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Charity Number: 1198847
Company Number: CE028953

MARFAN TRUST

FINANCIAL STATEMENTS
FOR THE YEAR ENDED

31 December 2025

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

Trustees as at 31 December 2025:

Dr Anne Child
James McCallum (appointed 25 September 2025)
Edward Stilliard
Mohamed Abdelrazek
Helen Syms
Andrew Scadding (deceased 23 January 2025)
Eleanor Hyde
Dr Nitha Naqvi
Robin Randall

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
Staverton
Cheltenham
GL51 0UX

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MARFAN TRUST

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2025

The Trustees present their report, together with the financial statements, for the year ended 31 December 2025

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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.

2025 was a very productive year for the Marfan Trust. The staff remained the same. We lost a trusted member of the trustee group, Andrew Scadding, and gained a new trustee Mr James McCallum, retired Chartered Accountant. It is hoped he will help with the Treasurer's role, and general financial advice.

The Trust maintained and expanded its sphere of influence and patient support, notably co-hosting a London meeting with the Marfan Foundation USA which was well attended by British Marfan and Loeys-Dietz Syndrome (LDS) families. Further details appear in the helpline and communications and clinical nurse specialist reports which follow.

FUNDRAISING

As with any charity, there is a constant need to replenish reserves through fundraising.

Action Planning helped replace our fundraiser Amanda with a new fundraiser, Athina Fokidou who inherited Amanda's database of trusts and foundations, and also added approximately 30 new trusts and foundations. Using 2 standard appeal letters, one for service, and one for research, she raised a total of £46,000. We are now in the process of trying to add a permanent full-time dedicated fundraiser to the Marfan Trust, as in the long run this will probably be cost saving, and time saving for present staff.

The Trustees have noted to use these unrestricted funds for their intended purposes for which they were raised. No funds were restricted. We have expanded our number of conferences, and our support groups, as well as publishing our bi-annual newsletter, and new pamphlets. We supported 3 summer students, and a new part-time laboratory assistant for Dr Aragon-Martin at the Sonalee Laboratory at QMUL. She will continue in September to attend courses towards a PhD, having obtained her MSc as an entry qualification. Her name is Jessica Alvarez Salgado, and she is a very talented and enthusiastic young scientist.

Travel funds have been provided for Victoria Hilton and Joanne Jessup to attend UK and European meetings to learn, and to represent Marfan Trust. In addition, Dr Aragon-Martin and Miss Alvarez Salgado were funded to present their research work on gene mutations causing neo-natal Marfan syndrome and genotype-phenotype relationships in Marfan syndrome at the American Society of Human Genetics.

Equipment was purchased for the Sonalee Laboratory, namely genotype analysis machine.

Our largest single expense with regard to service was the creation of a long PICKER questionnaire for patients regarding their experience of presentation and treatment of Marfan syndrome throughout the UK (£32,000). This was very successful and the results should guide our activities in the next 2 or 3 years.

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Of our summer students, one provided us with a summary pamphlet regarding pain management, the result of Dr Helen Cohen's webinar on the same topic. A second student Kannan Maheswaran analysed a postal questionnaire on the relationship between pain and fatigue in Marfan Trust Members with Marfan Syndrome, as well as those with Loeys-Dietz syndrome (LDS), a second inherited disorder which causes aortic dissection. We have increased our representation of families within inherited aortic dissection to include members with the second discovered condition of LDS. More will be added in the future. Are these symptoms of pain and fatigue actually the same thing? This is an attempt to discover how to treat fatigue, a highly prevalent and crippling manifestation of Marfan and LDS syndromes. This summary will be presented to Dr Helen Cohen and her neurophysiologist colleague at Royal National Orthopaedic Hospital in London, and contributed to the larger European study of fatigue in connective tissue disorders, especially Ehlers-Danlos syndrome.

Our large panel of specialists, which form our Advisory Committee, was increased by the addition of a dietician.

Publications of new pamphlets, and additions to the website, were enhanced by the publication of a collaborative paper on management of Marfan syndrome in the paediatric population (Ref: Marfan syndrome: diagnosis and management in childhood; Child AH, Aragon-Martin JA, Kazmi S, Naqvi N; Paediatrics and Child Health 36:3; 69-75).

New lectures and webinars were recorded and placed on our website. New leaflets were published and similarly made available to the public. These leaflets included a guide to physical activity, to pregnancy, to ENT problems, to dental aspects, to gastrointestinal manifestations and a guide to growing older with MFS.

New access to clinical nurse specialist knowledge was provided with the institution of special remote nurse-led clinics for parents with children with Marfan syndrome, and for adults with Marfan syndrome. Further collaboration with other similarly interested groups included addressing the aortic nurses symposium in Birmingham, and representing Marfan Trust at Aortic Dissection Awareness Day.

