Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders
Loeys Dietz
CONNECTING THE UNCONNECTED AND STRENGTHENING LIVES

Marfan Matters

Spring/Summer '26 Edition

For people affected by Marfan & Loeys-Dietz Syndromes

REGULAR FEATURES

SPECIAL FEATURES

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As summer unfolds in a blur of high-octane sporting events and intense heatwaves, it also heralds the season of fundraising fetes, walks, runs, quiz nights, cycling odysseys, human fruit machines and so much more. We've been overwhelmed by the generosity of our supporters and their campaigns. Thank you all so very much!

This newsletter edition reflects on the productive months of a long winter and late spring while hinting at what is to come later in the year.

Trusted Information Creator

Patient Information Forum

To hurtle headlong in on the most recent noteworthy event... In June, we received a tick of approval! The Patient Information Forum (PIF), the UKs independent organisation championing high-quality health information, awarded the Marfan Trust its coveted PIF TICK. In a world where information is plentiful but certainty is often harder to come by, unpicking myth from fact is not always straightforward, particularly when searching for trustworthy medical advice. The PIF TICK is an independent mark of quality, recognising organisations that produce evidence-based, accurate and accessible health information. It is poised to make an appearance on our website and leaflets.

For the latest on our research, webinars, symposia, and new publications, read on!

You can help to secure our future by visiting our shop, making a donation, or becoming a member today for just £3 per month. www.marfantrust.org

Marfan Trust, 24 Oakfield Lane, Keston, Kent, BR2 6BY

A Word from our Chair and Founder, Dr Anne Child

We're steeped in the warmth of long summer days, yet behind the scenes we're busier than ever with our helpline, social media and research. We also have some exciting staff news to share!

Staff

Welcome home, Joanne Jessup, our Nurse Specialist, who has returned from the Dominican Republic where her husband, Graham, has been stationed as a Diplomat. Joanne will continue to work part-time with the Marfan Trust to lend her aortopathy management expertise to our Marfan and Loeys-Dietz families.

She is also returning to her NHS post as an Aortopathy Nurse Specialist at Royal Sussex County Hospital, Brighton. She is thus serving our supporter community doubly.

New Trustee/Treasurer

Welcome, James McCallum, recently retired Chartered Accountant who was brave enough to volunteer for this post. He knows all about Marfan syndrome. He has many years of experience to offer and is also at present a charity trustee to the Coram's Fields Charity, a London-based organisation working to support children to independence. Mr McCallum is reviewing our financial practices and making suggestions for improvements in line with Charity Commission recommendations.

New PhD Student: Jessica Alvarez

The Marfan Trust is mounting a fundraising campaign to **Adopt a Scientist** (pages 5 & 6) to assist our Research Director Dr Jose Aragon-Martin PhD in our Sonalee Laboratory, William Harvey Institute, Queen Mary's University of London. The Marfan Trust **is guaranteeing her salary** as Scientific Assistant for the first year of her year PhD studentship. She begins in September 2026. We ask your help in raising her salary. She has other significant funding from her sponsor, the Mexican Government, who will pay her student fees. We have also applied to larger charities for her second and third-year support.

If you are interested in finding gene therapy for Marfan and Loeys-Dietz syndromes, please donate generously (read 5 & 6). Jessica will also be working on discovery of new genes which cause aortic aneurysm and dissection in UK families whose gene mutation has not yet been discovered.

Progress can only be made through research. The Marfan Trust is uniquely positioned to offer clinically relevant research, with the cooperation of our 4000 UK families.

Your help in this important matter is essential and greatly appreciated.

Thank you and we wish you a most enjoyable summer!

Anne H Child

Chair and Medical Director, Marfan Trust
Senior Research Associate, Imperial College

Helpline .... a Lifeline by Victoria Hilton

As the Trust gathers momentum and its reach continues to widen, more people are finding their way to our helpline each day. Since January, we have responded to over 350 enquiries. Behind every call and email is a different story, yet the reasons for getting in touch reveal a familiar pattern. Around 30% of enquiries come from people seeking help to understand and navigate a diagnosis, making it the most common reason for contacting the Trust.

Whilst physical features such as tall stature, hypermobility, arachnodactyly, slender limbs, and a protruding or indented chest can indicate a connective tissue disorder, they are also found in the wider population. Our role is to help people make sense of these signs and symptoms, understand what they may - or may not - mean, and guide them towards the most appropriate next steps.

Taken together, these conversations offer a fascinating window into the work of our helpline. Pain and fatigue account for around a quarter of all enquiries, the two often proving inextricably intertwined. Around 15% relate to Personal Independence Payment (PIP), while the remaining enquiries cover everything from aortic care, medication and headaches to scoliosis, chest deformities, foot problems and forthcoming surgery. Nor are these conversations confined to the UK; we've also heard from people in USA, South Africa, India, Norway and beyond.

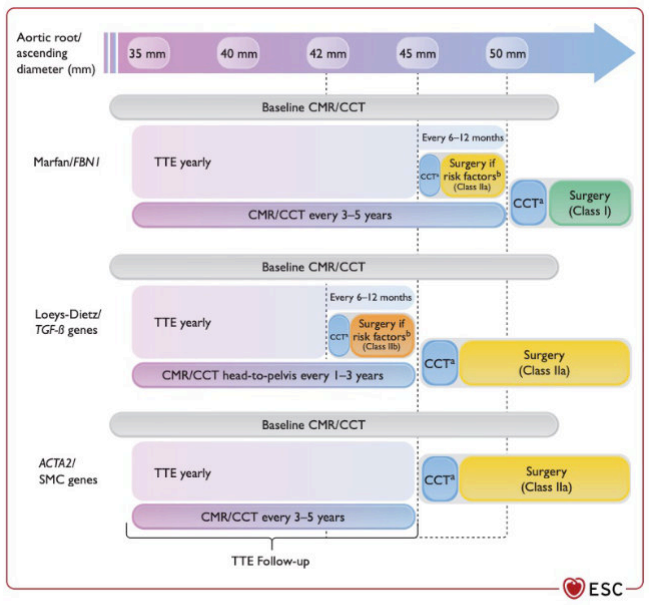


Figure 41 Algorithm for imaging surveillance in patients with syndromic and non-syndromic heritable thoracic aortic disease. CCT, cardiovascular computed tomography; CMR, cardiovascular magnetic resonance; DUS, duplex ultrasound; HTAD, heritable thoracic aortic disease; SMC, smoth muscle cell; TTE, transthoracic echocardiography. [a]Pre-surgical CCT. [b]See respective tables of recommendations for aortic surgery in Marfan (Table 62) and Loeys-Dietz syndrome (Table 66).

I have confirmed Marfan syndrome and am in my mid-fifties. I don't really have any aortic symptoms, and my cardiologist has discontinued my imaging and scans. Is this right?

Anyone with Marfan or Loeys–Dietz syndrome should undergo at least annual imaging of the aorta. The European Society of Cardiology has produced definitive guidance, with recommendations based on both the underlying condition and the size of the aorta. The chart on the left summarises the recommended type and frequency of imaging. Imaging frequency may change if you have had an operation.

After exercising recently, a bulge has emerged in my groin. I think it's a hernia and I wondered if this was a symptom of Marfan syndrome. If so, should it be treated differently?

