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Marfan Matters

Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders

Welcome to our Spring/ Summer 2022 Edition

Sophia Kazmi

June is in full bloom, heralding change, hope and growth. As the fragrance of fresh blossom fills the air, the Marfan Trust continues to evolve, expand and move. In a fairly seamless transition we are now happily ensconced in a new address with a new helpline of **0333 011 5256**. Update your diaries and all hail change!

From our new Marfan HQ we will grow our community of supporters and make new connections – parallel connections. A member of the connective tissue disorder family, Loeys-Dietz syndrome converges with and diverges from Marfan in its clinical features. We want to expand our successful Marfan support network to encompass this fellow condition, see page 4.

And as fresh life unfurls around us under the summery sun, this newsletter places a special emphasis on the young. Our cover star and Trust volunteer Sophia Kazmi has compiled a handy list of books for children. Children need to see themselves on the bookshelf and Sophia has carefully curated a selection of titles that captures something for everyone.

Dr Anne Child, Medical Director and Chair of Board of Trustees

Dr Anne Child MD FRCP

Keep all your old friends and keep making new ones. This is the secret mantra which has guided our staff this last six months. Our friends have supported us by volunteering as our six new trustees from all walks of life (see About Us page on our website). Through the talented hard work of Victoria and Gurpreet, our social media articles and casebooks are attracting new members at a gratifying rate. We are very grateful to all fundraisers whose donations are our major source of income (ps. 11-12).

After two and a half years of being kindly hosted by National Heart and Lung Institute courtesy of Professor Ed Chilvers we are moving onwards to a new office closer to staff homes and storage facilities.

Our Sonalee Laboratory has been invited to join the Institute of Ophthalmology, the research arm of Moorfields Eye Hospital. We have long been associated with this centre of excellence, co-discovering genes for glaucoma (which also affects 2% of Marfan patients) and dislocated lenses. Dr Aragon-Martin will work in the Department of Professor Mariya Moosajee, Professor of Molecular Ophthalmology and Consultant Ophthalmologist at the Institute of Ophthalmology of Moorfields Eye Hospital. Sir Peng Tee Khaw Consultant Ophthalmic Surgeon at Moorfields and Professor of Glaucoma and Ocular Healing at the Institute of Ophthalmology will also be involved. Jose will be working in this Centre of Excellence on further genes for congenital glaucoma and ectopia lentis. He is funded by an annual legacy for the next few years, and we are applying for external funding to continue looking for new genes for thoracic aortic aneurysm and dissection (TAAD). 70 new genes are waiting to be discovered.

We will continue to collaborate with our friends at the Brompton Hospital (Professor John Pepper, Dr Nitha Naqvi one of our new trustees, and Dr Deborah Morris-Rosendahl Head of the Genomic Medicine Centre).

Our Research projects are quite fascinating. A summer student from Bristol, Amy O'Reilly, has been awarded the Brian Adams Memorial Studentship for this summer of eight weeks. She will be working with the Canadian Loeys-Dietz Syndrome Foundation to find LDS people in the UK and set up a parallel support group together with our office manager, Mrs Katrina Parnacott (see p.4).

Mrs Rosalee Renamagboo at Bart's Health NHS Trust, was chosen Cardiac Nurse of the Year and is now commencing a three-year PhD project to look at psychological issues and surgical outcomes before and after aortic surgery. She will be summarising government health records. We wish her luck and hope all our members involved in this study will permit scrutiny of their notes. We will certainly publish her results in a future newsletter.

Our member questions and suggestions are always welcome, and have stimulated us to develop a very full programme for our annual Information Day (p.15) so please put Saturday, 8 October in your diary now. I hope to see you there!

Helpline ... A Lifeline

by Victoria Hilton


Victoria Hilton


Dr Anne Child

Forever relevant and increasingly busy, the Marfan Trust counsels supporters old and new. Dispensing a uniquely personalised and tailormade trove of advice, Dr Child continuously replenishes her knowledge and expands her advisory network, to cover every possible aspect of this complex, multifaceted condition. For as long as people continue to be diaganosed with Marfan syndrome, the Trust helpline remains an indispensable repository of information in a sometimes-disconnected world.

Underlying the niche helpline is a continuing pattern of enquiries. Of the **140** assorted calls taken since January it is the quest for diagnostic certainty that prevails. There were **38** separate calls from people suspecting that they, or a family member, may have MFS or a similar connective tissue disorder. Inevitably several of these callers proved just happily hypermobile whilst two have been since been diagnosed with Ehlers-Danlos and three with Marfan syndrome. This means five lives potentially saved.