Summary

In 2025 the Marfan Trust helpline communications and special remote support for patients and their families and doctors, continued to expand and be relevant to the UK and international aortopathy community. In addition, our continued membership of Marfan European Network (MEN) is to ensure that we are aware of developments across Europe in similar organisations, as well as with the American group Marfan Foundation.

Within the UK we continue to develop strong relationships with the Aortopathy clinics, our Marfan Trust community of support groups, and Aortopathy nurses as well as individual patients.

We established a basis for future care and research in 2025, and continue to be a successful charity, delivering on our goals of support, education and research.

HELPLINE REPORT FOR 2025 (Staff Member Victoria Hilton, Helpline Manager)

Continuing the momentum from 2024, during which we expanded our support services, replenished our resources and accelerated our social media activity, the year 2025 was highly productive. As the charity's central point of contact for both the helpline and communications, the Marfan Trust managed a consistently high workload.

SUPPORT: Helpline (the first of our charity's three pillars)

To render our helpline easily accessible, we are approachable not only through email and phone, but also via social media - Facebook and Instagram.

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NEW: To amplify our offering, the introduction of a nurse clinic was added, which has since seen 89 appointments (this figure is integrated into the total below). The clinic is held fortnightly on Fridays.

The different strands of patient care and community engagement are:

- A helpline via phone, email (managed by Victoria)
- Social media channels, and various Marfan & Loeys–Dietz forums (managed/navigated by Victoria)
- Parents' Corner (run by Victoria)
- A fortnightly Nurse Clinic on Fridays held by Joanne Jessup
- Local support groups (run by volunteers)
- Peer support network (one-to-one encounters orchestrated by Victoria)

During 2025, we took **530 enquiries** - a mix of medical, financial and emotional pleas for support. This represented an **8% increase** on 2024.

Marfan Trust take and triage each enquiry and respond accordingly, either resolving it inhouse, (seeking advice from the immediate team) or approaching the wider advisory panel.

A weekly helpline meeting is held on Thursdays at 2pm, when Dr Anne Child, Medical Director, Joanne Jessup, Nurse Specialist, and Victoria discuss and digest the questions, settling anything left lingering.

Medical Queries

A multi-faceted condition, Marfan syndrome causes a disparate array of health problems involving eyes, heart, lungs and skeleton. We take queries on each of these systems and expand our advisory panel accordingly, when a gap in expertise is identified.

In 2025 we appointed a new specialist covering the area of podiatry. Our medical panel now stands at 24 different experts, each representing a different manifestation of Marfan and Loeys-Dietz syndromes.

Practical Support/Patient Advocacy

A barometer of our times, the helpline has seen a surge in requests for assistance with claiming PIP (Personal Independence Payment) as the cost of living tightens its grip. We offer letters of support not only to underpin PIP and DLA (Disability Living Allowance) claims, but also to reinforce applications for early illness-induced retirement and to help children transition to the secondary school of their choice — one that understands their condition.

In 2025, we wrote **23** such letters: **12 were successful; 2 rejected**, **await to hear outcome of remaining 9**.

From a patient, Peter Barker: "*Dear Victoria, For all the wonderful and effective support that you and Fortunate have provided to resolve Marfan issues affecting my family, words alone cannot convey my gratitude. The work you are doing is much more than "a job". It really has life changing value to us, and we are very lucky to have such amazing people batting for us!"*

Local Support: During 2025 we visited Preston and Ealing to help create local support groups.

Emotional Support

Parents' Corner continued throughout 2025, offering an informal online space for parents of children with Marfan and Loeys–Dietz syndromes to gather and share common concerns. This support group was created in 2023 and is held monthly.

Thirty-three people attended ten drop-ins during last year.

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Peer support thrives and patients are introduced to each other, either for strategic one-off meetings prior to surgery or longer sustained friendships. We have also helped to revive local support groups and visited Preston in February 2025 to start one there. A total of 33 people form our peer network.

EDUCATION (the second of our charity's three pillars)

Information Guides

Complementing our helpline is our library of Information Guides, and in 2025 we introduced four newly revised and expanded leaflets, listed below. Our leaflets and resources are regularly downloaded by patients, while printed copies are distributed to clinics and genetic units across the country.

- Gastrointestinal Implications of Marfan and Loeys-Dietz Syndromes
- ENT Aspects of Marfan & Loeys-Dietz Syndromes
- Dental Aspects of Marfan & Loeys-Dietz Syndromes
- Growing Older with Marfan & Loeys-Dietz Syndromes

Webinars & Patient Information Days

During 2025, we organised and emceed three webinars/all-day online conferences featuring ten experts in their fields.