Unfortunately, hernias are more common in people with connective tissue disorders than in the general population and are also more likely to recur because the tissues are weaker. An intricate web of fibres binding skin to muscle and muscle to bone, connective tissue quite literally binds us together. When that web begins to weaken, hernias can develop as part of an internal organ pushes through a weakened area of the muscle wall. The surgeon is advised to sew mesh under the skin to reinforce the repair, to avoid recurrence. The use of tension-free mesh is recommended in several case reports (Zhang, 2026) documenting the repair of hernia in patients with Marfan syndrome.

I think that my child may have Marfan or Loeys-Dietz syndrome. My wife has noticed the lenses in their eyes are visibly shaky, they are long and thin, and they have a bifid (split) uvula in his throat.

We strongly urge you to seek a referral to your nearest genetics centre from your GP or hospital consultant. Here is the link to the list to the genetic clinics: **https://www.marfantrust.org/resources/category/9-regional-genetics-centres**

In the meantime, we would also strongly encourage you to seek a referral to cardiology for an echocardiogram. Whilst it can take many months to be seen by a geneticist, echocardiogram is usually arranged more quickly by your family doctor and would provide useful information.

My 16-year-old son with confirmed Marfan syndrome has pectus excavatum (indented chest) and is becoming increasingly breathless climbing the staircase. He is also very self-conscious about his chest in the school changing room. We are considering surgery but feel tentative about it.

The decision to operate on pectus excavatum is usually driven by symptoms rather than appearance alone.. Assessment typically includes a CT scan or MRI to gauge its severity and any compression of the heart or lungs, together with an echocardiogram, lung function tests and, where appropriate, cardiopulmonary exercise testing. These investigations help to determine whether surgery will improve symptoms and quality of life. Here is a link to a webinar we held on this subject with thoracic surgeon Mr Joel Dunning, an indefatigable champion of surgery who fought tirelessly to restore NHS England funding. **https://www.youtube.com/watch?v=2-Efn366TGw&t=14s**

We are delighted to acknowledge the very generous contribution of £1,000 from The *F Glenister Woodger* Trust CIO towards our helpline. This generous gift has enabled us to support several patients in Wittering.

Finally, a reminder that our helpline offers free fortnightly appointments with our Cardiac Nurse Specialist, Joanne Jessup, as well as monthly Zoom drop-ins for parents of children with Marfan and Loeys–Dietz syndromes. These sessions provide a warm, welcoming space to share experiences, exchange advice and be reminded that you're not alone. **https://www.marfantrust.org/pages/83-events**

Watch this space: Newly revised and expanded guides on Paediatrics, and the Musculoskeletal System in Marfan & Loeys-Dietz Syndromes will be published very soon. Keep your eye on our Resources section.

Results of our Nationwide Survey

Throwing open a window onto the nationwide experiences of people living with Marfan and Loeys-Dietz syndromes, reveals rare insight into care and what must change. Your voices help us understand today and shape tomorrow. Our recent survey uncovers the symptoms felt most acutely, the disparities running through healthcare, and the daily realities of life with these conditions. What happens next?

To inform our helpline, identify disparities in healthcare provision, and better understand the nationwide care experience of people with Marfan syndrome (MFS) and Loeys-Dietz syndrome (LDS), we undertook a survey at the end of 2025. Between September and November, the online survey was shared widely to capture detailed insights into daily life and the lived experiences of those affected.

We were not disappointed! A huge thank you to the **395 people** who completed the survey either for themselves, or on behalf of someone they care for. Every answer we received has provided valuable insights and a sharp focus on areas that we, as a charity, can target. Thank you!

Good

- **89%** of you told us you experience **good cardiology care**, with imaging AT LEAST every 2 years (although this should ideally be annually, if you have not had prior aortic surgery)
- **45%** of you r**eceived a confirmed diagnosis within one year** of first going to the doctor with symptoms
- **86% of you have received a genetic diagnosis** (although **only 66% have been offered testing for other family members**)

"I felt frustrated that care for Marfan syndrome focuses entirely on the heart. I have had to find my own support for other symptoms of the syndrome".

Areas for Improvement

- **1 in four** of you say that before diagnosis your health concerns were not taken seriously by healthcare professionals
- **56%** of you don't have a named health care professional (HCP)
- **53%** of you don't feel that the different HCPs involved in your care work well together
- **67%** report having to sometimes or often arrange or your own care
- **76%** of you felt that you didn't receive sufficient information from the NHS on your condition and ongoing treatment

Invisible Symptoms that can shape daily life:

- 69% of you want more access to mental health support
- 72% reported that their daily life is somewhat or extremely affected by pain while that figure was 87% for fatigue and 58% for gut issues.

Action

- We value every response we received and will endeavour to take action that improves the situation for people living with LDS/MFS.
  - In response to the high volume of those reporting gut problems, we arranged a webinar with a Dietician who is familiar with Connective tissue disorders on 25th Feb at 7pm and the recording is available here. **https://www.youtube.com/watch?v=WIKbt00FKG4**
  - We have planned a year of roadshows across the country to increase awareness amongst HCPs and Victoria opened this on Tuesday 10th Feb with a fabulous visit to the staff and patients at Birmingham Children's Hospital.
  - We are presenting our findings at conferences across the country to raise awareness of these issues among healthcare professionals. Victoria has already presented at the British Association of Nurses in Cardiovascular Care (BANCC), and Joanne shared the findings at the Aortic Nurses Symposium in London on 19 June. We will also be attending the Royal College of GPs Conference in October, where we will represent the charity with an exhibition stand and an abstract poster.
  - We are exploring projects and resources to provide you with the mental health support you have asked for and are speaking to the wonderful organisation, Rare Minds
  - We organised a pain-management webinar, Empowered Relief, the success of which has lead us to book one later in the year – watch this space.
  - We are working with organisations like Genetic Alliance to maximise our voice and influence health policies affecting people living with rare conditions like MFS/LDS
  - We are working to expand our network of in-person **regional support groups** throughout the UK, click here for details, email **info@marfantrust.org** if you would like to set up a local group with our support

We will continue to update you with news and initiatives that have come from this invaluable piece of work which we could not have done without you.

Thank you to everyone who participated. If you would like to get in touch, please email us **info@marfantrust.org** or call **03330115256**

Adopt a Scientist by Dr Anne Child

Imagine that your family are being stalked by a fatal illness, for which there is no known cause. Members die at any age, children included, suddenly with little or no warning. Such a condition is inherited as enlargement and rupture of a weak walled aorta - the largest blood vessel in the body which carries blood from the heart to all areas of the body.

Yet treatment is available. Modern medicines and surgery are lifesaving. Research is ongoing to discover the genes responsible for this familial condition.

The first gene was discovered in 1991 and others have followed. However, **the vast majority of such families (70%) still have no genetic cause identified**.

The laboratory techniques for analysing DNA samples are well known in our Sonalee Laboratory, taught and practiced by our Laboratory Director, Dr Jose Aragon-Martin PhD, Lecturer in Genomics at Queen Mary's University of London, in the William Harvey Research Institute.

To encourage his research, Marfan Trust has, with the help of supporters' donations, equipped his laboratory with the very latest DNA analysis machines.

Now, 20 large UK multi-generational families have volunteered to help in this project by giving blood samples from affected and unaffected members. It is our task to identify amongst the 20,000 human genes, the one error carried by those affected. In the lab, we must prove that this gene is not carried by unaffected members of the same family.

Jessica

This search aims to discover a further predicted 70 causative genes, one per family.

The families are waiting.

Some younger at-risk members are married and waiting to have their first baby, until the family mutation is discovered.

