

Charity Number: 1198847
Company Number: CE028953

MARFAN TRUST
FINANCIAL STATEMENTS
FOR THE YEAR ENDED
31 December 2024

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MARFAN TRUST

LEGAL AND ADMINISTRATIVE DETAILS

Marfan Trust was registered as a CIO with the Charity Commission on 5 May 2022. Previously an unincorporated charity known as "The Marfan Trust" which was set up by a Declaration of Trust dated 4 November 1988.

The Registered Number is 1198847.

Patrons:

Professor Sir Magdi Yacoub FRCS,
Dr Lady Maryanna Tavenor
Professor Marjan Jahangiri FRCS, FRCS (CTh)
Professor John Pepper OBE, MA, MChir, FRCS, FESC
Mr Ulrich Rosendahl MD, FETCS

Trustees as at 31 December 2024:

Mohamed Abdelrazek
Dr Anne Child (Chair)
Eleanor Hyde
Dr Nitha Naqvi
Robin Randall
Andrew Scadding
Ed Stilliard
Helen Syms

The Trustees are appointed at a meeting of the Trustees' Committee.

Medical Director:

Dr Anne Child MD, FRCP is now also a trustee.

Principal Address of the Trust:

Marfan Trust
c/o 24 Oakfield Lane
Keston
Kent
BR2 6BY

Bankers:

CAF Bank
25 Kings Hill Avenue
Kings Hill
West Malling
Kent
ME19 4TA

Auditors:

Hazlewoods LLP
Staverton Court
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Cheltenham
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TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

The Trustees present their report, together with the financial statements, for the year ended 31 December 2024

The objectives of the charity are as follows:

1. To fund medical research projects that aim to aid the diagnosis and treatment of Marfan syndrome patients.
2. To provide educational literature on Marfan syndrome and all its aspects to the medical profession and the general public, thus raising awareness of the condition.
3. To provide peer-to-peer support and medical guidance to those affected and their families.

The Trustees have paid due regard to the Charity Commissioners' guidance on public benefit in deciding what activities are undertaken to further the Charity's charitable purposes for the public benefit.

2024 was an exciting year for the Marfan Trust. Financially, we are doing well with the remainder of the legacy of the Marfan Association in our reserve account, supplemented with generous donations from our fundraisers. We have a new legacy of £50,000 per year which is supporting equally our laboratory research programme, and our Clinical Nurse Specialist, Mrs Joanne Jessup who is helping to answer clinical enquiries to our Helpline together with Victoria Hilton, our Helpline and Communications Director. Joanne is also working with other aortic nurses within the NHS nationally. She also hosts member drop-ins to help conversations between affected adults and parents of affected children. We thank both women for their many extra hours devoted to guiding and supporting the aims of the Marfan Trust, support, education and research.

The Marfan Trust has now become a Charitable Incorporated Organisation No 1198847, entitled Marfan Trust (no 'The'). The charity itself remains unchanged, as do our goals. This is merely a change in legal structure. We managed to use the existing CAF bank accounts without having to open a new bank account, the old accounts have been converted into the name of the CIO.

Dr Jose Aragon-Martin PhD, Director of the Sonalee Laboratory, has been awarded a permanent part-time teaching Fellow position at Queen Mary's College, University of London. He continues to be funded half-time by the Marfan Trust, and he and his students analyse DNA from families with Marfan syndrome and related disorders (ascending aortic aneurysm, joint hypermobility, glaucoma, dislocated lens) in his two laboratories. We have acquired new equipment to speed the work of Jose and his team of MSc students. They can easily identify new genes using Next Generation Sequencing (NGS), and can now sequence 1 individual's entire genome in just one day. His 2nd lab is at the Institute of Ophthalmology, where he supervises the programme of glaucoma research. Glaucoma is a chief cause of visual loss in the older population, but children can also be born with it. It affects 5% of all Marfan syndrome patients. He is also searching for new genes for dislocated lens, which is a feature of Marfan syndrome but does occur independently, and needs to be distinguished from Marfan syndrome.

Three Brian Adams Summer Student Research Projects advanced our knowledge of the gene mutations causing severe Marfan syndrome present at birth, psychological impact of the condition, and gastrointestinal disorders.

Publications included an international review of all Losartan/Irbesartan medication trials, which concluded that both medications are effective in delaying aortic root widening. If medication is started early, it can put off the need for surgery by approximately 5 years.

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A webinar on gastrointestinal disorders was held and is now available via YouTube. Publications have been written and updated. These include; A Guide To Heart Surgery, Marfan Trust Guide for Schools and Colleges, Neonatal Marfan syndrome, Psychological Impact of Marfan syndrome, and a book for children with Marfan syndrome, Jeremy Wins, presenting problems and solutions throughout childhood.

A definite highlight in the year was our International Patient Symposium. Collaborating with the Marfan Foundation USA, the Aortic Dissection Charitable Trust and Annabelle's Challenge created a joyful occasion. Over 200 patients attended the day-long conference, including 70 with LDS (Loeys-Dietz Syndrome) which is an overlapping clinically similar cause of aortic aneurysm and dissection. Raising awareness of the many causes of aortic disease is one of the main goals of the Marfan Trust, together with improving the quality and length of life for all those affected.

Continuing the momentum from 2023 when we expanded our support services, replenished our resources and accelerated our social media, 2024 was a productive and prolific year.