As ever, **gut and intestina**l queries were a popular line of enquiry with supporters troubled by bloating, constipation and digestive discomfort. Adapted into **Dr Child's Casebook**, Digestive Dilemmas resonated with readers and we have **published it below** to give you a taste of what to expect as a **member of the Trust**. **Skeletal** issues – pectus problems, scoliosis, but most debilitatingly constant pain prompted by amongst other unpleasant things, dural ectasia – are frequently raised. Feet, ankles and wrists are also a source of inhibiting everyday pain and we advise orthotics and physiotherapy. **Aortic enlargement** and its management through surgery and losartan or irbesartan is discussed, as are **eye** problems, the merits of lens replacement, and the complications of scleral lenses.

Many approach the helpline for peer support. Whether seeking advice on something specific such as breastfeeding, or craving a generally supportive conversation from one Marfan to another, more and more are **joining the conversation! "Mega helpful"** is how one supporter described her experience. Parent-to-Parent, child-to-child, person-to-person, we are happily matchmaking our Marfan family. Email Victoria at info@marfantrust.org

Casebook: Digestive Dilemmas

by Dr Anne Child & Victoria Hilton

The body's helpfully expandable storage tank, your stomach digests your food and can control your mood. It performs the daily grind, with its network of neurons mixing and absorbing your meals in a complex process that is inextricably connected to your brain and emotional state. This process is disrupted in a connective tissue disorder when deficient elastic tissue in the stomach wall impedes gastric activity.

Q: I have suffered embarrassing and unpleasant digestive symptoms for some time. These include heartburn, reflux and feeling sick. It has taken doctor after doctor to reach a diagnosis. They now believe that I have something called gastroparesis. Is this common in connective tissue disorders? I have Marfan syndrome, and I feel quite low.

A: Gastroparesis is a long-term condition where the stomach cannot empty in the normal way. Food passes through the stomach slower than usual. The symptoms you describe are typical and, as you say, it can leave you feeling low.

Although gastrointestinal symptoms are more frequent in patients with Marfan syndrome, gastroparesis is more common in a similar condition called Ehlers Danlos syndrome. I would check your diagnosis of Marfan syndrome with your regional genetics clinic. Medication can also be contributory, so please check with your general practitioner. For example, if you are taking medicine for pain such as Ibuprofen, and a daily dose of Omeprazole to protect the stomach, this can actually lead to delay in emptying. Some patients are on anti-depressants which can also aggravate stomach problems.

A review of diet with your dietician to decrease alcohol and coffee and spicy foods, and to avoid fatty and high fibre food, which are more difficult to digest, is recommended.

Frequent small meals rather than three large meals a day are easier for the stomach to digest. Regular gentle exercise and general reduction of stress are also helpful.

Your gastroenterologist will perform further tests to clarify this diagnosis, and can prescribe medications to relieve your symptoms. In extreme cases, gastric surgery can be offered.

Hopefully a simple but comprehensive review with your care team of your diet and medication will resolve these debilitating symptoms.

Marfan Awareness Month

Marfan syndrome still passes frequently unnoticed through GP surgeries and A&Es. We are increasingly approached with stories of those left fatally undiagnosed or wholly unsupported by their doctor. The potentially life-threatening gulf between early and late diagnosis underpinned our February 2022 Marfan Awareness Month campaign. Make Marfan Matter: Make Medicine Aware was our rallying, imploring cry to the medical establishment. Through a series of articles, interviews, quotes, videos, and supporter stories we spread the word with manifest, tangible results: a four-fold surge in calls to the helpline, a 10% rise in our Facebook following, and a Twitter campaign viewed by over 18,000 – an incredible feat for a small charity. Supporters were encouraged to take our two-page Signs and Symptoms pamphlet to local surgeries, and distribute our medical leaflets at relevant ports of call. Yet, whilst we bask in the afterglow of a successful campaign, raising awareness of MFS should not be confined to the month of February but a long-term continuing crusade, and so it is.

We thank Jonathan Edwards' family, Steffanie, Sarah, and Julie for sharing their stories; Lucy Atkinson for contributing so artistically to our Signs and Symptoms article; and Dr Nitha Naqvi and Professor Pepper for making such indelible impressions on our YouTube channel. https://www.youtube.com/channel/UC8lxjjN_6xxfTo9E19NDHZQ

Marfan Trust Research Update

LOEYS-DIETZ SYNDROME | *by Amy O'Reilly, Medical Student, Bristol University*

Loeys-Dietz Syndrome is a rare, genetic connective tissue disorder that shares some features with Marfan Syndrome. Like Marfan Syndrome, people with Loeys-Dietz syndrome can have changes affecting their heart, bones, joints, skin, eyes, blood vessels and internal organs. We would like to raise awareness of Loeys-Dietz Syndrome, to allow more people with this syndrome to gain a diagnosis and appropriate management of the condition.