Additionally, once a gene is found, all family members can be tested simply to see if they are carrying the genetic error, diagnosed, and treated to prevent illness and death.

What do we need to proceed?

We need skilled scientists.

From his MSc course of over 150 students, Dr Jose Aragon-Martin is most impressed by a young scientist from Mexico, Miss Jessica Alvarez, who eagerly offered her help in the laboratory, learning techniques quickly and easily and understanding complicated analysis methods intuitively.

The Trustees of the Marfan Trust UK have voted to grant her a Brian Adams Memorial Studentship for two years in a row, and funded her to attend the American Society of Human Genetics Meeting in Boston 2025, to present her project regarding the most serious gene mutations in Marfan syndrome, which cause symptoms in newborn babies, resulting in early childhood death.

Student Jessica asked the question; why are these gene changes so severe? She has analysed the location and type of mutation within the Marfan gene (FBN1) and is publishing her work. This year 2026 she presented her research at the European Society of Human Genetics in June with the title "spatial interactions of the neonatal Marfan syndrome variants".

Jessica entered Dr Aragon-Martin's course with a BSc Degree (achieving 85.6%) and has won a first-class honours MSc degree. She graduates in September 2026.

She is planning to stay on to obtain a PhD degree in the same field.

Because she has shown such promise, Dr Aragon-Martin has asked the Marfan Trust to support her research for the next three years. The Trust has committed to funding her as a part-time laboratory assistant in the Sonalee Laboratory to support her project, which will analyse samples from 20 selected families. These samples are already stored in our laboratory freezer, ready for analysis.

We ask your help to **ADOPT A SCIENTIST**. Jessica is a personable, highly intelligent, enthusiastic, capable, motivated assistant. She already has important financial backing from the Mexican Government who selected her for this sponsored degree programme at Queen Mary's University of London. Her fees (£35,000 per year) will be provided by the Mexican Government.

Her living expenses and travel to conference will be covered by her annual salary pledged by the Marfan Trust from supporter donations. For her first year the total sum (including University overheads) is £57,255.00.

She further requires funds for laboratory consumables with which to perform DNA analysis. Applications to larger heart charities have been made for these necessary expenses.

Perhaps you are not rich? Few of us are! But perhaps you have friends who are? Or if you are interested in active fundraising, we have ideas and materials freely available **https://www.marfantrust.org/pages/2-get-involved.**

What funds does Marfan Trust need to support Jessica's First Year?

Year 1 September 1st 2026 - August 31st 2027	
Salary	£54,755
Travel to Conference	£2,500
Total	£57,255

HOW TO DONATE

By bank transfer to CAFbank
Marfan Trust
Sort Code 40-52-40
Account number 00017677

Marfan Trust is a registered CIO charity no. 1198847

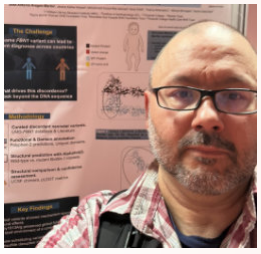
By cheque made out to Marfan Trust
Address: 24 Oakfield Lane
Keston
Kent
BR2 6BY
Thank you

Every donation, no matter how small, will help us reach our target.

All funds donated will be held in a separate account and ringfenced for this project only.

Regular progress reports will be provided to all donors. Jessica's CV is available upon request, and a video of her work in the laboratory is to be made available on our website. **https://www.marfantrust.org/pages/12-donate**

European Society of Human Genomics – June 2026

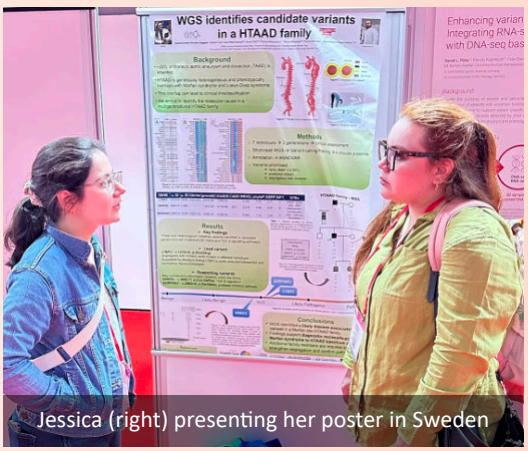


Amongst the dynamic discussions and discoveries unfolding at the European Society of Human Genetics in Gothenburg was research from the Marfan Trust. Our Laboratory Director, Dr José Aragon-Martin, and PhD student Jessica Alvarez were in full flow, presenting two posters that shone a light on some of the unanswered questions surrounding Marfan syndrome and inherited aortic conditions.

Dr Jose Aragon-Martin presented his poster, depicting families who were initially thought to have Marfan syndrome but whose genetic results suggest another cause may be responsible for their aneurysms. By exploring complex bioinformatic data in his first approach, Jose hopes to identify variants of interest beyond the FBN1 gene and uncover new clues about the genetic origins of aortic disease.

This work began with the detailed analysis of a single family and, following fresh ideas and discussions at the conference, the team is refining its approach. They hope to gain a clearer understanding of the underlying genetics by September or December 2026.

Meanwhile, Jessica discussed the three-dimensional protein interactions of variants associated with neonatal Marfan syndrome (nMFS). Having previously mapped the published data on nMFS variants, she is now adding a new dimension to the work, examining how these variants interact within the protein structure itself and what those interactions may reveal about this severe form of the condition.



Jessica (right) presenting her poster in Sweden

Research News by Jessica Alvarez

Over the past year, my research has focused on understanding the clinical and molecular consequences of variation in the FBN1 gene, which provides the instructions for making fibrillin-1, a protein that gives strength and elasticity to connective tissues throughout the body. This work spans ocular (eye) disease, hereditary aortopathy (inherited conditions affecting the aorta, the body's main artery) and severe early-onset Marfan syndrome.

At Queen Mary University of London, I'm working on hereditary thoracic aortic aneurysm and dissection (an inherited condition affecting the aorta) using whole-genome sequencing data from three families. I am integrating variant annotation (identifying and classifying genetic variants), inheritance patterns, population frequency, predicted functional impact and detailed phenotypic information (the clinical features seen in affected individuals) to prioritise candidate variants. Long-read sequencing evidence (a DNA sequencing technique that reads much longer stretches of DNA) is also being incorporated where available to clarify complex or previously uncertain findings. Attention is being given to genes and pathways involved in vascular smooth-muscle contraction (how the muscle cells in blood vessel walls function), extracellular-matrix integrity (maintaining the strength and structure of connective tissues), TGF-β signalling (a cell communication pathway important for growth, repair and connective tissue function), mechanotransduction (how cells sense and respond to physical forces) and RNA splicing (the process by which genetic instructions are edited before proteins are made).

For the Marfan Trust, I have been mapping FBN1 variants associated with neonatal and severe early-onset Marfan syndrome. This has involved curating and standardising variants from databases, published studies and clinical reports, then assessing their distribution across fibrillin-1 domains (different structural regions of the fibrillin-1 protein). I have also compared variants located within and outside the region traditionally associated with neonatal presentations. The aim is to test existing assumptions about genotype–phenotype correlations (how particular genetic changes relate to disease severity and clinical features), identify recurrent molecular patterns and support more accurate interpretation of severe early-onset cases. Structural assessment is additionally being used to explore how selected variants may disrupt calcium binding, disulfide bonding (chemical bonds that help stabilise proteins), protein folding (how a protein adopts its three-dimensional shape) and molecular interactions.

