inspiration, Ron Flewett (pictured here) who many of you know. Other friends rediscovered old hobbies, which they could do at home. As my wife, Hilary, says – some days are better than others, but every day is a gift to enjoy as much as you can!

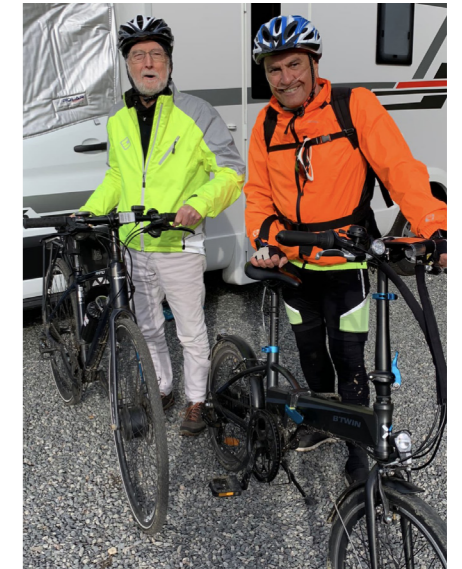
I love the coming of spring with longer days and the hope of warmer weather. The last two summers were tough because of the pandemic but, with covid numbers falling, I hope this year will be different.

I think we are all worried about the rising cost of living and the likely cost of energy next winter. APF will keep a close eye on this and on any schemes announced by the government. Our October issue of Insider will focus on this issue.

In closing, I would like to warmly welcome Professor Gisli Jenkins as APF's first President. Gisli was a founding trustee of APF and has dedicated himself to the work of the charity over the last nine years.

I hope you all have a good summer and don't forget: if you need us, we're always here for you.

**Steve Jones**



Action for Pulmonary Fibrosis is a patient-driven charity. Our vision is to find a cure for pulmonary fibrosis so everyone affected has a better future.

## Here to help...

Visit our website and Coronavirus Hub: [www.actionpf.org](http://www.actionpf.org)

Call our Support Line: **01223 785725**

Contact our Support Team: [support@actionpf.org](mailto:support@actionpf.org)



# Wellbeing

## Focus on nutrition

Ras Kahai is a cardiorespiratory dietitian at the Royal Brompton & Harefield hospitals. Ras works with patients with all respiratory conditions including pulmonary fibrosis.

“Nutrition is an essential part of our life, culture and society. It can be really challenging to not have an appetite and no desire to eat. I know it’s especially tough for family and friends to watch their loved ones struggling.”

Ras Kahai



**Nutrition is not a one box fits all. Patients may find their lung condition makes them put on weight, as it may become more difficult to exercise with increased breathlessness whilst others struggle to maintain or gain weight.**

Many people with pulmonary fibrosis have challenges with nutrition for a variety of reasons which can include breathlessness, fatigue, side effects of medications, anxiety, nausea or gastrointestinal disturbances. We know that nutrition gives you the energy and strength to do what matters to you. The energy and protein from food supports maintaining muscle and micronutrients to keep your body functioning.

There is increasing evidence pointing to maintenance muscle mass being a key factor in pulmonary fibrosis. Reduced muscle mass around your lungs and diaphragm may affect breathing. Additionally, if muscle is reduced around your arms and legs, it can make you less mobile and unable to do the things you want to.

## What can you do to maintain or increase muscle mass?

- Have a protein source with every meal such as meat, fish, beans or tofu.
- Talk with/to your physiotherapist/pulmonary rehab team and discuss what strengthening/muscle-building exercises may help.

## How can I lose weight?

- Eat mindfully; really concentrate on the taste and savour your food.
- Keep an eye on portion sizes (but not for vegetables) and try using a smaller plate.
- Plan your meals ahead of time to ensure you have healthier foods within reach. Try to have three balanced meals a day.
- Before snacking, try to have a glass of water to check your thirst is quenched. Consider having a protein or fibre rich snack.

