



LUNG TRANSPLANTATION: THE PATIENT PERSPECTIVE



ELF EUROPEAN
LUNG
FOUNDATION



European
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Networks

ERN-LUNG
RARE RESPIRATORY DISEASES

CONTENTS

02 Dimitris Kontopidis

Introduction

03 Natalia Maeva

A transplant is a miracle, but not everybody has access

05 Gill Hollis

A transplant is a lifelong commitment

07 Steve Jones

A life changing decision

09 Pisana Ferrari

There is still more to be done for patients

12 Ron and Maxine Flewett

The transplant gave us the opportunity to look to the future

INTRODUCTION

By ELF Chair, Dimitris Kontopidis

Advocating for those in need of lung transplants has been an important part of my life. I believe in empowering respiratory patients across Europe to improve their treatment conditions and reduce inequalities across borders. I know that this is possible from my 12 years of patient advocacy.

I was awarded the ELF Award in 2021 refusing a lung transplant to force change in Greece for people with cystic fibrosis. Then in 2023, I was welcomed as the ELF Chair and launched the ELF Chair's Campaign with the aim to raise awareness and demand equal access for all to lung transplantation.

The chances of receiving a lung transplant vary widely across Europe. In some countries, transplants are not an option. The standard of care also varies widely not just between countries but between centres within countries. There is a need for extensive knowledge sharing.

ELF have worked in co-operation with

ERN-LUNG and those who have kindly offered to share their stories. Together we want to raise awareness of the life journey of those with experience of lung transplants. We hope that this resource will help to not only inform patients starting their journey of transplantation, but also engage healthcare professionals and policymakers in conversation.



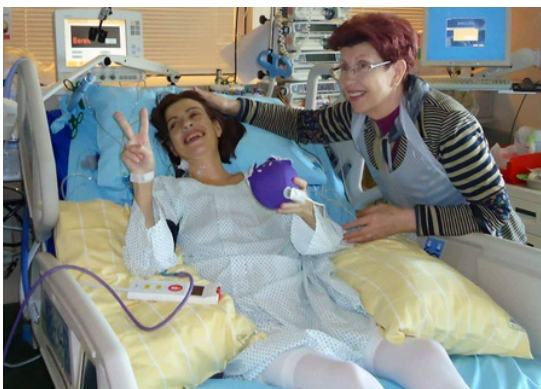
A TRANSPLANT IS A MIRACLE, BUT NOT EVERYBODY HAS ACCESS.

By Natalia Maeva

My trip into the world of pulmonary arterial hypertension (PAH) starts in 2009. I was added to the transplant waiting list in Vienna in 2015, after receiving triple therapy for PAH.

Since 2014, I had been on oxygen for many hours per day and I was unable to do tasks, such as cooking and cleaning, without feeling breathless. Every person who is waiting for lung transplantation feels their life is coming to an end, as if they could pass away every day – it is a strange feeling. Luckily, I received a transplant after 11 months of being on the list.

Receiving a transplant gives you a new life and you must remain active. As a full-time journalist, I never realised that I would have such a quality of life after the operation. I often ask myself: 'how is it possible I can do so much and not feel tired or breathless?' It is like a miracle.



The first year after receiving a transplant is very hard. For me, the drug treatments I received would make my hands shaky and I was also learning how to live with a new condition. I had to wear masks during flights and on my visits to the transplant centre, especially in winter. When the COVID-19 pandemic happened, other people also wore masks. This made me feel like other people, as no one was now asking me why I was wearing a mask. I was also happy that people had started to understand what it means to keep healthy.

For me, life after receiving a double lung transplant creates a new discipline because of the gratitude you feel towards your donor. It is very personal. My appeal is: help Bulgarian patients regain access to European centers for lung transplantation! Since 2019, the Bulgarian waiting list for this life-saving surgery has been just a list of names. We all know that there is always a way for life to triumph over death, and this is precisely the meaning of organ donation and transplantation.

In July 2024, I took a risk and proved that every transplant patient should be physically active. I participated in the European transplant sports championships 2024. Proof of this is that I won my first gold medal and became the European Badminton Champion in the 50-59 age category.

However, it is normal to feel afraid at first and many people do.

The week after my transplant, I had hallucinations which were like reality. But because I came from Bulgaria, where there have been unstable political situations and issues in terms of access to transplants, nobody had told me about the hallucinations.

This is an issue I always speak about. We do not have any chances in Bulgaria. Whilst there was initially good cooperation between Bulgarian doctors and the Vienna General Hospital until 2019, the Austrian government have begun to only accept Austrian citizens for a lung transplant. The only solution for patients needing a transplant from Bulgaria has been to emigrate to have the opportunity to join the transplant waiting list.