At the University College London Institute of Ophthalmology, I have been contributing to a research project examining the relationship between FBN1 variation and ocular manifestations (eye-related features of disease). This work involves reviewing current evidence on fibrillin-1 biology, extracellular-matrix organisation (the network of proteins that provides structure and support to cells and tissues) and the mechanisms through which pathogenic variants (disease-causing genetic changes) may affect ocular structures. The project also considers genotype–phenotype relationships (how specific genetic variants relate to the signs and severity of disease) and areas where further experimental and clinical research is needed.

Together, these projects combine genomic analysis (the study of a person's complete genetic information), literature synthesis (bringing together findings from published research) and structural interpretation to improve understanding of FBN1-related disease across different tissues and stages of presentation.

Newly Published Care Management Handbook for Loeys-Dietz Syndrome

Capturing two decades of discovery and growing insight, a new handbook has just been published for Loeys-Dietz syndrome, weaving together the many strands of this complex connective tissue disorder. Written by international experts, it takes a holistic, personalised approach to the condition and serves as an invaluable guide for both patients and clinicians.

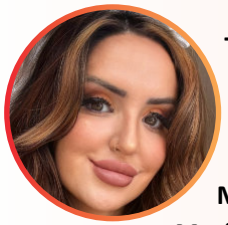
Since Loeys-Dietz syndrome was first described in 2005, medical understanding of the condition has evolved dramatically. Early guidance rightly prioritised the prevention of catastrophic aortic events, but a growing appreciation of the condition's complexity has led to a more holistic and personalised approach to care.

Recently published in Genetics in Medicine, this new handbook for clinicians reflects that changing understanding. It advocates a tailored, holistic approach to care, recognising that treatment should be shaped not only by an individual's genetic variant and family history of aortic disease, but also by their symptoms, circumstances and personal priorities.

Written by leading international experts in Loeys-Dietz syndrome, the publication is an invaluable resource for both clinicians and patients. It is freely available to download here:

https://www.marfantrust.org/articles/joining-the-dots-in-loeys-dietz-syndrome

Translating medical reality into eye-catching art By Zoe Ridgway



Translating medical reality into eye-catching art, fine artist Zoe Ridgeway has enlivened our social media graphics with her wonderful imagery. Zoe lives with Marfan syndrome and volunteers for the Marfan Trust. This is Zoe's story:

I am a mother, an artist, and a Teaching Cover Supervisor, and each of these roles has been shaped by my experience of living with Marfan syndrome. My life has been defined not only by the challenges of a lifelong genetic condition but also by the determination to find purpose, creativity, and hope through adversity.

Arachnodactyly III

Living with Marfan syndrome has meant navigating countless medical appointments, surgeries, chronic pain, and uncertainty. There have been moments when my body has felt fragile, but my spirit has refused to be defined by my diagnosis. Every setback has taught me resilience and has deepened my appreciation for the people who have stood beside me throughout my journey.

My family and my partner have been my greatest source of strength. Their unwavering love, patience, and encouragement have carried me through some of the most difficult periods of my life, particularly during major surgeries and recovery. They have reminded me to keep believing in myself, celebrated every milestone with me, and given me the confidence to continue pursuing my dreams despite the challenges Marfan syndrome has presented.

FBN1 - an abstract representation of the Fibrillin-1 gene

As a mother, my daughter is at the heart of everything I do. She inspires me to keep moving forward and to show that strength is not measured by physical ability but by determination, kindness, and hope.

My artwork is a visual language through which I communicate experiences that words often cannot express. Working primarily through abstraction, I explore the physical and emotional realities of Marfan syndrome, transforming pain, recovery, vulnerability, and resilience into colour, texture, and movement. My paintings are not simply representations of illness; they are reflections of survival, healing, identity, and the strength that can be found even in life's most challenging moments.

Beginning my role as a Teaching Cover Supervisor marks an exciting new chapter in my life. After overcoming significant health challenges, I am proud to return to supporting young people in education. I hope to encourage students to believe in themselves, embrace their individuality, and understand that obstacles do not have to define their future. The empathy, patience, and resilience I have gained through my own experiences are qualities I bring into the classroom every day.

When I am not teaching or painting, I enjoy reading, finding inspiration in stories that broaden my perspective and fuel my creativity. Whether I am with my family, in the classroom, or in my studio, I believe in the power of love, education, and art to create understanding, inspire others, and bring hope.

Marfan syndrome is part of my story, but it is not the whole story. My life is one of perseverance, creativity, compassion, and growth. Through my artwork, my work in education, and the support of my family and partner, I continue to demonstrate that even in the face of adversity, it is to build a life filled with purpose, resilience, and hope.

Trichterbrust

Empowered Relief webinar

With great excitement, we hosted our first Empowered Relief webinar on 9 June, led by Dr Lorelle Dismore. Developed by Stanford University psychologist Dr Beth Darnall, this evidence-based, two-hour programme equips people with practical strategies to manage chronic pain and has been shown to produce benefits comparable with an eight-week course of cognitive behavioural therapy (Darnall et al., 2024).

Our national survey revealed that 72% of respondents said pain significantly affects their daily lives, influencing everything from work and relationships to sleep and overall wellbeing. With NHS pain services often difficult to access, Empowered Relief offers a proactive, non-drug approach to pain management. Research has also demonstrated significant improvements in pain intensity and interference specifically for people with Marfan syndrome (Perez et al., 2026). The session received excellent feedback from attendees, and we're planning to run it again later this year.

What you need to know

- Watch our website and social media for details of the next session.
- Empowered Relief MUST BE DELIVERED LIVE and cannot be watched later as a recording.
- The greatest benefits come from regular practice of the techniques taught during the session, including use of the accompanying relaxation app.

References: Darnall BD, Burns JW, Hong J, et al. Empowered Relief, cognitive behavioral therapy, and health education for people with chronic pain: a comparison of outcomes at 6-month follow-up for a randomized controlled trial. **https://pubmed.ncbi.nlm.nih.gov/38288134/**

Pain Reports. 2024;9(1):e1116.Perez, L., Palenski, P., Monson, E.A. et al. Online 1-session Empowered Relief in Marfan syndrome and related diseases: a single-arm feasibility and pilot efficacy study. Sci Rep 16, 499 (2026). **https://doi.org/10.1038/s41598-025-29943-x**

Volunteers' Corner

Daisy McCrann

Breathing fresh ideas and new perspectives into the Trust are our volunteers. We are delighted to introduce Daisy and Henry. Here are their stories.

I decided to join Marfan Trust because this is a charity I can absolutely relate to.

All of my life I have had annual echocardiograms and check-ups, which all started from a stroke of luck in 2001, a few days after I was born, where my paediatrician considered Marfan Syndrome, because I had slightly longer fingers than usual for a baby.

It was then found in an echocardiogram that I had aortic valve regurgitation, known more commonly as an aortic leak. I have since been on medication to control my blood pressure. This discovery at birth led to the same condition being found in my Mum, who was then subsequently given medication and annual check ups for the condition.

My Grandad, aged around 56 at the time of my birth, began treatment for Marfan Syndrome with medication and he had an operation when I was very young. My Grandad sadly passed away in 2021 and we all do miss him dearly. I would say my Grandad's passing is a big part of my motivation for taking on this role is to help prevent more lives being cut short.

Marfan Syndrome was originally suspected in my Grandad's late twin sister, long before I was born. As a result, my Mum, Auntie Tracey and Grandad went for testing at their local GP, but there was very limited information on the condition at the time, and no diagnoses or follow ups took place.