SUPPORT: OUR HELPLINE

To render our helpline infinitely approachable and accessible to all, we have established many different means of contacting us, from social media to email and phone. We manage each of these different channels and strands.

A calm port in a storm, offering personalised advice and guidance, we are the only helpline in the UK dedicated to Marfan & Loeys-Dietz syndrome patients. During 2024, we took 489 different enquiries, a mix of medical, financial and emotional pleas for support. We aim to triage the 'call' and respond accordingly, either resolving then and there, seeking advice from the immediate team or approaching the wider advisory panel. A weekly helpline meeting is held on Thursdays at 2pm when we – Dr Anne Child, Medical Director, Victoria Hilton, Helpline & Communications Director and Joanne Jessup, Clinical Nurse Specialist - discuss and digest the questions, settling anything left lingering.

The number of queries increase from one year to the next but escalated during 2024, partly because we formally extended our charity (including our logo) to encompass Loeys-Dietz syndrome patients.

Medical

A multi-faceted condition, Marfan syndrome causes a disparate array of health problems involving eyes, heart and skeleton. We take queries on each of these systems but the most common call to our helpline concerns the diagnostic odyssey. Approximately 35% of enquires are from patients suspecting they, or a loved one has Marfan syndrome and they wonder how to approach a diagnosis.

In response to questions raised from the helpline, we can identify gaps in our expertise, and will expand our advisory panel accordingly. Last year alone, we appointed three new specialists covering the areas of occupational health, pain management and genetics. Our medical panel now stands at 23 different experts, each representing a different manifestation of Marfan and Loeys-Dietz syndromes.

The arrival of our cardiac nurse specialist, Joanne Jessup, in 2022, added a new, invaluable dimension to our helpline. Patients often seek help in deciphering a medical report, interpreting cardiac follow-up letters, or simply navigating the NHS.

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A fantastic supplement to our helpline is our library of information leaflets. During 2024 we widened our collection with new titles and updated existing ones. These are all written in a friendly and accessible layman's style. *Please see next section for details.*

Financial

A barometer of our times, the helpline has seen a surge in requests for assistance in claiming PIP (Personal Independence Payment) as the cost of living tightens its grip. We meet the patients to discuss their specific situation and create a persuasive letter of support to reinforce their claim.

Our letters are not confined to PIP but extend to supporting parents hoping to claim DLA (Disability Living Allowance) for their children, and reinforcing adult claims for early, illness-induced retirement. This approach reaps results with one Marfan supporter winning a case against her employer to secure early retirement. *"I want to say a heartfelt thank you (which seems inadequate) to you and Dr Child. From the first time I contacted and spoke to you, to our Teams meeting, to the unwavering kindness, empathy and support you've offered, I have felt 'seen'. You really were the first person in my 53 years who actually seemed to 'get it'"*

General (Emotional) Support

From the helpline emerged an urgent need for parents of children with Marfan & Loeys-Dietz syndromes to meet in their own 'space' where they can start a network and share common concerns. In response, we began a zoom-based monthly Parent Drop-In in June 2023 which flourished throughout 2024 over 11 sessions. We facilitate conversation whilst answering questions that crop up. Similarly, Joanne Jessup continued her monthly drop-ins for Marfan patients who wish to discuss their worries and issues in a safe and confidential environment.

A need also became apparent for regional support groups which existed throughout the country but disbanded before lockdown. Towards the end of 2024, We started to facilitate the (re)creation of these groups and three have become firmly established in Birmingham, Kent & Bristol respectively, with more to come.

Another strand of our helpline is peer-to-peer support and we have amassed a vast network of mentors and mentees who meet online and occasionally in person for a cathartic conversation.

EDUCATION & AWARENESS

Our online public face is our social media and website, and these are alive with supporter stories, informational material, industry news, events, videos and more. Through these channels we celebrate our patient community, raise awareness of Marfan & Loeys-Dietz syndromes, and educate both the public and professionals.

Social Media & Website

Underpinning our social media strategy are several staple, regular 'publications': supporter stories, pithy factoids, research and industry news, and Dr Child's Casebook.

Supporter Stories: Nothing resonates more with our 'community' than tales of life with Marfan syndrome and our generous supporters find it cathartic to share their stories of surgery, navigating their chronic condition, managing their mental health, etc. We published 36 patient articles last year, each serving as a source of solace and useful information for our online audience.

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Friday Fact: We aim to respond to commonly asked questions from the helpline and devised a new weekly series dubbed “Friday Fact”. Over 40 publications, we demystified the difference between echoes & ECGs, clarified costochondritis, unravelled the complexities of genomics, explained many manifestations of Marfan & Loeys-Dietz syndromes and more. These were all couched in pithy, friendly layman’s terms. They have been widely read and now exist as a fantastic supplement to the Resources section of our website.

Dr Child’s Casebook: This (once weekly) series was devised during lockdown and continues apace, attracting membership to the Trust while resolving knotty, burning questions. It follows a Q&A format, plucking a question from the helpline, one that is unique yet universal, and publishing this alongside the response from our medical team. The language is simple and friendly, and the patient is completely anonymised. We posted 17 Casebooks during 2024.

Industry Updates: As developments emerge in the medical world, we keep our audience up to date through our social media channels. During 2024 the aorta was elevated to the status of an organ and funded surgery for chest deformities (pectus excavatum) was restored to NHS England. We acknowledged these through a variety of articles.