Over the past three years, there have been unstable political situations. There must be stable political decisions and money to be able to perform lung transplants. Although Bulgarian doctors were given the opportunity to be educated in Vienna General Hospital, this was stopped due to COVID-19. PHA Europe are trying to rebuild this connection, but this is dependent on doctors and political decision makers.



I am a big optimist, and I believe good things can happen for patients. But we must fight and without political stability, the mission is not possible. This is the main problem we have here in Bulgaria. Also, it is not possible in our country to create our own programme for lung transplantations because we have a small population of 6 million and not enough organs.

Transplantation and organ donation give you a valuable chance to start a new life, and it is a big advantage of contemporary medicine. It is a miracle, but not everybody has the opportunity to access the miracle.

A TRANSPLANT IS A LIFELONG COMMITMENT

By Gill Hollis

In 1992, I was diagnosed with Lymphangioleiomyomatosis, usually called LAM; a very rare lung disease which only affects women. At that time there was no treatment or cure for LAM, and lung transplants were still very new. I was told that my condition was likely to be fatal within 10 years.

However, a few years later, doctors told me that I might be a candidate for a lung transplant. For some people, being told they need a transplant must be terrifying, but for me it was wonderful news. A transplant gave me hope for my future.

Being on the transplant list is hard because, in addition to your physical symptoms, there is a psychological impact both on the patient and the people around you. You are all waiting for that phone call; the phone call which gives you a second chance at life. You need both mental and physical resilience to get through the wait, the transplant surgery and potentially difficult times afterwards.

Coming around after the surgery and realising that I had actually made it through was fantastic. I was in hospital for 3 weeks but every day I was seeing an improvement. By day 10 I was taken off the oxygen, which was a big thing because before the transplant I had been using oxygen for two years.



My recovery was good but not straightforward. I worked on my fitness, gained muscle and regained a good quality of life. This was amazing because I had been so unwell in the years leading up to my transplant.

Some of the best advice I got in hospital was to expect setbacks. Transplantation is such a rollercoaster ride, but your transplant team can help overcome setbacks when they occur. I still work hard to keep fit and well. Having a transplant is not like any other surgery where you just go in, have the surgery, and walk out. It is a lifelong commitment and association with the transplant unit.

TRANSPLANTATION IS A ROLLER COASTER RIDE.

Having a positive attitude and having hope is so important. Even the possibility of a transplant gave me hope at a time when I thought my life was going to be very short.

HOW CAN THE JOURNEY BE IMPROVED?

1 Improve information and knowledge

- The organ donation process needs clear communication at a national level to avoid misunderstandings
- Better patient information is required for individuals and their carers to understand the full process of transplantation at their individual centre
- Pre-transplantation information should put an emphasis on the risks and benefits of the procedure so each individual is fully informed
- Information should also consider the needs of carers
- Patients and patient organisations have a role to play in offering peer learning opportunities



A LIFE CHANGING DECISION

By Steve Jones

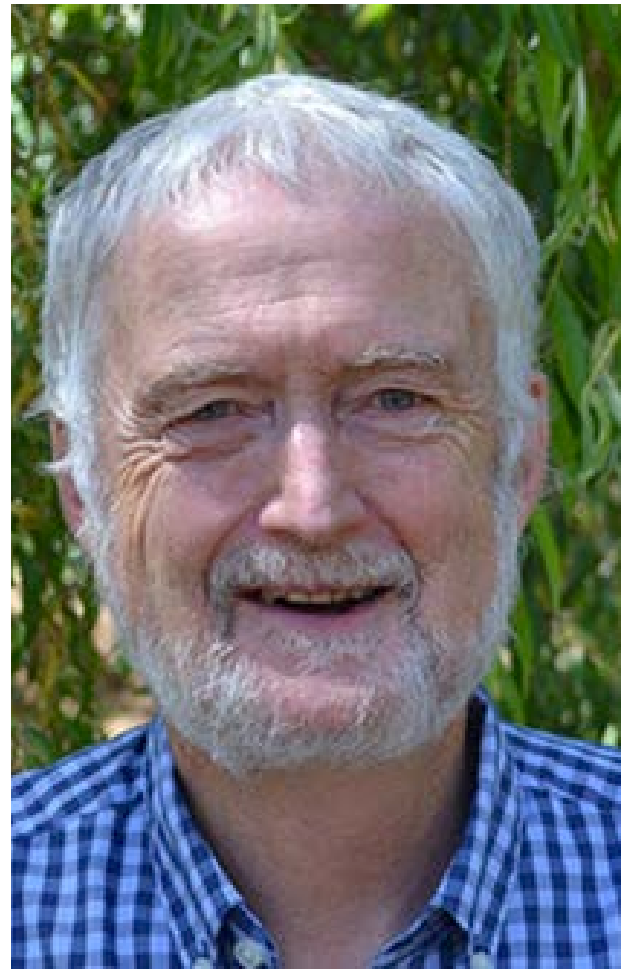
I was diagnosed with idiopathic pulmonary fibrosis (IPF) in 2008, based on a tickly cough and breathlessness.