- **Genetics of Marfan & Loeys-Dietz Syndromes** with Professor Anand Saggar: 32 attendees
- **Navigating the Education System with Marfan Syndrome**: with Occupational Therapist Natasha Woodgate: 25 attendees
- **Marfan & Loeys-Dietz Patient Information Day**: 144 attendees

We recorded and edited each of the above and they are available on our YouTube channel. https://www.youtube.com/@marfantrust3841/videos

Birmingham Patient Day

With Genetic Counsellor Marie O'Donnell from Birmingham Women's and Children's Hospital, Marfan Trust devised, organised and hosted an in-person Patient Information Day in Birmingham: Living with Marfan & Loeys-Dietz Syndromes.

The successful day involved 13 expert speakers, 130 adult patients, 15 paediatric patients, a magician and a play team. We booked the venue Austin Court, which was intimate, beautifully designed for conferences and perfectly tailored to such an event. Marfan Trust organised travel bursaries, catering etc. Marfan Trust hosted a meal on the eve for the speakers. Throughout the day we manned a table of merchandise, meeting and taking questions from patients. The overall cost came within budget - £13,000.

Amy Morgan, wife and mother to Loeys-Dietz patients:

"I just wanted to say a huge thank you for such an incredible day! We came away with so much useful information and advice, and it's left us feeling really positive about the future living with LDS. It was clear how much effort you put into making it all happen, and everyone had a wonderful time. The kids especially loved their day, which made it even more special for us."

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Sharon Kennedy, patient with Loeys-Dietz syndrome:

"I *want to say what a wonderful job you did organising the Loeys Dietz conference on Saturday. We learned so much from the incredible doctors, consultants, geneticists, researchers and other families with lived experiences. The time and effort you spent organising this event has enriched so many lives for families living with Loeys Dietz and Marfan Syndrome. You have helped so many families break down barriers by enriching them with knowledge to share positively with their extended families and their doctors, who haven't heard of Loeys Dietz in particular. You are a very, warm, welcoming, knowledgeable, hardworking and passionate individual who oozes generosity of time and support. Thank you."*

Website & Social Media

Our online public face is our social media and website, both alive with supporter stories, educational material, industry news, events and videos. Through these channels, we celebrate our patient community, raise awareness of Marfan and Loeys–Dietz syndromes, and educate both the public and professionals. Volunteer Darren McDean creates the accompanying images and together we have devised a house style for the Trust.

Throughout 2025, we published 40 patient stories, celebrated numerous fundraisers, shared emerging research on PEARS, pregnancy and exercise, posted industry updates and infographics, and highlighted the work of our Sonalee laboratory, amongst much more. These posts are a mix of static and video.

Marfan Awareness Month

February marked Marfan Awareness Month and our campaign theme - *See the Signs, Save a Life, Support the Trust*. Throughout the month we posted prolifically, sharing new content every day designed to help people recognise and understand the signs of Marfan and Loeys–Dietz syndromes. Each post sparked significant engagement and conversation across Facebook.

We also published patients' stories, infographics, research news and fascinating facts, tagging relevant organisations - including podiatrists, dentists and optometrists - to widen our reach and encourage professionals to recognise the signs within their own fields. We also secured an article in *Optometry Today*, which has a Facebook following of 26,000.

During the month, we organically reached our largest audience to date: 32,000 people, with an engagement rate of 10%. Crucially, this far exceeds the average engagement rate for non-profit organisations, which stands at approximately 0.31%. On Facebook during February we acquired 81 new followers. On Instagram we reached over 17k accounts.

Newsletter

Traditional and treasured, our bi-annual newsletter *Marfan Matters* is published twice a year. We assemble and edit the contents while contributing pieces including an article on Terumo Aortic. The newsletter is designed by our in-house volunteer, Darren McDean, and sent by post to approximately **1,450 recipients**. The digital version is emailed to approximately **2,500** recipients and reaches many more on social media.

Social Media / Email Stats

We concluded the year with:

Facebook 2.5k followers (an increase of 24% throughout the year) **Instagram 1,106 followers** (an increase of 11%) / **Email subscribers 2,590** (increase of 10.64%)

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Industry Visits, Conferences and Networks

1. **Terumo Aortic:** On 11 June, Marfan Trust visited Terumo Aortic, a factory in Glasgow showcasing Scottish artisanal skill in the handcrafting of life-saving medical devices. Many of our patients have been given a new lease of life through these devices, which made it especially meaningful when Terumo subsequently attended our Birmingham symposium to interview several patients whose lives had been transformed by them. We subsequently turned the visit into a feature article for our newsletter.
2. **Scottish Adult Cardiac Congenital Services Conference (SACCS):** On 28 November, Marfan Trust attended the SACCS Conference in Glasgow, where we hosted our exhibition stand, introduced medical professionals to the Trust's work, and raised awareness of Marfan and Loeys–Dietz syndromes.
3. **Marfan European Network**: United behind the motto Together We Can, the Marfan Europe Network (M.E.N.) is a coalition of 18 patient organisations. Victoria Hilton represents the Marfan Trust during these meetings – six throughout the year - where we swap news and share updates.
4. **Vascular Voice Network** (VVN) The first and only organisation in the UK for people and families affected by brain aneurysms, the VVN has assembled many different charities into their network, all united by the fact that their disease includes brain aneurysms as a feature.