Research News: From the discovery of a potentially causative gene for thoracic aortic aneurysm & dissection, to the acquisition of new equipment that will hasten genetic analysis, we inform our supporters of developments in our Sonalee Laboratory through videos and written pieces. Our community is also invited to physically visit our Lab and an A’ Level student with Marfan syndrome did so last year.

Marfan Awareness Month: Managing Marfan syndrome and its many manifestations was the theme of our awareness campaign in February 2024. Throughout the month we ran a series of articles, features, interviews, patient stories and videos on everything from navigating excessive height and chest surgery to physical activity and the benefits system. The campaign culminated in a piece on the future for Marfan syndrome patients which looks increasingly bright and personalised. We reached over 24,000 on Facebook with an engagement of over 6k. This vastly exceeds the average engagement for non-profit organisations which is 0.31%. Our overall reach exceeded 30k accounts across social media.

Ad hoc pieces: Transcending our captive audience is integral to spreading the word and raising awareness of Marfan. We constantly approach and ‘tag’ organisations with relevance to Marfan syndrome such as podiatrists, dentists etc and we secured pieces in **Optometry Today** (with a Facebook audience of 26k) and **AIMS Journal** (Aims for a Better Birth) – the latter publishing an article we wrote on pregnancy.

Resources: New, and newly revised, Information Guides were published in 2024. These were: *Guide to Physical Activity* (by Victoria Hilton), *Guide to Heart Surgery* (by Joanne Jessup), *General Guide to the Charity* (by Victoria Hilton), *Guide to the Eye in Marfan Syndrome* (by medical student Navaneethan Adityaraj), *Guide to Dural Ectasia* (by Joanne Jessup) and *Guide to Loeys-Dietz Syndrome* (by medical student Amy O’Reilly). Together with our in-house volunteer graphic designer, Darren McDean, we oversee the production of these guides from inception to publication.

Our **Resources Section** was further updated and expanded with pieces written in response to supporters’ questions including: How to Navigate a Genetic Diagnosis and the Benefits System. It is also supplemented by helpful videos – glimpses into our laboratory and short informative titbits etc.

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Newsletter

Traditional and treasured, our paper newsletter *Marfan Matters* is published twice a year. We assemble and edit the contents while contributing pieces on the helpline, webinars, and fundraising feats. It is designed by our in-house volunteer, Darren McDean, and sent to approximately 1,600 recipients.

Webinars

During 2024, We organised and collaborated on four webinars, emceeing three of the four and marketing them across our social media channels.

Helping nascent charity **Pectus Matters** and collaborating on their inaugural webinar: **28 attendees**

Collaboration with Aortic Dissection Awareness UK & Ireland on a webinar unveiling the **Psychosocial Effects of a Diagnosis of Cardiovascular Manifestations of Marfan syndrome: 62 attendees**

Collaboration with the Marfan Foundation on **The Medical Management of Marfan Syndrome: 84 attendees**

Marfan Information Day: securing speakers for our annual information day, devising the running order, booking the videographer, emceeing the proceedings and editing the resulting film, creating 9 videos for our YouTube Channel: **158 registrants**

International Patient Symposium

We were invited by our counterparts in the United States, the Marfan Foundation, to join the planning committee for an International Patient Symposium in London on Living Better with Marfan, Loeys-Dietz and Vascular Ehlers-Danlos Syndromes. This proved a perfect collaboration between four like-minded charities.

The structure of our symposium evolved through careful planning with the Marfan Foundation, the Aortic Dissection Charitable Trust and Annabelle's Challenge. To render it readily accessible and family friendly, we suggested we offer travel bursaries to low-income households and provide a playroom for children. We worked alongside our bid-writer to secure sponsorship for these facilities and it reaped results as we received a series of donations worth over £28,000 for the symposium. We helped to devise the programme for the day, securing speakers from the Marfan Trust to represent our patients' concerns. Alongside our immediate medical team, Dr Anne Child and Joanne Jessup; Marfan Trust advisors Dr Nitha Naqvi, Mr Robert Henderson and Gareth Owens (patient advocate) led sessions and gave presentations.

The Symposium was an unambiguous success as 220 patients, 13 medical experts and 5 patient advocates flooded the Radisson Blu in Bloomsbury on Saturday, 31 August. Interestingly, the patients had travelled from nine different countries and were equal parts Marfan and Loeys-Dietz syndrome. The playroom was particularly popular with two children previously unknown to each other discovering that they were navigating the same medical journey at the same hospital and becoming firm friends.

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Conferences – General

Marfan European Network: United behind the motto 'Together We Can', the Marfan Europe Network (M.E.N.) is a coalition of 18 patient organisations. In September 2024, We attended their four-day meeting in Vienna at which we toasted M.E.N.'s new legal status and discussed Europe-wide collaborations. We presented for the Marfan Trust and made many new meaningful connections, including a German paediatrician who gave a lecture on Loeys-Dietz syndrome at our Marfan Information Day. We are also collaborating on the creation of a new website for the M.E.N.

We attended further, ad hoc conferences during the year including London Aorta and the newly formed Vascular Voice Network.

MARKETING & FUNDRAISING

Marketing & PR

Critical to a long healthy life for Marfan and Loeys-Dietz syndrome patients is early diagnosis. This can be achieved only through awareness of the condition. We strive tirelessly to spread the word through many means including marketing and PR, reaping tangible results in 2024.