## What if I can't manage my main meal?

- Try to eat small, frequent meals, aiming for 6 to 7 small meals per day as large portions can be overwhelming.
- Include a high calorie/protein nourishing snack or drink if you can't finish your main meal.
- Establish regular mealtimes and eat at the same time each day, aiming to eat 2–3 hours apart.
- Make the most of meal times when your appetite is good during the day and try to eat more.



## What are your tips for both patients and carers?

- Encourage your loved one to eat in a kind and compassionate way, whilst also giving them space. It can be difficult for patients who struggle with appetite to be constantly nagged and this can impact on your relationship.
- If appetite is poor, check with your GP as to whether a ‘healthy’ diet is still relevant. They may give permission to eat a wider variety of foods outside of public health guidance.
- When you are having blood tests, request your vitamin D to be checked alongside.



## What are the danger signs to look out for – when do you need urgent help?

- Significant weight loss is the biggest one. As little as 5% loss of your body weight has been likened to worsened outcomes in pulmonary fibrosis. Consider weighing yourself every now and again or look out for changes in clothes size or jewellery not fitting.  
*You can calculate your body mass index (BMI) via the NHS website – [www.nhs.uk/live-well/healthy-weight/bmi-calculator](http://www.nhs.uk/live-well/healthy-weight/bmi-calculator)*
- Watch out for a reduction in strength.
- Poor appetite and eating less than a quarter of your normal intake for consecutive days.
- If you're feeling increasingly concerned you can request a dietetic referral from your GP, consultant or specialist nurse.

To find out more head to APF's nutrition page on their website:  
[www.actionpf.org/information-support/eating-well-with-pulmonary-fibrosis](http://www.actionpf.org/information-support/eating-well-with-pulmonary-fibrosis)

# Life with PF

## What we've learned

Living with pulmonary fibrosis is different for everyone. How patients and carers make the most of every day in a changing landscape can really help others. Here they share insights and experiences as we head into the summer months – whether you're staying at home or travelling in the UK or abroad.



*"Number one tip, live life to the fullest you can, enjoy all the things you once did but adapt to suit the person you are today. I know to avoid spray lotions and perfumes and freshly cut grass. Learn to know what triggers you, we're all unique and what affects my breathing may not affect others."*

*Enjoy your summer life, relax and bring sunshine into your day in whatever way you can. If you can, visit the sea and gently breathe in that air, it's a free tonic."*

**Elaine**

*"My best times have always been in the sunshine. I suggest taking time, pacing yourself, and staying hydrated. Do what makes you feel like you. These last few days being able to sit outside and rest with warmth on me has been a gift. I wish many more for us all."*

**John**



*"Did you know you can get your oxygen delivered even when visiting family or friends for one night? Check with your hotel or Airbnb too for deliveries. You can also get your prescription sent to where you're going. It really takes away all that stress."*

**Maxine who cares for her husband Ron**



*"The day is long and gets longer... enjoy it a little, and stay hydrated. Buy a teppenyaki (smokeless bbq)."*

**Jyoti Smith**

*"When booking [a cruise], we ask for a cabin near to a lift in the middle of the ship. We head to the Medical Assistance area as I require a wheelchair and the staff guide you through the booking-in process and security."*

*Excursions can be very tiring so we've found it's better to have a rest day in between days out. Dining areas are often large, so we request a table near the doors and close to the lifts. Just remember everything is optional. Try to be flexible and enjoy the experience!"*

**Ian and Dorothy regularly enjoy cruises**



*"I've learned from a challenging experience on a flight earlier this year to make sure you have all your paperwork including relevant medical notes with you. You sometimes need proof. Check and double-check they have oxygen onboard."*

**Sylvia who cares for her partner Reg**

\*Note: We have become aware that some operators are not accepting bookings from anyone who requires supplementary oxygen or other medical equipment at the moment. We strongly recommend you check at the time of booking.



## Seasonal tips

"Remember to cover up, wear a broad brimmed hat and put plenty of factor 50 [sun cream] on. Drink plenty of cool water, but most of all enjoy the weather and try to enjoy your garden, or walk with family and friends."

**Northern Trust Pulmonary Fibrosis Support Group**

# 60 seconds with our President Professor Jenkins

Professor Gisli Jenkins is an international leader in the field of PF and founding trustee of APF. This June we are absolutely delighted to welcome him as the first President of APF.