Research (the third of our charity's three pillars)

Victoria assisted Joanne who led on our national state-of-the-nation snapshot survey, the first of its kind conducted here in the UK or elsewhere. We collaborated with the team from research company Picker on this project, entitled "Understanding the Care Experiences of People with Marfan Syndrome and Loeys–Dietz Syndrome: A UK Survey." Involvement spanned every stage of the process, from questionnaire design and scoping interviews through to the delivery of the survey itself. The survey was open for participation from 6 September to 17 November and received just under 400 responses from individuals across the UK. It reaped results that will inform our helpline and fundraiser The final report is anticipated in early 2026, with further outputs to follow.

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 consistently spread the word through many means including marketing and PR.

1. **Membership**
   To secure our future, we encourage membership of the Trust, tempting our community with the opening paragraph to Dr Child's Casebook – a Q&A taken from the Helpline. 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 2025:
   23 people joined the Trust as Best Friends, 8 as Family Friends, 4 Overseas Friends

2. **Webshop**
   Our shop is kept fresh and alive with new offerings, and last year we introduced Marfan Trust branded water bottles.

3. **Social Media**
   three to four posts are created each day, ranging from patient stories and fundraising achievements to articles on signs and symptoms, emerging treatments, medical developments, research, and more. Visits are planned to Marfan and Loeys-Dietz forums when tagged or of interest and offer help. Volunteer Darren McDean creates the accompanying image and together we have devised a house style for the Trust.

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Fundraising

We are not government funded but rely solely on the goodwill of our fundraisers. During 2025 we liaised with fundraisers across the country, and visited in person:

- **Norfolk:** for a supporter's funeral
- **Cirencester**: to meet a patient with a newly published novel
- **London's Sloane Club:** for a supporter's book launch with donations going to the Marfan Trust
- **New Forest:** for a Brave the Shave fundraising do
- **Elgin**: for the Cannonbawz Run

Marfan Trust also worked quite closely with our freelance bid-writer on securing grants and applications, proving copy, facts and figures.

Numbers …

- **Helpline:** 530
- **Local Support Groups**: 43 attendees
- **Parents' Corner**: 10 sessions- 31 attendees**Webinars**
  - The Genetics of Marfan & Loeys-Dietz Syndromes: 32
  - Navigating the Education System with Marfan & Loeys-Dietz Syndrome: 25
  - Marfan Information Day: 144
- **Marfan & Loeys Dietz Information Day**: 130
- **Newsletter:** 1,450
- **Email Communications:** 2,590
- **Leaflet Distribution & Downloads:** 550
- **Social Media – FB (2,500) & Instagram (1,106)**: 3,606
- **Peer Support Network**: 23

In 2025, the Sonalee Laboratory continued advancing research on Marfan syndrome (MFS) and other connective tissue disorders, including Hereditary Thoracic Aortic Aneurysm and Dissection (HTAAD), Loeys-Dietz syndrome (LDS), Ectopia Lentis, hypermobile Ehlers-Danlos syndrome (hEDS), scoliosis, and Primary Congenital Glaucoma (PCG).

Research was conducted across Queen Mary University of London (QMUL, UK), Imperial College (IC, UK), the Institute of Ophthalmology (IoO, UCL, UK), and international collaborators in the USA and Qatar. The laboratory also hosted MSc, summer, and work experience students, contributing to training the next generation of researchers.

MSc, summer, volunteer and work experience students contributed significantly to research, training, and data analysis.

Collaborations

Glaucoma Projects:

- Collaborations with Professor Mansoor Sarfarazi (University of Connecticut Health, CT, USA) and Professor Mariya Moosajee (IoO, UCL, UK).

- Samples from the USA were received in the UK and are pending shipment to Sidra University, Qatar, for free NGS screening once the Material Transfer Agreement (MTA) is finalised.

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Collaborations (continued)

- Dr. Nicky Cronbach (PhD, UCL) is analysing the glaucoma data for her thesis, comparing results with Moorfields Eye Hospital.

Aortic Aneurysm and MFS projects:

- Collaboration with Professor Panos Deloukas (QMUL) and Professor Oo (Bart's Hospital) to apply for funding to support a PhD student project studying aortic aneurysm families without a genetic diagnosis.

Zebrafish Project:

- Ongoing collaborative work with Professor Moosajee at IoO. Currently focused on method development and training.

Achievements & Performance – Research Activities
The Sonalee lab is focused on advancing research into MFS, HTAAD, LDS, Ectopia Lentis, hEDS, scoliosis and PCG during 2025.

1. Manuscripts published

No primary research manuscripts were published during 2025.