BBC Radio 4's The Life Scientific (TLS) – the BBC's most prestigious science show was the perfect setting for Dr Child to discuss her life & career, while introducing Marfan syndrome to the world. In January 2023, we approached the producer of TLS, pitching Dr Child as a potential interviewee for Professor Jim Al-Khalili. Lucy responded immediately and positively, and Anne appeared on national radio on 2 July 2024. Two million and counting tuned in, and our helpline calls increased ten-fold.

Membership

To encourage membership of the Trust, we tempt our community with the opening paragraph to Dr Child's Casebook. The Casebook is thereafter locked and the answer withheld, available only to paying members. With every Casebook broadcast, there is a small flurry of new memberships. During 2024, 31 people joined the Trust as Best Friends; 4 as Family Friends, and 5 Overseas Friends.

Webshop

Our shop is kept fresh and alive with new offerings. We designed three new tote bags featuring, respectively, our newly expanded logo, our mascot Willow and festive Willow. Beanie hats were also introduced, alongside cuddly giraffes and giraffe pens.

Fundraising

We are not government funded but rely solely on the goodwill of our supporters. We constantly liaise with the Marfan Trust fundraisers, sharing their campaigns across social media and attending their events where possible. During 2024, we presented from an upturned bucket at the Downham Young Farmers' Convention in January and for 7Formation Construction Company in February. We also attended football matches and golf tournaments. It was a lucrative year for the Marfan Trust and culminated in our Christmas Fayre at the Royal Brompton Hospital.

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The number of those benefiting from our Helpline, Communications, Webinars, Symposiums & Newsletters during 2024:

Helpline: 489

Local Support Groups: 30 attendees

Parents' Corner: 11 sessions- 45 attendees

Joanne's Drop-in: 8 sessions - 19 attendees

Medical Management of Marfan syndrome: 84

Pectus Matters: 28

Heads, Hearts & Minds: 62

Marfan Information Day: 158

International Patient Symposium: 200

Newsletter: 1,600

Email Communications: 2,000

Leaflet Downloads: 250

In total, we helped **4,965** patients during 2024.

Achievements & Performance – Research Activities

Sonalee lab is concentrated on the following achievements, and projects:

1. Manuscripts published:

- a. On the 20th of December 2024 we published, with one of our Ectopia Lentis collaborators, Dr Aman Chandra, a review on Ectopia Lentis. Marfan syndrome was mentioned 4 times. This research attempts to update the relationship between genes and the lens moving out of its original place in the eye. Here is the information from the paper published.

Chipeta C., **Aragon-Martin J.A.**, and Chandra A. Zonulopathies as Genetic Disorders of the Extracellular Matrix. Genes, 2024;15:1632 (DOI: <https://doi.org/10.3390/genes15121632>)

2. Working on manuscripts to be published during 2025 or later:

- a. Review of Neonatal Marfan syndrome.
- b. Review of Marfan syndrome.
- c. Marfan syndrome – Genotype-Phenotype associations using Fisher's exact test.
- d. Marfan syndrome – Genotype-Phenotype associations using a new tool from QMUL for statistical analysis.

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- e. Marfan syndrome – Pathogenic variants in the intronic regions and deep intronic regions.
 - f. Marfan syndrome – Expectations and Challenges of Gene Editing.
 - g. HTAAD (Hereditary Thoracic Aortic Aneurysm and Dissection) – analysis of Whole Exome Sequencing in 2 families.
 - h. hEDS (hypermobile Ehlers-Danlos) – analysis of Whole Exome Sequencing and Whole Genome sequencing in 2 families.
 - i. EL (Ectopia Lentis) – Variant interpretation from variants in *ADAMTSL4* gene.
3. Conference presentations: We were able to present 1 poster presentation at the ASHG2024.
- a. We attended the London Aorta 2024 in October for two days (3rd and 4th) thanks to the generosity of Marfan Trust. We were able to network and learn about the different treatments across UK, Europe, and the rest of the world.
 - b. The study used 2 families with HTAAD and 2 families with hEDS. We looked at areas of the gene that normally are not used for screening (e.g. intronic regions, deep intronic regions, 5'UTR (beginning of the gene), and 3' UTR (end of the gene)). It was very difficult to analyse the beginning and the end of the gene, but we have some promising results from the intronic regions in one of the HTAAD families (*RNF207*), and one of the hEDS families (*DPYD*). These two candidate genes could have some influence on the clinical features of these families, but further research needs to be done before we can conclude anything concrete.
4. Analysing large datasets that were processed on NGS platforms:
- a. Whole Exome Sequencing (WES) data in a large HTAAD cohort is being studied to rule out known TAAO genes. A few samples in this HTAAD cohort have mutations in the *FBN1* gene (Marfan syndrome gene) and this needs to be studied appropriately. This is an ongoing project.
 - b. Whole Genome Sequencing (WGS) data in a first large hEDS family is being studied to search for their causative gene. This is an ongoing project.
 - c. Whole Exome Sequencing (WES) data in a second large hEDS family is being studied to search for their causative gene. This is an ongoing project.
 - d. New glaucoma data from Professor Sarfarazi needs to be organised and compiled to extract the data from those samples that will be used for a collaboration on inherited eye disease. Professor Moosajee at IoO-UCL. This is an ongoing project.
5. 2024.11.15 – Talk to ~20 students concerning the Genetics of Familial Hypercholesterolaemia (duration – 1.5 hours).