In 2003, my Auntie Tracey had heart surgery to repair her faulty mitral valve, which was discovered by the GP. She does still have an aortic leak, but like mine, it is checked regularly and not of great concern as long as it stays a manageable size.

In 2024, I had my official diagnosis and later that year my Mum had open-heart surgery - she had her aortic root replaced but her valve was able to be repaired, as the surgeon thought this may need replaced too.

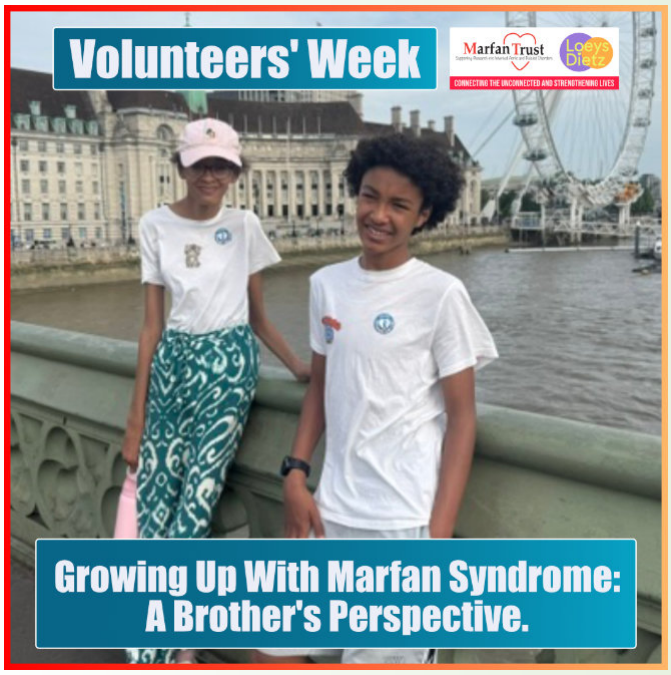
I am an only child, and very close to my Mum and Dad, so this was a very challenging time for us. However, it is amazing that she is doing so well now. My Mum is a very big inspiration to me, as she was so brave and resilient before, during and after her surgery.

I find ongoing medical advancements into Marfan Syndrome research and treatment so fascinating. My diagnosis wasn't a surprise, as it was suspected for all of my life, however it was difficult nonetheless. I was so grateful though, that I could be tested and have it confirmed, to show that the treatment I have been receiving was correct and was working. I find it so clever and reassuring for my future now that patients can adopt IVF to detect and isolate healthy embryos from the faulty gene that causes Marfan Syndrome.

I would like to help spread our message to those who may not know much about Marfan Syndrome and other connective tissue disorders, if at all. I would also like to reach other young people who may have feelings like confusion and isolation due to their, or a loved one's diagnosis, and what it may mean.

I just graduated last week with a Master's degree in Marketing, which I am so proud of. I currently work as a charity shop manager, with a team of around 35 volunteers. I have a collection of over 70 records and most Mondays I go to a local pub quiz with my friends. In my spare time I love reading, going to gym classes, going out for coffees and rummaging other charity shops. Some may call it filling my flat with things I do not need but I prefer the term "scouting my competition"!

Henry Odong



Quietly watching his sister navigate a chronic health condition has shaped Henry's understanding of human resilience. Henry is 14 and his younger sister Isabella has Marfan syndrome. Together they've devised safe and creative ways to play that will not put her at risk. Henry has since volunteered his many skills to the Marfan Trust as part of his Duke of Edinburgh's Award. Henry has helped with our videos, subtitling them using his wizard skills. Do read his wonderful article, Growing Up with Marfan Syndrome: A Brother's Perspective!

Hi I'm Henry Odong and my sister has Marfan syndrome.

Marfan syndrome is a genetic disorder that affects the body's connective tissue which is basically the "glue" that holds everything together. Because connective tissue is found throughout the body, the condition can affect many different systems, including the heart, eyes, joints, and skeleton.

Watching my sister navigate life with Marfan syndrome has been eye-opening as it has taught me a lot about resilience, family, and what it truly means to be supportive.

The Balancing Act of Daily Life

One of the hardest parts of watching a sibling live with Marfan syndrome is seeing the limitations it can cause. Because of the risk of aortic enlargement (a bulge in the aorta, the biggest artery), contact sports and heavy lifting are off the table. As a brother, you want to protect your sibling, but you also want them to experience everything life can offer and make it fun.

We had to find new ways to have fun. Instead of high-impact activities, we focused on things we could do together like drawing and more creative things.

Strength that you would never see

If you looked at my sister, you might just see someone who is tall and slender. You wouldn't necessarily see the eye specialist appointments, or the daily fatigue that can come with the condition.

What I like most about her is her quiet strength and how she handles things. She doesn't let her diagnosis define who she is. She perseveres through it. Instead, it's just one part of her story. It's a part that has made her incredibly resilient, empathetic, and mature beyond her years which as a brother I'm very proud about.

Spreading the Word by Victoria Hilton

Bringing Marfan syndrome beyond a captive audience and into the public conversation is essential. In June, PEARS pioneer Tal Golesworthy helped do just that when he spoke to the BBC World Service about his life-saving invention and his own experience of living with a connective tissue disorder.

As a boy, Tal was the tallest pupil in his school, unaware that the condition responsible for his height would one day have implications for his heart. He describes himself as eccentric, a quality that proved instrumental in the ingenuity and determination that ultimately led to his remarkable invention. Here is the link to his interview: **https://www.bbc.co.uk/sounds/play/w3ct8jkq**

Meanwhile, **Marfan and Loeys-Dietz Awareness Months** are our opportunity to breach barriers and bring these conditions into sharper focus. We emerged from the campaigns exhausted but exhilarated after setting social media ablaze. Throughout February and March, we shared daily posts under the theme See the Signs, Save a Life, weaving together patient stories, medical information and infographics drawn from our national survey. Together, they shone a light on both the visible and invisible realities of MFS and LDS, guiding supporters towards the ever-growing resources on our website.

Among the most widely shared posts were Scott Stowell's remarkable journey from Texas to London for the PEARS procedure and Rachel Linford's moving account of the toll Marfan syndrome has taken on her mental health. Meanwhile, the striking artwork of Zoe Ridgway, a young artist living with Marfan syndrome, gave the campaign its distinctive visual identity. Darren McDean's inspired graphic design brought Zoe's work vividly to life, culminating in a memorable Rare Disease Day post that received more than 200 reactions.

The February campaign for MFS extended our reach significantly, acquiring more than 300 new Facebook followers, generating over 212,000 views, almost 13,000 engagements and more than 900 shares. Most importantly, it ensured that thousands more people encountered the signs and symptoms of Marfan and Loeys-Dietz syndromes and discovered where to turn for trusted information and support.

Loeys-Dietz Month was similarly successful. During February we held webinars with Consultant Paediatric Cardiologist Dr Nitha Naqvi and Dietitian Chloe Hall.

PACES Ahead


Derek is fourth from left

Flanked by members of the medical profession, Derek is quietly educating clinicians about Marfan syndrome. At the recent PACES Ahead doctors' mock exams, he was assessed by 150 doctors-in-training and, after some prompting (and a glimpse of his INR booklet), between 40 and 50% correctly identified his condition. Derek said "things are definitely travelling in the right direction".