2. Working on manuscripts to be published

- Genotype-Phenotype associations – calcium-binding cbEGF-like domains in Marfan syndrome. This study investigates the relationship between variants in the calcium-binding cbEGF-like domains of FBN1 and the corresponding clinical phenotypes in Marfan syndrome patients.

- Neonatal Marfan syndrome – *FBN1* fine mapping and 3D protein interactions. This study focuses on fine mapping of FBN1 variants in neonatal Marfan syndrome and uses AI-generated 3D protein models to explore interactions between these variants.

- Ectopia Lentis – *ADAMTSL4* variants. Analysis of a Sonalee Laboratory cohort to identify and interpret pathogenic variants in *ADAMTSL4* associated with Ectopia Lentis. This study evaluates the clinical significance of these variants across the cohort.

- Review – genetics of Ectopia Lentis. A comprehensive review of current knowledge on the genetic causes of Ectopia Lentis, including both classical and novel gene associations.

- Marfan syndrome – genotype-phenotype associations using statistical approaches. This study applies Fisher's exact test to analyse Marfan syndrome FBN1 variants in the Sonalee Laboratory cohort, linking genotypes to defined phenotypes.

- Marfan syndrome – genotype-phenotype associations using new analytical tools developed at QMUL. Using novel bioinformatics tools developed at QMUL, this study evaluates the Sonalee Laboratory cohort of Marfan syndrome FBN1 variants and associates specific genotypes with clinical phenotypes.

- Marfan syndrome – pathogenic variants in intronic and deep intronic regions. A review of current knowledge on pathogenic variants in intronic and deep intronic regions of *FBN1*, highlighting their potential clinical significance.

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- Marfan syndrome – expectations and challenges of gene editing. This review examines recent advances in gene editing, discusses the underlying scientific rationale, and evaluates potential applications, limitations, and challenges for Marfan syndrome.

- HTAAD – analysis of whole exome sequencing in two families. Investigation of HTAAD families using WES to identify novel candidate variants contributing to Hereditary Thoracic Aortic Aneurysm and Dissection.

- hEDS – analysis of whole exome and whole genome sequencing in two families. This study analyses WES and WGS data from two families with hypermobile Ehlers-Danlos syndrome (hEDS), where the causative gene has not yet been identified, using the most up-to-date NGS tools.

3. Conference presentations

Marfan Trust delivered 4 poster presentation at the ASHG 2025.

- Genetic Analysis of Shared Candidate Genes Across Connective Tissue Disorders: Variant Interpretation in MFS, hEDS, HTAAD, and Scoliosis – *presented by Archana*. Investigating variants in genes shared across connective tissue disorders to identify potential common genetic contributors.

- Genetics of HTAAD and hEDS: Structural and Copy Number Variant Discovery in Familial Cases – *presented by Chandana*. Analysis of SVs and CNVs in two HTAAD and two hEDS families to explore complex genetic contributions using WES and WGS.

- Genetic Profiling in Marfan Syndrome: Refining Genotype–Phenotype Associations in *FBN1* – *presented by Jose Antonio*. High-resolution analysis of *FBN1* variants in cbEGF-like domains to uncover clinically actionable genotype–phenotype patterns.

- Genetics of Neonatal Marfan Syndrome: Mapping Variants Within and Beyond the Classical Region – *presented by Jessica Esther*. Systematic mapping of FBN1 variants in neonatal Marfan syndrome and classical Marfan syndrome to refine genotype–phenotype understanding.

Collaborative Meeting during ASHG 2025:

Met with Professor Sarfarazi to discuss glaucoma data and the ongoing Primary Congenital Glaucoma (PCG) study in collaboration with Professor Mariya Moosajee at IoO-UCL. Plans were made to share additional data for further analysis.

4. Laboratory Research

- Whole Exome Sequencing (WES) data in a large HTAAD cohort is being studied to rule out know TAAD 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.

- Whole Genome Sequencing (WGS) and Whole Exome Sequencing (WES) data in two independent hEDS family are being studied to search for their causative gene. This is an ongoing project.

- Whole Exome Sequencing (WES) data in several families with scoliosis are being studied to search for their causative gene. This is an ongoing project.

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- New glaucoma data from Professor Sarfarazi needs to be organise and compile to extract the data from those samples that will be used for a collaboration in eyes with Professor Moosajee at IoO-UCL. This is an ongoing project.

- Studying RNA-seq data from a single family to clarify a novel variant in *ADAMTSL4* gene.

- Supervision of MSc, summer, and work experience students: Pedigree creation, literature reviews, genotype–phenotype correlations, CNVs, SVs, intronic variants, and UTR analysis. Students included: Chandana Veshala, Jessica Alvarez, Jisan Ahamed, Tansy Xue, Gemma, Tolu – Barakat Toluwanimi Adeleke, Archana Rai.