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6. Delivering two lectures to Panos' Group at William Harvey Research Institute at QMUL. During 2024, we had the opportunity to contribute to the group by presenting different topics related to Sonalee Laboratory research:

a. 2024.02.23 - QMUL - ADAMTSL4-related ectopia lentis; A case of pseudodominance with an asymptomatic parent.

b. 2024.10.17 - QMUL - Candidate genes in HTAAD and hEDS update.

7. Delivering workshops in LONDON. This approach gave us the opportunity for networking, increasing our profile as a lab for students to come and help in the lab as volunteers, and also, to be heard discussing Marfan syndrome. We were asked to present in different parts of London workshops to students and staff of different universities and/or private laboratories.

a. UCL (2024.05.20), private lab (2024.05.28), and QMUL (2024.05.31): WGS/WES data processing - NGS Workshop - FASTQ - VCF - filter variants.

b. UCL (2024.06.20): NGS Workshop - Bioinformatics Workshop - Variant Interpretation

8. Preparing grants to fund Sonalee Laboratory research & activities.

a. British Heart Foundation – Grant Project Proposal (£250,000).

▪ Resubmission for 2 years: after January 2024.

9. The summer studentship in 2024 is going to be very important to Sonalee Laboratory since we are short of hands to help with research. Silvia La Penna joined our lab group to help us create HTAAD family pedigrees. This will help us to clarify family organisation to the funding bodies, and to choose the right samples to be processed in NGS (Next Generation Sequencing) machines.

We are planning to address the following questions:

1. How many HTAAD families do we have in our cohort?
2. How many HTAAD probands?
3. How many HTAAD families are large enough to be used for screening?
4. How many of the HTAAD families we can draw family pedigrees from the research notes? Do we need help from other clinicians to accomplish this?

We need to host students who are excellent in their research. For this reason, Sonalee Laboratory is planning to host during the Summer 2024 Silvia La Penna, who has applied for an MRes this September 2024. We have previously hosted Silvia when she was doing a laboratory project in Sonalee Lab back in 2022-2023 academic year at QMUL. We think that her previous experience with us, and after her degree, makes her the best candidate to address the HTAAD research project with efficiency and reliability.

Raising Awareness

We began 2024 with a new weekly series of 'Friday Facts' on our social media channels. These proved popular and gave us the opportunity to provide snippets of information about all aspects of Marfan syndrome in an understandable, bite size format. Topics were varied from explaining the difference between an echocardiogram and an electrocardiogram to explaining the importance of good blood pressure control. The facts prompted discussion on social media and gave us the opportunity to answer some questions we are commonly asked on our helpline.

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We have also continued the successful 'Casebook' series; we choose an interesting helpline question which may be very relevant to many of our patients, and we publish an anonymised version of the question and answer (with the patient's permission). This gives us an opportunity to review some of the literature surrounding a particular topic and providing this in an easy to understand, longer format than that of the 'Friday Fact'.

Leaflet Publications

We continue to review and update our library of resources to ensure that all the information we provide is relevant, useful and easily accessible. We have worked to ensure we have a full panel of engaged clinical advisors who can review the leaflet relevant to their area of expertise. In 2024 the following leaflets were reprinted and added to the website for free download:

- Marfan Trust Guide to Heart Surgery
- Guide to Loeys-Dietz Syndrome
- General Guide to Marfan Trust
- Marfan Trust Guide to the Eye
- Marfan Trust Guide to Physical Activity
- Marfan Trust Guide to Dural Ectasia

We provide leaflets to patients, parents and carers for their own reference and send them to General Practitioners, and schools to help them provide appropriate support to individuals. We also send our resources to genetics clinics and aortopathy clinics across the country in order that they can provide patients with resources if they are newly diagnosed, for example. This has the added benefit of raising awareness of the charity and signposting new patients to our network of support and resources.

The eye leaflet was researched and drafted by one of our 3 summer students, Navaneethan Vanaraj. We supervised his work from March to June and we liaised with our clinical advisor, Mr Aman Chandra and his Specialist Registrar, Mr Chim Chipeta. The leaflet is a valuable addition to our resources and uses lay language to describe the medical and surgical options that may be available to individuals with the eye complications of Marfan syndrome.

Conferences/Webinars

We presented at 2 different meetings this year.

- In May, we presented remotely at the Network for Inherited Cardiac Conditions Scotland (NICCS) monthly meeting - 'What is Marfan Syndrome' presentation for nurse specialists and patients
- In September, we presented at the annual London Aorta conference.

In August, our International Patient Symposium took place, and we welcomed over 200 people affected by Marfan or Loeys-Dietz syndromes. This was a great opportunity for people to network and create connections.

In October, our online Marfan Information Day was another great opportunity to raise awareness and provided the perfect platform to share latest research and developments in the field of Marfan syndrome and other connective tissue disorders. The introduction of 'virtual coffee rooms' by Victoria has added an extra dimension to the day and gives the opportunity for further networking and time for more informal discussion and questions.

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Providing Support

We have developed several ways for people to access advice and support from the charity.