After my IPF diagnosis, I became aware that transplants might be an option. After transplant assessment, I was asked if I wanted to go on the transplant list. I replied: 'it's a no brainer!' I would be dead in three months – why would I not do this? In early 2016, I was offered a transplant, which took place in March that year.

After the transplant, I spent a day in intensive care before I moved onto the general ward. I picked up two lung infections while I was there, but I went home after 4 weeks. The progress of my recovery was slow and incremental – I was going on walks and getting further each day. At my 8-week appointment, I asked my consultant: "When does this get better?" But, by the 13th week, I felt I had overcome the trauma of the operation and was rapidly improving.

I remember a few things hitting me - I had to be very careful about hygiene and what I ate. I understood acute rejection but had never heard of chronic rejection and that felt like a slight black cloud on the horizon.

In terms of drug treatments, using the nebuliser can be an unpleasant



experience. It can be hard work washing it, especially when you have little energy. However, it is a small price to pay for receiving a lung transplant.

However, one thing about receiving a transplant is that getting a lung infection could result in hospitalisation. We are used to shielding and being careful as this is something we desperately try to avoid.

**I WOULD BE DEAD IN
THREE MONTHS -
WHY WOULD I NOT
DO THIS?**



The COVID-19 pandemic was a worrying time and has made me more careful. I have been entrusted with the wonderful gift of a lung and it is our duty to make the very best of it.

The inequalities in lung transplantation between countries is something that I focus on a lot with my work for the European Pulmonary Fibrosis Federation.

A big problem is that those in some countries, including many Eastern European countries, do not have any transplant facilities and find it difficult to travel to other countries. We are beginning to see organ sharing networks being established and this is very good news and something we would like to see more of.

In the future, I also would like to see more lungs available for transplantation and developing new immunosuppressive drugs that do less damage to other organs, including our kidneys and liver.

We also need to find a treatment for Bronchiolitis Obliterans Syndrome (BOS), which is the most common reason for rejection of transplanted lungs. I think there is work going on it now, but until there is a solution, BOS will seriously limit the effectiveness of lung transplants compared to other organs.

THERE IS STILL MORE TO BE DONE FOR PATIENTS.

By Pisana Ferrari

In my early thirties, I was diagnosed with pulmonary arterial hypertension (PAH). This is a rare and progressive condition affecting the lungs and the heart.

At the time there was very little knowledge of the disease, even among medical professionals, and there were no treatments for PAH. Over the next 12 years the disease gradually progressed and my condition became critical. In the year 2000, a newly approved PAH drug with vasodilative properties, administered by intravenous 24/7 infusion, helped me bridge the two years between being listed and my double lung transplant surgery in 2002.

In the early days after my transplant, I had a tube inserted into my windpipe to restore my breathing for a prolonged period. I also experienced ICU delirium, left heart failure, kidney failure, pain, discomfort and organ rejection. Although I was discharged after two months, I stayed in a rehabilitation clinic for a further two weeks.

I lost muscle mass and could barely walk. I was in a state of shock and it took several months to recover and go back to “normal.”



During my recovery, I was given a long list of things that I could no longer do and should avoid. These included having pets, gardening, swimming and taking baths. I was also advised to avoid crowded places.

IT TOOK SEVERAL MONTHS TO RECOVER AND GO BACK TO “NORMAL”

I also had to take high doses of steroids to prevent rejection of my new lung. Initially, I found my drug regime to be complex and difficult to follow as I often confused the pills and doses. Over time, this becomes routine, but it is still a challenge to take your pills and not run out.

At first, I was terrified of infection, rejection, cancer, and dying. However, since my surgery, I have lived a normal life, had a full-time job, travelled the world, and enjoyed spending time with my family and friends. I take good care of my body and I am a 'hygiene freak.' Over time you learn to live with the fear. It is in the back of your mind but does not impact your life.