5. Teaching, Workshops, and other meetings

The Sonalee Laboratory participated and/or contributed to multiple workshops, lab meetings, and other events that facilitated teaching and knowledge dissemination throughout 2025, supporting training, research dissemination, and patient engagement.

This approach gave us the opportunity for networking, increase our profile as a lab for students to come and help in the lab as volunteers, and also, to be heard by discussing Marfan syndrome in different academic and/or intellectual environments.

- **On 10 February 2025 – UCL IoO (Mariya's Lab Meeting)**
  Topic: Updates on research in the UCL lab.

- **On 28 February 2025 – QMUL**
  Pedigrees for Publication Workshop
  Focus: Use of Madeline2 tool in command line for pedigree generation.

- **On 11–12 March 2025 – QMUL**
  NGS Workshop
  Focus: Whole Genome Sequencing (WGS) and Whole Exome Sequencing (WES) workflows.
  Content included: FASTQ to VCF processing and identification of candidate variants.

- **On 28 March 2025 – QMUL (Panos' Lab Meeting)**
  Topic: Genotype–phenotype associations in Marfan syndrome.

- **On 28 April 2025 – UCL IoO (Mariya's Lab Meeting)**
  Topic: Updates on research in the UCL lab.

- **On 12 June 2025 – UCL IoO (Mariya's Lab Meeting)**
  Topic: Updates on research in the UCL lab.

- **On 13 June 2025 – QMUL (Panos' Lab Meeting)**
  Topic: ASHG 2025 presentation abstracts.

- **On 6 September 2025 – Marfan Trust, Birmingham (Information Day)**
  Topic: Living with Marfan and Loeys-Dietz Syndromes - Research at the Sonalee Lab [Marfan Trust lab]

- **On 8 September 2025 – UCL IoO (Mariya's Lab Meeting)**
  Topic: Updates on research in the UCL lab and zebrafish project on gene sox.

- **On 24 September 2025 – UCL IoO (Mariya's Lab Meeting)**
  Topic: Updates on research in the UCL lab and zebrafish project on gene sox.

- **On 11 October 2025 – Marfan Trust (Information Day Online)**
  Topic: Virtual patient engagement and education.

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- **On 7 November 2025 – QMUL (Panos' Lab Meeting)**
  Topic: Update on Structural Variants.

- **On 16 December 2025 – UCL IoO (Mariya's Lab Meeting)**
  Topic: Updates on research in the UCL lab and POAG project in collaboration with Professor Mansoor Sarfarazi using previously generated data from USA.

6. Preparing grants to support/fund Sonalee Laboratory research & activities.

- British Heart Foundation (BHF) for HTAAD project in collaboration with Professor Panos Deloukas.
  - **Application submitted:** Ongoing during early/mid 2025.
  - **Outcome:** it was reviewed in late 2025 – no award.

- Bart's Hospital Charity for HTAAD project
  - **Application submitted:** it is £350,000 for a 3-year project with PhD studentship. Final submission: By October 2025.
  - **Outcome:** We were summoned for a first interview. Results in 2026.

7. Summary

The summer studentship in 2025 was very important to Sonalee Laboratory since we are short of hands to help with research. Jessica Esther Alvarez Salgado approached our group and was interested in learning as a volunteer since we met her in January 2025. When she joined our lab group, she started helping with *FBN1* fine mapping the neonatal Marfan syndrome (nMFS) variants from our database and from external databases. This will help us to clarify if there is only one region specific to nMFS.

We are planning to address the following questions:

- Where are the nMFS mutations?
- Are there any ore clusters like the neonatal MFS region?
- Are all the nMFS patients with the same phenotype?
- Can we use the tool "alphafold" to study any possible interaction with other parts of the FBN1 protein?

We need to host students who are excellent in their research. For this reason, Sonalee Laboratory was planning to host during the Summer 2025 Jessica Esther Alvarez Salgado, who was also planning to apply for an PhD next year 2026. We have known Jessica since January 2025 when she started as a volunteer, and also we are supervising her laboratory project in Sonalee Lab from the 2025-2026 academic year at QMUL (submission expected September 2026). We think that her previous experience with other laboratories and with our laboratory, and after her MSc degree in Genomic Medicine, will make her the best candidate to address the HTAAD research project with efficiency and reliability.

ANNUAL ACTIVITY January – December 2025

Joanne Jessup – Nurse Specialist

Joanne's role is closely intertwined with that of Victoria Hilton as we together to respond to the growing number of helpline enquiries that we receive.

Raising Awareness

Work liaising with other health care professionals continues and we send information and resources as requested. We also have a list of genetics and aortopathy clinics that receive a selection of our materials.

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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 2025 the following leaflets were updated

- Guide to Physical Activity
- Guide to Pregnancy

The following leaflets were newly published

- Guide to ENT problems
- Guide to Dental Aspects of Marfan and Loeys Dietz Syndromes
- Guide to Gastrointestinal Manifestations of MFS and LDS
- Guide to Growing Older with MFS

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.