- Helpline (via phone or email)
- Social media channels
- Local support groups (run by local volunteers)
- Monthly parents' drop-in session (run by Victoria) via Zoom
- Monthly general drop-in session (run by Joanne) via Zoom (10 sessions in 2024)
- Adhoc online appointments with Joanne to discuss issues in further depth

These different formats hopefully provide everyone with a route with which they feel comfortable. Initial contacts are often made via email or phone to our dedicated email address or phone line. We can refer to our specialist clinical advisory panel if questions are complex or require further expert input. We can signpost to further services as necessary.

The helpline is receiving increasing numbers of calls regarding Personal Independence Payment (PIP), Disability Living Allowance (DLA) and problems accessing other forms of support. We provide letters of support and help advocate for our patient group in these stressful circumstances.

Another problem commonly raised is the 'diagnostic odyssey' that many families experience. There are ongoing problems accessing specialist referrals and input from genetics clinics. Again, we work with patients to discuss their symptoms and help them to advocate for themselves when attending appointments.

In response to questions received we have written further information pieces in our Resources section of the website including:

- How to apply for PIP
- Preparing for a Genetics appointment

Research

The main research work by the Trust is the genetic work being undertaken in the Sonalee Laboratory by Dr Aragon-Martin. However, the Trust is exploring the possibility of carrying out a National Survey of patient experience with Marfan syndrome in order to help us set priorities and develop strategies for the coming 3-5 years.

We are exploring options for contracting a research organisation who can help us design, deliver and analyse the survey in order that we can collect high quality data that will be as generalisable to the Marfan population as possible. Two such companies have been approached to provide quotes for this work: Picker and IQVIA. We await further information and will move forward to discussions with the Trustees and final approvals once proposals are received.

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Other Conferences

Other conferences attended this year for the purposes of professional development and remaining up to date with current research in the field of aortic dissection and connective tissue disorders:

- Aortic Dissection Charitable Trust (ADCT) Aortic Nurse Conference – London (June)
- Aortic Dissection Awareness UK (ADAUK) Conference – Edinburgh (September)

Other Work

Aortic Nurses Network

Following London Aorta 2023, a group of aortopathy nurses, including myself, have been working together to set up a network of nurses working within this field throughout the UK. The aim is to provide a support network, a source of information and mentoring and a possible platform for future research. This is all with the ultimate goal of improving the experience and care of patients living with aortic diseases.

We are working on the committee along with 5 other nurses and The Aortic Dissection Charitable Trust (TADCT) to create the network. TADCT held a successful 'Aortic Nurses Symposium' in June 2024 at which it was clear there was an appetite for such a network, and we have begun working to develop it with the feedback of all attendees in mind. The plan is for the network platform to go live in early 2025 with an inaugural webinar and introduction of the platform that can be used by health care professionals to seek advice/support and share best practice.

Financial review

During the year, the Trust received total income of £287,083 (2023: £631,283). The Trust incurred expenditure of £246,011 (2023: £31,059). This year, there was a surplus of £41,072 (2023: £600,224). During the year ended 31 December 2023, the charity was only active for the final two months of the year.

As at 31 December 2024, total funds stood at £641,296 (2023: £600,224), of which £393,621 (2023: £550,224) relates to general funds and £247,675 (2023: £50,000) relates to designated funds.

Reserves policy

The charity intends to maintain its current level of reserves and distribute any future income and surpluses in the form of grants in the furtherance of the charity's objectives. At the end of each financial year, the Trustees designate an amount from the general fund that will be sufficient to service the ongoing core costs and research costs for 2 years. The Trust aims to generate increased income year on year to reach a break-even position whereby income is utilised to facilitate and progress research and fulfil the objectives of the Trust.

MARFAN TRUST

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2024

Funds of £247,675 have been designated in order to fund the work of Dr Jose Aragon-Martin at UCL Institute of Ophthalmology.

Statement of disclosure to Auditors

So far as the Trustees are aware, there is no relevant information of which the charity's auditors are unaware and each Trustee has taken steps that they ought to have taken as Trustees in order to make themselves aware of any relevant audit information and to establish that the charity's Auditors are aware of such information.

TRUSTEES' RESPONSIBILITIES STATEMENT

The trustees are responsible for preparing the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice.


Law applicable to charities in England and Wales requires the Trustees to prepare financial statements for each financial Period. Under the law the Trustees have elected to prepare the financial statements in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law).

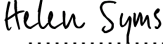
The financial statements are required by law to give a true and fair view of the state of affairs of the charity and of the income and expenditure of the charity for that Period. In preparing these financial statements, the Trustees are required to:

- select suitable accounting policies and apply them consistently;
- make judgements and estimates that are reasonable and prudent;
- state whether applicable accounting standards have been followed subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume the company will continue in operation.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charity and to enable them to ensure that the financial statements comply with applicable law and the Trust deed. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

For and on behalf of the Trustees of the Marfan Trust 23/10/2025 2025.


.....
Dr Anne Child
Chair


.....
Helen Syms
Trustee

INDEPENDENT AUDITORS' REPORT TO THE TRUSTEES OF MARFAN TRUST

We have audited the financial statements of the Marfan Trust for the year ended 31 December 2024 which comprise the Statement of Financial Activities, the Balance Sheet and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

Opinion on the financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the Charity's affairs as at 31 December 2024, and of its incoming resources and application of resources, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the 'Auditor's responsibilities for the audit of the financial statements' section of our report. We are independent of the charity in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustees' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from when the original financial statements were authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The other information comprises the information included in the annual report, other than the financial statement and our auditor's report thereon. The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

INDEPENDENT AUDITORS' REPORT

TO THE TRUSTEES OF MARFAN TRUST

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charity and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report.