Gisli is based at Imperial College, London where he leads the Margaret Turner Warwick Centre for Fibrosing Lung Diseases at the National Heart and Lung Institute.

## Have you always wanted to work in respiratory medicine?

During my medical degree, I found respiratory medicine fascinating. It encompasses a diverse range of conditions that each generated its own set of diagnostic and management challenges. I did dabble with the idea of studying diabetes and endocrinology for a little while, but soon returned to respiratory medicine due to some personal experiences and meeting some inspirational leaders in the field.

## What motivates and inspires you in your work?

Observing the hardships and struggle that patients go through every day and thinking I may be able to help that in some way motivates me to learn and understand, to look under every stone to find the answer to what is causing such a cruel disease. Seeing the resilience and fortitude of patients with PF and their families and carers inspires me to keep going when circumstances are challenging.

## What's your view on the role of medical research and PF?

It's absolutely crucial if we are to find a cure. It's the very first step in identifying biological pathways that may be amenable to being

manipulated by drugs. This will change how disease cells and lungs respond to injury. Shifting the balance back towards repair and away from scarring. Ultimately it is very difficult to fix something if you don't know why it has gone wrong.

## Do you think finding a cure for PF is realistic and if so, when?

I think finding a cure is realistic, but challenging. It's also difficult to predict when, because many of these discoveries rely on either a chance finding or the accumulation of small bits of information that accelerate our understanding, ultimately leading to a step change. As Samuel Goldwyn famously said, 'the harder I work, the luckier I get' and so the more effort we put into finding a cure the more likely it is we will succeed.



## As a founding trustee of APF – how do you feel about becoming their first President?

It is really humbling and a great honour to be the first President of APF. It is hard to explain how amazing it is to have been involved with an organisation as successful as APF. I remember at the meeting where we considered the possibility of forming a patient charity it just didn't seem possible that it would grow into something this amazing. This has inspired me to believe in the aspirations of patients and I hope that together we will be able to find a cure for pulmonary fibrosis.

## What do you enjoy when away from work?

Away from work I enjoy riding my bicycle and watching Tottenham Hotspur play football. Cycling gives me a time to reflect and see the world from a different perspective as well as allowing me to eat perhaps a little more cake and chocolate than I should. Supporting Tottenham over the years has helped me deal with disappointment and manage expectations at the same time as always believing that success is just around the corner.

# Focus on research: clinical trials

Dr Molyneaux talks to Insider about taking part in clinical trials and the impact they have on the treatment of PF.

As the Clinical Research Facility Director at Royal Brompton, Dr Molyneaux is responsible for overseeing the delivery of all respiratory research at the centre. He leads a team of nurses and research coordinators who set up and run clinical trials across pulmonary fibrosis, pulmonary hypertension, asthma, cystic fibrosis, COPD and infection.



## What is a clinical trial?

Essentially it's a study to evaluate a treatment, device or procedure in a group of patients. This can mean simply observing what happens when treatment is given to everyone (an observational study) or comparing it to a placebo, where we compare how the new drug works compared to a sham/sugar pill.

## How many trials are you currently leading?

At present we're running 14 trials in PF, some are studies run by Imperial College, London and others are run and organised by commercial companies where we are one of many sites across the world.

## What impact have you seen in the treatment of people with PF as a result of clinical trials?

When I started my training, there were no proven or approved therapies for PF. In the past decade, we have seen positive studies in IPF, scleroderma and PF-ILD, which have all resulted in NICE approval and access to life

extending therapies for patients. None of this would have been possible without the generosity of the thousands of PF patients who participated in these clinical trials.

## Are clinical trials safe?

Clinical trials are very tightly controlled in the UK. For example, clinical trials in England are stringently reviewed and monitored by the Health Research Authority (HRA) to ensure they are safe for participants. Any trials including a drug also undergo review by the Medicines and Healthcare products Regulatory Agency (MHRA). Often studies are running simultaneously across a number of countries and continents and therefore undergo similar reviews in each country.