Conferences/Webinars

6th June 2025 – Aortic Nurse's Symposium, Birmingham

6th September 2025 - Joanne ran an interactive session at our Patient symposium 'Preparing for an Emergency'

We hosted our Patient Symposium in Birmingham on 6th September where we welcomed over 130 people affected by Marfan or Loeys Dietz syndromes. This was a great opportunity for people to network and create connections. Victoria and Joanne manned a table full of resources and spent large parts of the day speaking to people, answering questions, providing advice and support and hearing new ideas from patients and clinicians.

18th September 2025 – Joanne represented Marfan Trust at Aortic Dissection Awareness day in Leicester on 18th September.

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.

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 parent's drop-in session (run by Victoria) via Zoom
- Adhoc online Zoom appointments to with Joanne

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New for 2025

Joanne has introduced a fortnightly clinic. Every other Friday Joanne has 6 slots available for patients to book a 30-minute zoom appointment to discuss their concerns.

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, this is triaged by Victoria, and she will pass on relevant calls or discuss them with myself or Dr Child at our weekly meetings. 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.

In 2025 Joanne dealt with 89 helpline calls specifically who needed further advice or input and who required a longer call to deal with their issues or a letter of support. These numbers are also included in the general helpline numbers.

Research

Joanne led on delivering our National Survey 'Understanding the care experiences of people with Marfan syndrome and Loeys-Dietz syndrome: A UK Survey'. Joanne worked closely with Victoria on this, along with a team from Picker. We were involved at every step from questionnaire design, scoping interviews and delivery of the survey. It was available for completion from 6th September until 17th November and we received just under 400 responses from people across the UK. Final report is expected early 2026 and outputs will follow.

Other Work - Aortic Nurses Network

Joanne continued her work on the Steering Committee of the Aortic Nurses Community of Practice, we now have a web platform hosted by The Aortic Dissection Charitable Trust (TADCT) which has around 40 members, we hosted the 2nd symposium in June and are running a series of webinars entitled 'Back to Basics'. The first webinar, delivered in November was entitled 'The Genetics of Aortic Dissection and Aortopathy'. Further webinars are planned on a quarterly basis.

Appointment of Trustees

Trustees are appointed according to the objects and their selection is based on their professional standing. Any person wishing to become a Trustee of the charity must be approved and is appointed by the current Trustees.

Financial Review

During the year, the Trust received total income of £178,887 (2024: £292,619). The Trust incurred expenditure of £300,520 (2024: £251,547). This year, there was a Deficit of £121,633 (2024: surplus of £41,072).

As at 31 December 2025, total funds stood at £519,663 (2024: £641,296), of which £315,803 (2024: £393,621) relates to general funds and £203,860 (2024: £247,675) relates to designated funds.

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MARFAN TRUST

TRUSTEES' REPORT FOR THE YEAR ENDED 31 DECEMBER 2025

Reserves policy and risk management

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.

Funds of £203,860 have been designated 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 Charity 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.

Approved for and on behalf of the Trustees of the Marfan Trust on 21/10/2026

Dr Anne Child	Helen Syms
Chair	**Trustee**

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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 2025 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 2025, 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 Charity'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. 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.

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.

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INDEPENDENT AUDITORS' REPORT

TO THE TRUSTEES OF MARFAN TRUST

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.

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.

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- 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.

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 ..... 21/10/2026 .....

Ryan Hancock (Senior Statutory Auditor) Date
For and on behalf of Hazlewoods LLP, Statutory Auditor
Staverton Court
Staverton
Cheltenham
GL51 0UX

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MARFAN TRUST
YEAR ENDED 31 DECEMBER 2025
STATEMENT OF FINANCIAL ACTIVITIES

	Note	2025	2024
Income		**£**	**£**
Voluntary income			
Donations, covenants and Gift Aid		169,899	281,488
Investment Income			
Bank interest receivable		8,988	11,131
Total Income		**178,887**	**292,619**
Expenditure			
Cost of raising funds			
Costs of raising voluntary income	2	(71,430)	(37,354)
Charitable activities			
Education, awareness and support	3	(67,088)	(66,738)
Staff costs	4	(108,727)	(125,074)
Donations		(45,015)	(7,377)
Governance costs	3	(8,260)	(15,004)
Total expenditure		**(300,520)**	**(251,547)**
Net movement in funds		**(121,633)**	**41,072**
Funds balances brought forward at 1 January		641,296	600,224
Funds balances carried forward at 31 December		**519,663**	**641,296**

All of the charity's activities are continuing activities.

For the year ending 31 December 2025 all funds are unrestricted.