We have nothing to report in respect of the following matters where the Charities Act 2011 requires us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the trustees' report; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charity's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charity or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists.

Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

INDEPENDENT AUDITORS' REPORT

TO THE TRUSTEES OF MARFAN TRUST

As part of an audit in accordance with ISAs (UK), we exercise professional judgment and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the charity's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the trustees.
- Conclude on the appropriateness of the trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charity's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charity to cease to continue as a going concern.
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.
- Obtain sufficient appropriate audit evidence regarding the financial information of the entities or business activities within the charity to express an opinion on the financial statements. We are responsible for the direction, supervision and performance of the charity's audit. We remain solely responsible for our audit opinion.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

Irregularities, including fraud, are instances of non-compliance with laws and regulations.

We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below.

We assessed the susceptibility of the charity's financial statements to material misstatement, including obtaining an understanding of how fraud might occur, by:

- making enquiries of management as to where they considered there was susceptibility to fraud, their knowledge of actual, suspected and alleged fraud; and
- considering the internal controls in place to mitigate risks of fraud and non-compliance with laws and regulations.

INDEPENDENT AUDITORS' REPORT
TO THE TRUSTEES OF MARFAN TRUST

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charity's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charity and charity's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Ryan Hancock
.....
Ryan Hancock (Senior Statutory Auditor) 27/10/2025 2025.

For and on behalf of Hazlewoods LLP, Statutory Auditor

Staverton Court
Staverton
Cheltenham
GL51 0UX

MARFAN TRUST
YEAR ENDED 31 DECEMBER 2024
STATEMENT OF FINANCIAL ACTIVITIES

	Note	2024	* 2023
Income		£	£
Voluntary income			
Donations, covenants and Gift Aid		275,952	19,533
Investment Income			
Bank interest receivable		11,131	2,356
Funds transferred into the charity		-	609,394
Total Income		287,083	631,283
Expenditure			
Cost of raising funds			
Costs of raising voluntary income	2	(37,354)	(208)
Charitable activities			
Education, awareness and support	3	(61,202)	(6,127)
Staff costs	4	(125,074)	(22,092)
Donations to The Marfan Foundation		(7,377)	-
Governance costs	3	(15,004)	(2,632)
Total expenditure		(246,011)	(31,059)
Net income before other recognised losses		41,072	600,224
Net movement in funds		41,072	600,224
Funds balances brought forward at 1 January		600,224	-
Funds balances carried forward at 31 December		641,296	600,224


All of the charity's activities are continuing activities.
For the year ending 31 December 2024 all funds are unrestricted.

* During the year ended 31 December 2023, the charity was only active for the final two months of the year.


MARFAN TRUST
BALANCE SHEET AT 31 DECEMBER 2024

	Note	2024 £	2023 £
FIXED ASSETS			
Investments	5	6,750	6,750
Tangible fixed assets	6	15,962	5,436
Total fixed assets		22,712	12,186
CURRENT ASSETS			
Cash at bank and in hand	7	636,830	613,416
Debtors	8	3,482	9,018
Total current assets		640,312	622,434
LIABILITIES			
Creditors: due within one year	9	(21,728)	(34,396)
CURRENT ASSETS LESS CURRENT LIABILITIES		618,584	588,038
NET ASSETS		641,296	600,224
THE FUNDS OF THE CHARITY			
Designated	10, 11	247,675	50,000
General	10, 11	393,621	550,224
Total FUNDS OF THE CHARITY		641,296	600,224

Approved by the Board of Trustees on23/10/2025..... 2025.



 Dr Anne Child
 Chair



 Helen Syms
 Trustee

MARFAN TRUST

NOTES TO THE FINANCIAL STATEMENTS

for the year ended 31 December 2024

1 ACCOUNTING POLICIES

Basis of preparation

The financial statements have been prepared under the historical cost convention and in accordance with the Statement of Recommended Practice 'Accounting and Reporting by Charities (SORP 2019)', issued in January 2019, the Financial Reporting Standard applicable in the United Kingdom and Republic of Ireland (FRS 102) and the Charities Act 2011.

Fund accounting policy

Unrestricted income funds are general funds that are available for use at the trustees' discretion in furtherance of the objectives of the charity. Designated funds are unrestricted funds set aside at the discretion of the trustees for specific purposes.

Income

Donations are recognised where there is entitlement, certainty of receipt and the amount can be measured with sufficient reliability. Income derived from events is recognised as earned (that is, as the related goods or services are provided). Investment income is recognised on a receivable basis.

Expenditure

Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to the expenditure. All expenditure is accounted for on an accruals basis.

Costs of generating funds comprise the costs associated with attracting voluntary income and the costs of trading for fundraising purposes.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Grants payable are payments made to third parties in the furtherance of the charitable objectives. Where the charity gives a grant with conditions for its payment being a specific level of service or output to be provided, such grants are only recognised in the Statement of Financial Activities once the recipient of the grant has provided the specific service or output.

Grants payable without performance conditions are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.

Provisions for grants are made when the intention to make a grant has been communicated to the recipient but there is uncertainty about either the timing of the grant or the amount of grant payable.

Support costs include costs of the preparation and examination of the statutory accounts, the costs of trustee meetings and the cost of any legal advice to trustees on governance or constitutional matters.