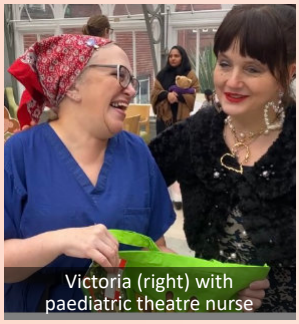
Standing at 5ft 7, Derek surprised many of the medics, who had expected someone with Marfan syndrome to be much taller. This proved fortuitous, reinforcing an important point - height is relative, and not everybody with Marfan syndrome is unusually tall compared with the general population.

Meanwhile, once Derek's diagnosis had been confirmed, many of the medics asked him to demonstrate some of his hypermobile hand party tricks. He also noticed that far fewer doctors were familiar with Loeys-Dietz syndrome.

If you'd like to help raise awareness of Marfan or Loeys-Dietz syndrome, then click here. **https://tinyurl.com/2temju74**

Conference News and Medical Roadshows

Birmingham Heart Roadshow - 14 February by Victoria Hilton


Victoria (right) with paediatric theatre nurse

United on matters of the heart, the Marfan Trust and several like-minded charities converged at Birmingham Children's Hospital for a day of education and conversation. Marking Heart Awareness Week, we hosted an exhibition table and chatted with the many passing parents, patients and healthcare professionals, from cardiologists to dietitians and dentists.

The nursing team challenged us to assemble a jigsaw heart, testing our knowledge of its anatomy. We also met the parents of a child with Kawasaki disease, a rare condition that causes the blood vessels to swell, usually affecting children under the age of 5. Conversations such as these remind us that, although every condition is different, families often share many of the same questions and worries.

We spoke to a dietitian and ate their home-made biscuits, especially tailored for people to eat after heart surgery. These were low in saturated fat and sugar.

It was an occasion shaped by learning, connection and an enthusiastic response to our Willow lime-green tote bags!

British Association of Nursing for Cardiovascular Care Annual Conference by Victoria Hilton

In the wake of our nationwide survey, we took its findings on the conference circuit, beginning with the British Association of Nursing for Cardiovascular Care's annual conference in April. Our poster presentation started some fascinating conversations. Whilst some nurses were already familiar with Marfan and Loeys–Dietz syndromes, others were encountering the conditions for the first time. The lovely nurse standing by our poster presentation recalled learning about Marfan syndrome during her training, and, of all its features, the one that stayed with her was the high-arched palate.

Sustainability was the overarching thread running through the presentations, with one talk focusing on recycling ICDs (Implantable Cardioverter Defibrillator) and delivering them to countries where they are most needed. One schoolgirl's life in Kenya has been saved four times by an ICD!

Liverpool Aortic Symposium – 4 & 5 June by Joanne Jessup

Some of the world's greats in aortic surgery and genetics assembled for Aorta: Structure to Rupture. Liverpool hosts this aortic conference biennially and I was proud to represent the Marfan Trust with Jessica, one of our in-house researchers. We hosted an exhibition table, attended lectures and mingled with clinicians, nurses, patients, and visitors from the US including Dr Duke Cameron, Dr John Elefteriades and Dr Dianna Milewicz.

Amongst the many lectures and discussions unfolding across the symposium was a fascinating conversation around how AI may begin to improve the diagnosis of connective tissue disorders (CTDs) by recognising some of the facial features associated with different CTDs. Technology is also playing an increasingly important role in developing our understanding of how and why the aorta dilates and sometimes tears, while exciting work on the flow dynamics of blood in the aorta is helping researchers detect and, hopefully in the future, predict where problems may arise.

Yet perhaps the symposium's most memorable moments came when patients with Loeys-Dietz syndrome were given the chance to meet the very clinicians behind its name. Following their keynote lectures, Dr Bart Loeys and Dr Hal Dietz hosted a lunchtime forum for patients and we were fortunate enough to join them. The duo were extraordinarily generous with their time, discussing treatment options, fears and concerns, and the ongoing research taking place in the field.

Aortic Nurses' Annual Symposium by Joanne Jessup

Their take-home messages included:

- The importance of providing advice within the context of the specific gene change
- Considering family history when thinking about surgery and the risk of dissection, getting as much family history information as possible is really helpful
- Dr Dietz emphasised the importance of medication within the Angiotensin Receptor Blocker group, e.g. Losartan, Irbesartan. He commences medication in patients at a young age, regardless of aortic size. He also aims to get individuals to the highest tolerated dose possible. For example: it is better to be on a good dose of either beta blocker or ARB than a very small dose of each.
- Both doctors highlighted the importance of physical activity and remaining active at all stages of life.

On a sunny June day, around 80 specialist nurses from across the UK convened in London for the third annual Aortic Nurses Symposium, hosted by The Aortic Dissection Charitable Trust. It was a valuable opportunity to share best practice, hear the latest research and learn from both clinicians and patients.

Joanne Jessup

Highlights included Dr Vikas Kapil's session on blood pressure management after aortic dissection, which explored how virtual wards are empowering patients to monitor their condition at home with ongoing support from specialist nurses. We also heard about Professor Julie Sanders' Beating Bias research, highlighting the different experiences of women with aortic dissection and the need to improve recognition and treatment.

I was proud to present the findings of our National Survey, sharing your priorities with a national audience. These included the need for personalised advice on exercise, better coordination between healthcare teams, and a dedicated NHS contact to help navigate care. My overriding message was simple: Marfan and Loeys–Dietz syndromes are systemic conditions. You are not just an aorta, but a whole person.

In Memory

Karl Grice (03/01/1981 - 18/03/2026)

Karl was truly a great man, full of life, fun, and with a sense of humour like no other. He brought laughter into every room he entered and, no matter what he was going through, always had a smile on his face.

Karl was a devoted family man, my soulmate and deeply loved partner of 26 years, and the greatest dad to Lewis and Kayleigh. His children were, in his own words, his greatest achievement, and he was immensely proud of them both. He was a cherished son to Christine and Peter, brother to Craig, Kerry and Nicky, a loved uncle, nephew, cousin and dear friend to many.

In his spare time, Karl loved being with his family, watching his beloved Manchester United, fishing with friends, and walking in the countryside with his furry best friend, Bobby.

Behind his easy-going smile was a true warrior. In 2003, aged just 22, Karl was rushed into surgery with an aortic dissection. It was then that he was diagnosed with Marfan syndrome, a condition we had never heard of. His father, Peter, had died from an aortic dissection when Karl was only 11, but no connection had been made. Our son and one of Karl's siblings were diagnosed soon afterwards. Over the next 23 years, Karl underwent multiple operations and procedures, facing every challenge with remarkable strength and determination.

Karl was passionate about raising awareness of Marfan syndrome. He welcomed medical professionals and students to learn from his condition and even allowed one of his operations to be filmed for educational purposes.

Devastatingly, but peacefully, Karl lost his final battle and passed away in March 2026. His loss has left an enormous void in all our lives, but his legacy of strength, kindness and resilience will live on.

To honour his memory, we asked for donations to The Marfan Trust instead of flowers. Thanks to the incredible generosity of everyone who knew and loved him, £1,200 was raised to support the work he believed in so deeply.

Karl, you fought so hard and loved us so well. You will never be forgotten. x

Lee Joyce

by his sister ***Louise Joyce***

Lee was always the clever one in the family. He excelled at GCSEs and A-levels at St Peter's in Wolverhampton and even appeared on Blockbusters ("Can I have a P please, Bob...?").