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MARFAN TRUST
YEAR ENDED 31 DECEMBER 2025
BALANCE SHEET

	Note	2025	2024
		£	£
FIXED ASSETS			
Investments	5	6,750	6,750
Tangible fixed assets	6	29,103	15,962
Total fixed assets		**35,853**	**22,712**
CURRENT ASSETS			
Cash at bank and in hand	7	485,457	636,831
Debtors	8	1,150	3,482
Total current assets		**486,607**	**640,312**
LIABILITIES			
Creditors: due within one year	9	(2,797)	(21,728)
CURRENT ASSETS LESS CURRENT LIABILITIES		**483,810**	**618,584**
NET ASSETS		**519,663**	**641,296**
THE FUNDS OF THE CHARITY	10, 11		
Designated		203,860	247,675
General		315,803	393,621
TOTAL FUNDS OF THE CHARITY		**519,663**	**641,296**

Approved by the Board of Trustees on 21/10/2026

Dr Anne Child
Chair

Helen Syms
Trustee

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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.

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Staff costs

The costs of employing staff, including wages and salaries, social security costs and pension contributions, are recognised in the Statement of Financial Activities in the period in which the employees provide services. Short-term employee benefits are measured on an undiscounted basis and are recognised as an expense as the related service is provided.

The charity operates a defined contribution pension scheme. Contributions payable to the scheme are charged to the Statement of Financial Activities in the period to which they relate. Any unpaid contributions at the reporting date are included within creditors.

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	2025 £	2024 £
	Cost of generating voluntary income		
	Fundraiser's expenses, website and newsletters	71,430	37,354

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3 ANALYSIS OF CHARITABLE ACTIVITIES

Education, awareness and support	2025	2024
	£	£
Office consumables	27,503	20,602
Advertising & marketing	11,395	3,114
Laboratory expenses	5,091	17,990
Telephone & Internet	3,728	4,068
Travel	917	3,632
Students paid	-	1,000
Insurance	-	1,286
Printing & stationery	6,385	7,978
Office equipment depreciation charge	7,964	1,532
Rent	1,077	-
Subscriptions	696	-
Gift aid write-off	2,332	5,536
	67,088	66,738

Governance costs	2025	2024
	£	£
Audit fees	2,340	1,500
Accountancy fees	5,282	4,521
Legal and professional fees	638	8,983
	8,260	15,004

4 STAFF COSTS

	2025	2024
	£	£
Wages and salaries	100,945	113,078
Social security costs	2,535	6,839
Pension costs	2,362	2,742
Secretarial salary & expenses	2,865	2,415
	108,727	125,074

The average number of employees who were employed by the Charity during the year was 3 (2024: 3).

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

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5 SUMMARY OF INVESTMENTS

	£
Market value at 1 January 2025 and 31 December 2025	6,750

The Trust holds 100,000 shares in Eurovestech PLC.

6 TANGIBLE ASSETS

	Plant and Machinery £
Cost	
At January 2025	18,714
Additions	21,105
At 31 December 2025	39,819
Depreciation	
At January 2025	2,752
Charge for the year	7,964
At 31 December 2025	10,716
Net book value	
At 31 December 2025	29,103
At 31 December 2024	15,962

7 CASH AT BANK AND IN HAND

Cash at bank and in hand is held as follows:

	2025 £	2024 £
NatWest current account	22,434	22,214
Treasury tracker account	85,501	84,392
CAF gold savings account	288,540	481,003
CAF cash current account	88,982	49,222
Total cash at bank and in hand	485,457	636,831

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8 DEBTORS

	2025 £	2024 £
Gift aid recoverable	1,150	3,482

9 CREDITORS – due within one year

	2025 £	2024 £
Trade creditors	-	12,249
Accruals	2,797	1,999
Wages payable	-	23
PAYE payable	-	7,457
	2,797	21,728

10 ANALYSIS OF NET ASSETS BETWEEN FUNDS

	Unrestricted Funds £	Designated Funds £	2025 Total funds £	2024 Total Funds £
Fixed assets	35,853	-	35,853	22,712
Current assets	282,747	203,860	486,607	640,312
Current liabilities	(2,797)	-	(2,797)	(21,728)
Total net assets	**315,803**	**203,860**	**519,663**	**641,296**

11 ANALYSIS OF FUND MOVEMENTS

	Balance at 1 January 2025 £	Incoming resources £	Resources expended £	Transfers between funds £	Balance at 31 December 2025 £
Unrestricted funds	393,621	176,555	(254,173)	(200)	315,803
Designated funds	247,675	-	(44,015)	200	203,860
Total funds	**641,296**	**176,555**	**(298,188)**	**-**	**519,663**

Funds of £203,860 (2024: £247,675) have been designated to fund the work of Dr Jose Aragon-Martin at UCL Institute of Ophthalmology.

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12 TRANSACTIONS WITH TRUSTEES

Trustees received no remuneration and were not reimbursed any personal expenses by 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 £5,594 (2024: £7,431).