## What are the disadvantages of taking part in a clinical trial?

Normally the main sacrifice for patients is their time, as they generally involve multiple visits to hospital. However, we find that the majority of our patients ultimately

find this to be of benefit as they receive regular face-to-face reviews and lung function checks from a specialist team of doctors and nurses experienced in PF and clinical trials.

## Ultimately what motivates people to get involved?

I feel altruism is one of the leading motivators. Many patients I see hope to help those diagnosed in the future. They recognise how devastating the disease is and how powerless they feel when they are unable to get answers as to why they developed the disease and how it may progress.

## How can patients access trials and get involved?

Ask your local clinician or specialist nurse. You can email us directly at R.ILD@rbht.nhs.uk to ask about studies here (and you don't have to move your clinical care). Your local PF support group and APF will also often provide details of upcoming studies.

[www.actionpf.org](http://www.actionpf.org)



*"My dad has taken part in a number of clinical trials in the past year. Primarily, he participated so he could help progress treatments. Overall, with no trials there can be no progress – but it's provided so much more than this. Not only has he been given the best care and monitoring from detailed lung function tests, he's also been able to spend time discovering more about his condition and discussing his own PF journey. I know my dad's felt less alone having had these conversations and is able to understand what's happening to him. It's extremely comforting for his family to know this."*

Sam, daughter of Tony (pictured opposite)



Ron Fish took part in the Walk for Hope over the Easter weekend raising vital funds towards APF's life-changing research! He tells us why staying active and funding research is important to him and his family.

**“I was diagnosed with familial pulmonary fibrosis in October 2015 having lost two elder sisters to this awful disease. It is therefore very important to our family that research continues into the causes and ultimately a cure, which gives hope to future generations.**

As my walking is severely limited by breathlessness and use of oxygen, we needed somewhere suitable for my mobility scooter. We chose Milton Country Park, which has made up paths. I know doing a walk on a mobility scooter sounds a bit like cheating, but it's the thought that counts and the whole family walked!

We assembled on Easter Sunday morning with my wife Sylvia, our two children, their other halves, five grandchildren and even our great grandson aged 2! Maybe the mention of Easter eggs was an incentive for some!

I feel that one should stay as active as possible with PF and get out in to the fresh air. Keeping up some activity is important, even if it's just a short walk.

Our Hope for All research appeal will help us change lives in the future, and could one day lead to a cure. I hope the Fish family walk has helped in some small way.”

**We need to raise £1.2million to fund vital new research into PF**

The disease devastates hundreds of thousands of lives in the UK each year and cases are rising globally. Research gives us hope of changing lives in the future, but we can't do it alone.

To donate or set your own fundraising challenge visit [www.actionpf.org](http://www.actionpf.org) or call **01733 475642**.

**Join us this September for PF Month!**

Could you Go the Distance by doing a sponsored walk with family and friends, or could you Create a Stir with a coffee morning or cocktail party? Fundraise your way this PF month and help us raise money to change lives through research and support.

**Campaigning: spotlight on Tom McMillan**



If you ask friends and colleagues about Tom McMillan, who is a loving husband and carer to his wife, Una in Ballycastle, Northern Ireland, the same words keep coming up.

‘Never gives up’, ‘inspirational’, ‘tenacious’ and ‘energetic’ are just a few of these words. This former fire fighter has had to be all of that and more since Una was diagnosed with IPF five years ago.

Tom and Una met in Belfast when they were just 15 years old. They've been married for over 50 years and have three children and two grandchildren. They live on the beautiful Antrim coast, near the Giant's Causeway. During their working lives they both enjoyed successful careers, Una in nursing and Tom in the Fire Service.

Una, Tom and their family have been making a difference to the lives of other IPF patients as members of the Northern Trust Pulmonary Fibrosis Support Group, of which Tom is Chairman. Tom talks to Insider about what drives his work.

**What was it like when Una received the diagnosis – how did you react?**

The despair and desperation that hits everyone with a terminal illness soon turned to action and hope.

I was determined to dedicate my time and efforts to making life better for Una and others suffering from this devastating illness.