Bob Holness introduced him as one of the tallest ever contestants. I still have the episodes on VHS and am getting them converted to USB so we can watch them again – Lee even completed five Gold Runs on his own.

At 6'9", Lee's height affected everyday life, from finding clothes that fitted to driving a suitable car. Although it attracted plenty of attention, he was a quiet, gentle giant who never liked being the centre of it.

He studied French at university and spent a year living in Lyon, immersing himself in the language and culture.

Years later, when I was 30 and Lee was 33, I needed a pacemaker after developing heart problems. As Lee had also been experiencing symptoms, he was scanned, admitted the same day and, 10 days later, underwent surgery to replace his aortic root and valve. It was then that we discovered he had Marfan syndrome, which had caused his aortic dissection. Although our heart conditions were unrelated, the experience brought us much closer and he became one of my best friends.

Lee met the beautiful Rachel on 21 March 2021, as lockdown was ending. She changed his world. They moved in together in 2022 and soon welcomed two beautiful cats, Willow and Dinah.

I will always be thankful they found each other. Lee was truly happy, deeply loved, and it was obvious how much he loved Rachel.

Lee was intelligent, funny and witty, with a great love of storytelling, pub quizzes and making people laugh. He was also kind, patient and caring. Everyone who knew him spoke highly of him.

A couple of years ago, doctors discovered that Lee's aortic arch was dissecting and that he had an aneurysm requiring further surgery. Tragically, while waiting for the operation, the aneurysm ruptured and Lee died on 28 December 2025. We were all heartbroken.

At his funeral, we chose flowers in the colours of Wolverhampton Wanderers Football Club and asked for donations to The Marfan Trust instead of additional floral tributes. We raised around £648.50 in cash, with further donations made directly via the QR code.

We are still coming to terms with losing Lee. He has left a huge hole in our lives.

Marco Shaunt Grant

by his daughter, **Charlotte**

Marco Shaun Grant was not diagnosed with Marfan syndrome until he was in his 40s. Being diagnosed later in life helped him to understand some of the health issues he had growing up, such as really bad eyesight. He ended up having lens surgery which meant he could then drive. Unfortunately, once diagnosed it was noted that my dad had a lot of the health issues related to Marfan syndrome. He had numerous surgeries due to aneurysms and had two triple heart bypasses. The most recent being in February this year. Little did we know that my dad wouldn't leave hospital and this was surgery would be the worst and he would not recover from it.

My dad had a real zest for life and is well known by many due to DJ'ing around the country and dressing up in colourful fancy dress outfits. Right up until his last moments he was the colourful character he had always been.

Marco was a doting dad to me, Michael and Curtis who loved him dearly. He also had lots of fun with his grandchildren, Macey, Micah, Theo and Kyrie-Francis.

He loved his wife dearly too and she was with him in his final moments

Marco passed away on 20th April 2026 in hospital. We celebrate his life and take comfort from the amazing person he was.

RIP dad love always Your children Charlotte, Michael and Curtis And your wife Julie

Sam Robinson

by his mother **Jules Lovell**

0n 2nd May 2025 our beloved Sam gave up his fight with Marfan.

Sam was diagnosed at the age of five due to a lens dislocation. With constant monitoring Sam led a fairly normal life until his teens and then his chest started to become extremely inverted. Nuss bar surgery was unsuccessful. When Sam was 24 years old Marfan really started to affect his everyday life. Retinal detachments left Sam blind in his right eye and partially sighted in his left eye, however this didn't stop him from being a fantastic photographer for musicians such as Muse, Pink, Good Charlotte, Alice Copper, Papa Roach and many more. In 2020 during Covid Sam suffered a descending aortic dissection and had emergency surgery which was very touch and go. A while later Sam became the second person in the UK to receive Thoracaflo surgery, a life saving device made by Terumo Aortic based in Glasgow. Sam suffered pain on a daily basis, he became very tired, his scoliosis meant he was unable to lie flat and would prefer to sleep sitting up on the sofa. He had surgery on his eyes countless times and it was down to the fantastic Mr Aman Chandra who managed to give Sam some sight back in his left eye. Sam never complained, he worked full time and continued his photography work, he bought his own apartment and had a huge group of friends. He was also a huge Birmingham City FC fan.

On 2nd May 2025 after an evening watching a film and chatting with us, Sam went to get ready for bed and suffered an ascending aortic dissection. We take some comfort from being there with him as he passed.

Sam's funeral was attended by over 240 people which raised just over £2500 for the Marfan Trust. Sam worked at Solihull hospital and the funeral cars drove through the hospital grounds where over 200 hospital staff came outside to say goodbye. The funeral cars were also escorted by 6 Storm Troopers to honour Sam's love of Star Wars. Sam's step dad Danny has run 3 half marathons and raised £3500 so far. A family friend also raised £1000 by running a half marathon the day after Sam passed away, making it a very emotional run for her.

Sam is a true hero to us. He was such an inspiration with a wicked sense of humour. He went through so much in his short life but also achieved so much. He is so deeply missed by us and his younger sister and his close group of friends. As a family we are devastated but will continue to raise awareness and funds for the Marfan Trust to keep our beloved Sam's memory alive.

Fundraising Feats

Every mile run, every challenge conquered and every pound raised helps change lives. We are forever grateful to our incredible fundraisers who breathe life into our work every day. Here is just a small glimpse of the remarkable things they have achieved.

Cannonbawz Run

Resuming their exhilarating fundraising rally in April withtheir own largest-ever gathering of supercars, the Cannonbawz Run has entered its eleventh year. Kris O'Neill and his crew cruised past some of Scotland's most breathtaking scenery, including the North East, the Lecht Ski Centre and Corgarff, in their latest adventure in support of the Marfan Trust.

Driving north along the Moray Coast, the journey passed through Peterhead and Fraserburgh before following the spectacular coastal road to Gamrie, one of the rally's most memorable stretches, where dramatic sea views provided a fitting backdrop to the final leg of the drive.

Through these remarkable fundraising rallies, Kris continues to honour the memory of his brother, Liam. We look forward to joining the Cannonbawz Run in August.

Lyndsey Ingram

The sole figure in her family affected by Marfan syndrome, Lyndsey once believed the condition was vanishingly rare. Yet as more diagnoses emerged in the wider world, her sense of isolation gave way to determination. Throughout February, Lyndsey fundraised for the Trust, and spread the word on Marfan syndrome! Thank you so much, Lyndsey!

by ***Lyndsey Ingram***

Marfan syndrome has affected many aspects of my life. I'm 6ft 1, although I might have been even taller had my knee growth plates had not been operated on. when I was 11 years old.

I was born with dislocated lenses, which were replaced, and I have also undergone a cornea transplant. My eyesight remains a daily challenge. I also have an enlarged aorta, which is being managed with medication and, thankfully, seems to be stable. I have stretchy skin, am extremely flexible, and experience many of the other features associated with the condition.

Now aged 43, I live independently and work at Orchid Orthopedic Solutions in Sheffield. To mark Marfan Syndrome Awareness Month, I organised a raffle to raise awareness of the condition and support the Marfan Trust. Thanks to the generosity of my company, friends and family, who donated the prizes, it raised over £500.


Derek in the middle

Bexleyheath Working Men's Club & Derek Goodger

Always ready to lend his time as generously as his support, Derek hosted a Marfan syndrome awareness evening at his local Working Men's Club in Bexleyheath. Filled with music from the resident organist, raffles and friendship, the evening raised a wonderful £253.20 for the Trust. Thank you, Derek!