I find it sad that some people cannot receive a transplant because there are no transplant centres in their country. I feel privileged to have had a transplant, but guilty that less fortunate patients are dying. My surgery costs were covered by the national health service, but I am aware that this is not the case for all countries. Socio-economic status should not prevent access to lifesaving surgery and these inequalities need to be addressed.

I FEEL PRIVILEGED TO HAVE HAD A TRANSPLANT, BUT GUILTY THAT LESS FORTUNATE PATIENTS ARE DYING.

We must continue to organise awareness campaigns as there are still misconceptions about transplants and still many family refusals. I am following developments in machine perfusion, regenerative medicine and xenotransplantation in the hope that one day organs will be more readily available. But this remains a complex issue with no easy solution.

Deciding whether or not to have a transplant is a very personal decision and sometimes there is no choice. For some diseases like PAH, not having a transplant means dying. People debating whether to have a transplant need to consider all the issues at stake to make informed decisions. For this, it is also important that patients are given comprehensive information and advice about recovering from a transplant. This is not currently happening. I believe a lot more can be done to help patients manage the short- and long-term challenges after the surgery.

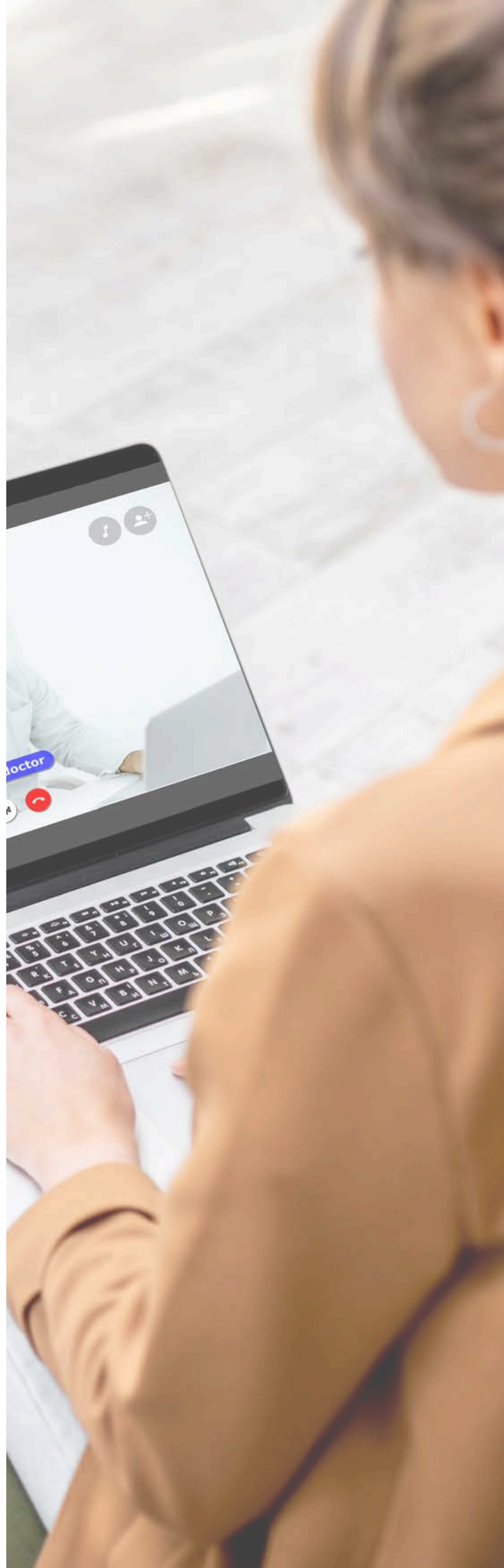


HOW CAN THE JOURNEY BE IMPROVED?

2

Advances in care

- Improvements in care are needed across the board from new medication to robust digital monitoring programmes
- Patient-reported outcomes should be routinely used to monitor outcomes for transplantation recipients



THE TRANSPLANT GAVE US THE OPPORTUNITY TO LOOK TO THE FUTURE

By Ron and Maxine Flewett

I remember that even just going for a simple walk would make me extremely tired due to my idiopathic pulmonary fibrosis.

When you are being put onto the transplant list, the doctors not only check your medical condition, but also your mental health and the support network around you. Something that we found difficult to begin with was how doctors often begin by telling you the risks of having a lung transplant. It can be hard to think you have a 20% chance of not surviving the operation.

IT CAN BE HARD TO THINK YOU HAVE A 20% CHANCE OF NOT SURVIVING THE OPERATION

When we got the call, they said a set of lungs had become available. When we arrived at hospital, the operation went ahead 12 hours later after undergoing many tests. I had high anxiety levels at this point; extremely high. This was accompanied by the difficult moment of saying our goodbyes, since there was a chance I may not survive the operation.