**What did you learn about IPF?**

Northern Ireland has the highest prevalence of IPF in the UK, with an estimated 1,200 sufferers. Despite this the care and provision for patients is well below England and other parts of Europe. Unfortunately, Una's family has a history of IPF; she lost her mother and three siblings to IPF and another sister is also suffering from PF.

**Tell us about your support group and wider campaigning work?**

We provide support for people living with PF and their families from all over Northern Ireland. We're now very successful in raising awareness in Northern Ireland. We're members of the all-party working group for lung health in Northern Ireland and work closely with our politicians, the press, media, and other organisations and charities to try to improve the lives of our PF community. We also attend and initiate many fundraising events and have our name and logo on display at several venues.

I've also become a patient advocate with the EU-IPFF under their development programme and Una and I work on patient advisory groups with the European Respiratory Society. Currently, we're working on a support care plan for newly diagnosed people living with PF, which should be published later this year.

Late in 2021, we recognised that there was more that could be done to help our PF community and a decision was made to move the support group to full charity status and provide a respite facility for our PF community; we also saw the need to employ our own support staff. I'm so proud of our achievements and we hope to have full charity status this year.



## Support team

Meet the members of our team – wherever you live in the UK we're here to support you!



**Debra Chand – National Support Manager**

"I've worked in the charity sector for most of my working life. Hearing the relief in someone's voice or email on knowing you're not alone with a diagnosis as tough as PF always gets me. Making life that bit easier, whether through the welcome of a support group, a reassuring support line or a befriender's listening ear, is so worthwhile. With such a positive and skilled team of staff and volunteers at APF, many with lived experience of PF, everything feels possible!"



**Joanna Ruck – Support Coordinator Team Lead**

"From experience working as a respiratory physiotherapist for many years and helped to set up and run a PF support group in my local area, I feel passionate about the positive difference that good support can make to patients and families affected by PF. I feel privileged to work together with the PF community across the UK towards a brighter future, where no one with PF has to feel alone and where everyone has access to good quality support wherever they live."



**Alison Stewart – Scotland Support Coordinator**

"A newcomer to APF, but coming from a Scottish charity supporting those living with respiratory conditions, I worked closely with people coping each day with distressing and overwhelming lung diseases. I'm happy and proud to have come to work with an organisation where I can continue to provide support and guidance to those living with PF, their carers and families."



**Andy Bright – Regional Support Coordinator (South)**

"Having survived PF for 12 years, I know how hard it is for patients, family and friends to live with this devastating disease. I was lucky to have received a lifesaving double lung transplant in 2018. I'm now even luckier to be able to work with my colleagues at APF to do so much in improving the lives of those affected and ultimately helping to find a cure."



**Wendy Jones – Regional Support Coordinator (North)**

"It was a privilege to care for my mum and meet all the amazing people involved in her care. It is now my privilege to have the opportunity to support other patients, carers and support group leaders on their journey too."



**Annabel Lotsu – Peer Support and Advisory Service Lead**

"I am really proud to be a part of a growing charity that is working tirelessly to improve the care and support that is available for patients and carers affected by PF. Growing the APF support line and recruiting more volunteers are some of the ways we can support people affected by pulmonary fibrosis and I am very much looking forward to developing these services further."



**Pauline Baird – Support Line Advisor**

"As a nurse for 35 years I feel incredibly privileged to be able to offer support through the helpline. I have met many amazing people with PF who are so positive about the support they have received from APF and have said it felt like a lifeline. I am incredibly lucky to work with such a wonderfully supportive team who put everything into making a difference for people with PF."



**Dee Bryan – Support Line Advisor**

"Being a Volunteer Befriender and working on the Support Line is such a privilege. Talking with patients and carers for either practical support or offering reassurance is invaluable. Having first had experience of caring for someone with IPF, I know how it personally feels to receive that support."



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Registered Charity SC050992 in Scotland.  
Registered Charity 1152399 in England and Wales.

[www.actionpf.org](http://www.actionpf.org)



**Support line**  
**01223 785725**



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**Action for Pulmonary Fibrosis**