Danny Lovell – Running for Sam

Exhausted but exhilarated, Danny Lovell completed the Rhodes Marathon on Sunday 1 May under the searing Greek sun. It was a poignant run, marking the first anniversary of the death of his stepson, Sam 'Bam Bam'. Sam died on 2 May 2025 from complications of Marfan syndrome, just two weeks before he was to fly to Rhodes to celebrate his 30th birthday.

A week later, Danny completed the Birmingham Half Marathon, raising nearly £2,000 for the Marfan Trust. Thank you so very much, Danny.

You can read the tribute to Sam by his mother in our In Memory section.

Katie Mahers

Katie's fundraising journey began at the start of February to mark Marfan Syndrome Awareness Month and quickly gathered momentum. Through daily social media stories, a workplace bake sale and the generosity of friends and colleagues, she soon raised £170.85.

Encouraged by the wonderful support she received, Katie continued the momentum throughout the month. She organised a social media giveaway, held a workplace raffle and, with her choir the Firebird Singers, organised a second raffle and bake sale. Every share, every donation and every conversation helped to raise both awareness and funds for the Marfan Trust.

By the end of her campaign, Katie had raised an incredible £903.

Katie inherited Marfan syndrome from her father. A talented singer and a wonderful supporter of the Marfan Trust, she has been a whirlwind of fundraising.

Mayor of Swanley, Michael Horwood

An inauguration, an exciting new role, and a generous gesture!

Michael Horwood, the newly anointed Mayor of Swanley, has chosen the Marfan Trust as one of three charities he will support throughout 2026, in memory of his friend and colleague, Councillor Darren Kitchener, who had Marfan syndrome.

Michael has organised a steady stream of fundraising events, the first of which event took place on Armed Forces Day in June, when we hosted a stall in Swanley Recreation Ground and spoke to passers-by about Marfan and Loeys-Dietz syndromes. Under a sweltering summer sun, we also enjoyed a horse show while the stirring strains of the bagpipes blasted across the grounds creating a rousing atmosphere throughout the day.

In July, we joined the Mayor's curry night (pictured below) and raffle, again raising both awareness and funds. Victoria introduced guests to the work of the Marfan Trust with a short impromptu speech. Hearteningly, one diner had listened to Dr Child's interview on BBC Radio 4's The Life Scientific!

These wonderful events – civic and personal - will continue throughout the year, and we look forward to keeping you updated.

[Pictured: The Clove Curry Night raffle on 7 July and Victoria and Mayor Michael Horwood on 27 June at Armed Forces Day]

Stamp for Charity!

Every perforated picture tells a story. Stamps have celebrated and commemorated people, fashion, and events, keeping us connected in a disconnected world. And they make a tidy sum for the Marfan Trust.

Pauline and her late husband Raymond Moses have been collecting stamps, old and new, turning them into donations for our Charity, in memory of their beloved son Peter whom they tragically lost to complications from Marfan syndrome.

Please remove the postage stamp from the envelope (leaving 1cm of envelope bordering each stamp and being careful that you don't damage the stamp itself). Retain the barcode if there is one but if no barcode leave quarter of an inch. These stamps can be of any description and from any country.

Please send to: Mrs Pauline Moses The Waves, Coast Drive, St Mary's Bay, Romney Marsh, Kent TN29 0HN

Second International Symposium in London

A gathering of experts, a community of patients, and the opportunity to meet, learn and thrive.

Join us on Saturday 10th October in London when we resume our collaboration with the Marfan Foundation for the Second International Symposium: Living Better with Marfan, Loeys-Dietz, VEDS and Stickler.

Attendees will learn from a team of international medical experts, liaise with professionals and others on a similar medical journey, and enjoy a "Creating Connections" lunch. Breakfast is also available and activities for Children 5-12 will be Provided for in a separate area by trained adults.

The symposium is free, but registration is required.

The Second International Symposium/London: Living Better with Marfan, Loeys-Dietz, and VEDS is brought to you by The Marfan Foundation US, the Marfan Trust UK, The Aortic Dissection Charitable Trust and Annabelle's Challenge. https://www.marfantrust.org/events/second-international-symposium-in-london

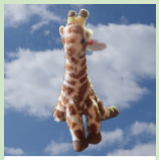
Space is limited to book your ticket today! **https://www.marfantrust.org/events/second-international-symposium-in-london**

Remote All-Day Conference: Saturday 14 November

Resuming our annual remote Information Day slightly later in the year, to make way for our International London Symposium, this year's webinar features a focus on feet. Our summer student for 2026, Amelie Teferle is studying medicine at Cambridge University and encountered Marfan syndrome during a lecture. She was immediately interested in the condition and is now exploring orthotics, podiatry, podiatric surgery and a wide range of clinical case studies. Her work will culminate in a new Guide to Feet, and she will present her findings during our all-day conference.

Elsewhere, the programme will feature a podiatric surgeon alongside talks on cardiology, pain relief and much more. **https://www.marfantrust.org/events/remote-all-day-conference**

The Marfan Trust Online Shop


Willow

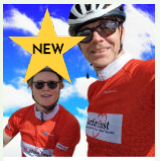
Tote Bag


Marfan Pen

Marfan Cap

Heart Keyring


Marfan Mug



Cycle Tops

Jeremy Wins

Water Bottle


Wristband

Pin Badge


Marfan T-shirt

Zest for Life

Marfan/LDS Band

Beanie

Green Tote


Three Kings


Angels


South Bank

Watermill

LDS T-shirt

Welcome to our shop, a trove of lovely things, newly expanded with our branded water bottle and more.

Visit Our online shop for a larger selection of merchandise.

www.marfantrust.org/pages/32-shop

☐ I am eligible for Gift Aid: (please tick if relevant and leave name and address below)

Signed ..... Date .....

Please return the response slip to: Marfan Trust, 24 Oakfield Lane, Keston, Kent, BR2 6BY. Please make cheques payable to the Marfan Trust. Thank you!

Name .....

Address .....

Email .....

Please include cost of postage (£3) in sum total. All cards are in packs of 10.

Item								Price	Quantity	Total
Cycle Top ★	Small ☐	Medium ☐	Large ☐	XLarge ☐				£43.00 (each)		
Marfan/LDS Wristband ★	☐	☐	☐	☐				£2.50		
LDS T-shirt ★	Small ☐	Medium ☐	Large ☐	XLarge ☐				£11.00		
Marfan Trust T-shirt	Small ☐	Medium ☐	Large ☐	XLarge ☐				£11.00 (each)		
Willow, the Marf Giraffe								£9.00		
Jeremy Wins Book								£8.00		
Marfan Trust Tote Bag								£6.00		
Marfan Trust Pen								£2.00		
A Zest for Life Cookbook								£6.00		
Heart Keyring ★								£3.00		
Marfan Mug								£9.00		
Marfan Trust Wristband								£2.50		
Marfan Trust Water Bottle ★								£15.00		
Marfan Cap ★								£10.00		
Marfan Trust Pin Badge								£2.00		
Watermill Card (10 cards)								£4.00		
Beanie Hat ★			Black ☐	Grey ☐				£8.00		
Green Willow Tote Bag ★								£5.00		
Three Kings of Orient Card (10 cards)								£4.00		
Angels Card (10 cards)								£4.00		
South Bank Card (10 cards)								£4.00		
Postage cost								£3.00		
SUM TOTAL (including postage)										