I woke up thankful the operation was a success although it took 13 hours with many complications. Two weeks later I had a respiratory failure, where I was rushed back to critical care where a second operation was required to fix a titanium plate to my sternum. Although they warn you that these things can happen, it is so intense when they actually do, because your emotions are so fragile.

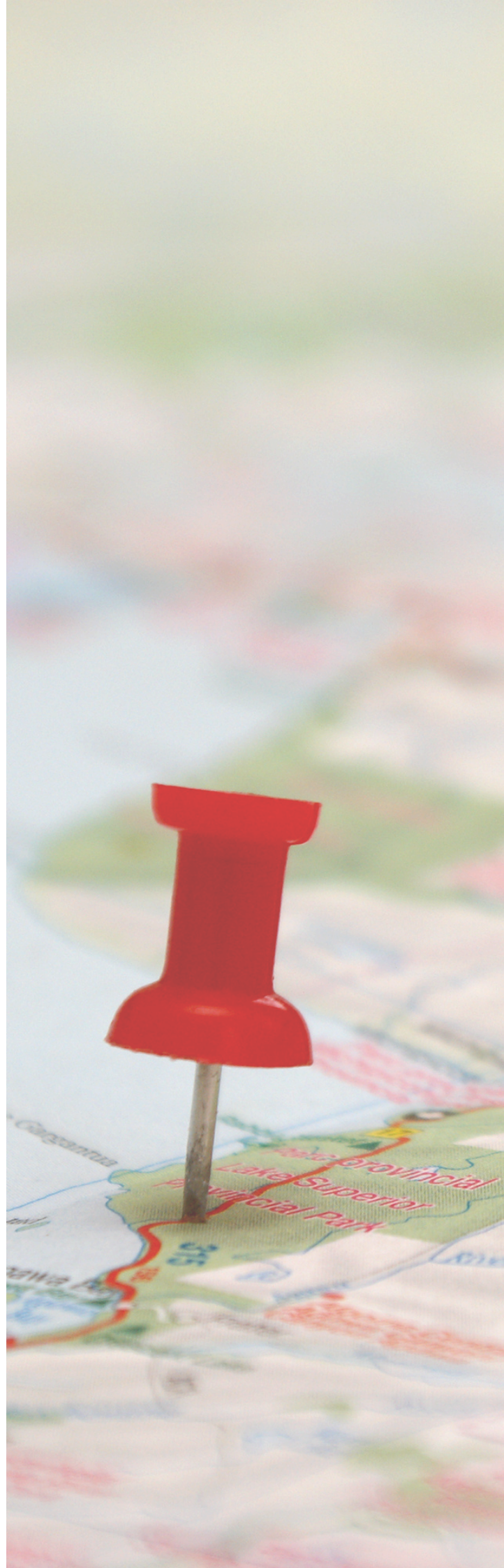
All I kept thinking was 'I have to get better for my donor because if it hadn't been for them, I wouldn't be alive.' After all, my doctor had told me that my lungs probably would not have lasted me until Christmas 2023 had I not received a transplant.

I am very grateful to have received a transplant. Any problems I have now are negligible compared to what they could have been. The transplant has given us the opportunity to look forward to the future, something that we could not do for years until my operation.

HOW CAN THE JOURNEY BE IMPROVED?

3 Equal access to transplantation

- Access to transplantation should not depend on an individual's socio-economic status
- Patients and professionals can work together as a community towards this goal
- Coordinated approach to holistic care, including access to physiotherapy, exercise and psychological support.



LUNG TRANSPLANTATION: THE PATIENT PERSPECTIVE

This booklet was produced by the European Lung Foundation (ELF) and the European Reference Network for Respiratory Diseases (ERN-Lung).

ELF is a patient-led organisation that works internationally to bring patients and the public together with healthcare professionals to improve lung health and advance diagnosis, treatment and care. ELF works in partnership with the European Respiratory Society (ERS) to develop the union between lung health professionals and patients. Find out more: europeanlung.org.

ERN-LUNG is a patient-centric network of European healthcare providers and patient organisations, committed Europe-wide and globally to reducing morbidity and mortality from rare lung diseases in people of all ages through patient care, advocacy, education, research and knowledge-sharing. Find out more: ern-lung.eu/

ELF and ERN-Lung wish to thank all contributors who took the time to share their stories.

An article aimed at healthcare professionals providing the patient perspective on lung transplantation is also due to be published in December in the ERS Monograph; a quarterly book series from the ERS. Find out more: books.ersjournals.com