MARFAN TRUST**NOTES TO THE FINANCIAL STATEMENTS**

for the year ended 31 December 2024

Staff costs

The Marfan Trust first became an employer in October 2019 under the old unincorporated structure and provides an auto enrolment pension scheme in line with statutory requirements. Employees at the time of conversion to a CIO remained employed by Marfan Trust.

Investments

Fixed asset investments are included at market value at the balance sheet date.

Realised gains and losses on investments are calculated as the difference between sales proceeds and their market value at the start of the Period, or their subsequent cost, and are charged or credited to the statement of the financial activities in the period of disposal.

Unrealised gains and losses represent the movement in market values during the Period and are credited or charged to the statement of financial activities based on the market value at the year end.

Tangible fixed assets

Individual fixed assets are initially recorded at cost, less any subsequent accumulated depreciation and subsequent accumulated impairment losses.

Depreciation and amortisation

Depreciation is provided on tangible fixed assets so as to write off the cost or valuation, less any estimated residual value, over their expected useful economic life as follows:

Asset class	Depreciation method and rate	
Plant and machinery	20% Straight-line basis	
2 COSTS OF GENERATING FUNDS	2024	2023
	£	£
Cost of generating voluntary income		
Fundraiser's expenses, website and newsletters	37,354	208
	<hr/>	<hr/>
3 ANALYSIS OF CHARITABLE ACTIVITIES		
Education, awareness and support	2024	2023
	£	£
Office consumables	20,602	3,478
Advertising & marketing	3,114	226
Laboratory expenses	17,990	559
Telephone & Internet	4,068	644
Travel	3,632	-
Students paid	1,000	-
Insurance	1,286	-
Printing & stationery	7,978	-
Office equipment depreciation charge	1,532	1,220
	<hr/>	<hr/>
	61,202	6,127
	<hr/>	<hr/>

MARFAN TRUST**NOTES TO THE FINANCIAL STATEMENTS**

for the year ended 31 December 2024

3 ANALYSIS OF CHARITABLE ACTIVITIES (CONTINUED)

Governance costs	2024	2023
	£	£
Audit fees	1,500	2,082
Accountancy fees	4,521	-
Legal and professional fees	8,983	550
	<hr/>	<hr/>
	15,004	2,632
	<hr/>	<hr/>

4 STAFF COSTS	2024	2023
	£	£
Wages and salaries	113,078	19,023
Social security costs	6,839	1,997
Pension costs	2,742	472
Secretarial Salary & Expenses	2,415	600
	<hr/>	<hr/>
	125,074	22,092
	<hr/>	<hr/>

The average number of employees who were employed by the Charity during the year was 3.

During the year, no employees received emoluments of more than £60,000.

5 SUMMARY OF INVESTMENTS	2024	2023
	£	£
Market value at 1 January	6,750	-
Additions	-	6,750
	<hr/>	<hr/>
Market value at 31 December	6,750	6,750
	<hr/>	<hr/>

The Trust holds 100,000 shares in Eurovestech PLC.

MARFAN TRUST

NOTES TO THE FINANCIAL STATEMENTS

for the year ended 31 December 2024

6 TANGIBLE ASSETS

	Plant and Machinery £
Cost	
At January 2024	6,656
Additions	12,058
At 31 December 2024	18,714
Depreciation	
At January 2024	1,220
Charge for the year	1,532
At 31 December 2024	2,752
Net book value	
At 31 December 2024	15,962
At 31 December 2023	5,436

7	CASH AT BANK AND IN HAND	2024 £	2023 £
	Cash at bank and in hand is held as follows:		
	NatWest current account	22,214	21,496
	Treasury tracker account	84,392	83,088
	CAF gold savings account	481,003	370,008
	CAF cash current account	49,221	138,824
	Total cash at bank and in hand	636,830	613,416
8	DEBTORS	2024 £	2023 £
	Gift aid recoverable	3,482	9,018
9	CREDITORS – due within one year	2024 £	2023 £
	Trade creditors	12,249	-
	Accruals	1,999	3,981
	Wages payable	23	23
	PAYE payable	7,457	30,392
		21,728	34,396

MARFAN TRUST**NOTES TO THE FINANCIAL STATEMENTS**

for the year ended 31 December 2024

10 ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted Funds £	Designated Funds £	2024 Total funds £	2023 Total Funds £
Fixed assets	22,712	-	22,712	12,186
Current assets	392,637	247,675	640,312	622,434
Current liabilities	(21,728)	-	(21,728)	(34,396)
Total net assets	393,621	247,675	641,296	600,224

11 ANALYSIS OF FUND MOVEMENTS

	Balance at 1 January 2024 £	Incoming resources £	Resources expended £	Transfers between funds £	Balance at 31 December 2024 £
Unrestricted funds	550,224	287,083	(196,011)	(247,675)	393,621
Designated funds	50,000	-	(50,000)	247,675	247,675
Total funds	600,224	287,083	(246,011)	-	641,296

Funds of £247,675 have been designated to fund the work of Dr Jose Aragon-Martin at UCL Institute of Ophthalmology.

12 TRANSACTIONS WITH TRUSTEES

Trustees received no remuneration or expenses from the charity during the year.

13 RELATED PARTY DISCLOSURES

During the year, the charity paid for printing services for the newsletters, educational leaflets and pamphlets, to a company in which one Trustee is a director. Rendered costs totalled £7,431 (2023: £nil).