Many individuals with Loeys-Dietz Syndrome are the first in their family to have the condition, and therefore it is likely to be underdiagnosed in the population.

There are four main characteristics often seen together in Loeys-Dietz syndrome, that are not typically seen together in other connective tissue disorders such as Marfan Syndrome. These are:

1. Aneurysms – an aneurysm is a widening or dilation of an artery. This is most often seen in the aortic root- where your aorta (the large blood vessel that carries blood from the heart to the rest of the body) meets the heart.
2. Arterial tortuosity- twisting or spiralling arteries.
3. Hypertelorism - widely spaced eyes
4. Bifid (split) or broad uvula- the uvula is the small piece of flesh that hangs down from the back of the mouth

However, not all patients with the syndrome will have all four of these characteristics, and people with the condition can have a wide range of symptoms. More information on these can be found at: https://www.loeysdietz.org/en/medical-information

Based upon the success of our Marfan Syndrome support group, we would like to create a support group for patients either diagnosed with Loeys-Dietz syndrome, or those who suspect they might have the condition. This group would allow people to reach out with any questions they might have regarding their condition, or to seek assistance with getting a diagnosis. We are also aiming to create patient webinars for our support group, to allow patients to speak to experts about Loeys-Dietz syndrome.

For more information on Loeys-Dietz Syndrome, there are several helpful resources. Examples include the Loeys-Dietz Syndrome Foundation Canada: http://www.loeysdietzcanada.org and the Marfan Foundation: https://marfan.org/conditions/loeys-dietz/.

If you have any questions regarding the support group, or if you have a diagnosis of Loeys-Dietz syndrome and would like to complete our questionnaire, please email annechildgenetics@outlook.com for further information.

SURVEY OF MORTALITY AND MORBIDITY IN MARFAN SYNDROME AORTIC SURVEY

Cardiac Nurse Mrs Rosalee Renamagboo (pictured) at St Bart's Health NHS Trust is about to commence a secondary data analysis using routinely collected data from the Office of National Statistics Hospital Episode Survey and the Healthcare Quality Improvement Partnership. She is not recruiting volunteers, but has contacted the Marfan Trust for permission to display a patient information poster to identify and reach out to potential MFS patients, only if they would like to opt out from her data collection. This is one of the requirements for data processing.

The poster has been approved by the Confidentiality Advisory Group for display on our website and in surgeries.

We hope very much that all our members who have had heart surgery are willing to cooperate to gather statistics around cardiac surgery, which will help improve care in the future.

Rosalee has also formed a Committee to look at the psychological aspects pre- and post- aortic surgery, and our patient representative is Darren McDean who has had aortic root and valve surgery. We are very grateful to him for participating to represent the view of our members.

Rosalee's results will be published in a future newsletter.

SONALEE LABORATORY | *by Dr José Aragon-Martin*

New Laboratory Arrangements: The Sonalee Lab has now departed from the Guy Scadding Building and moved to the Institute of Ophthalmology, next to Moorfield's Eye Hospital, London. Professor Mariya Moosajee will be hosting me in her laboratory regarding congenital eye disease. There, I will continue with dislocated lens (ectopia lentis) and congenital glaucoma projects. The lab have been very welcoming, and have already supplied me with an MSc student and a PhD student to help with these projects.

The cardiovascular research part of our programme (looking for mutations in genes for Marfan syndrome, thoracic aortic aneurysms, Ehlers-Danlos syndrome, Loeys-Dietz syndrome, and other connective tissue disorders) can also be continued at the Institute of Ophthalmology, if we do not find a separate laboratory for these projects. We have contacted St Bartholomew's Hospital which has a very strong interest in aortic aneurysm surgery, and a very active research department at the William Harvey Institute, Queen Mary's University. They are considering our grant supplication to British Heart Foundation, and if they have laboratory space, then they will co-sponsor this application.

By the time of the next newsletter, these arrangements should be settled, however, our plan is to continue our research programme to look at all these exciting disorders simultaneously.

The equipment donated to the Sonalee Laboratory over the years is going with myself to the Institute of Ophthalmology or to a second laboratory. It has been put in secure storage temporarily.

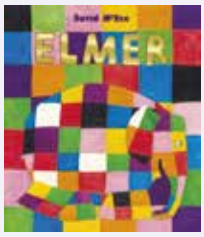
Thank you for your continued support. We cannot make progress in Marfan syndrome or related disorders without an active laboratory.

Bury Yourself In Books

Every child should feel seen in the pages of a book in one guise or another. Every child should feel represented and reflected. We invited our Trust volunteer and aspiring medical student Sophia to review a selection of books for the reading pleasure of our niche community.

Hi, I'm Sophia, one of the volunteers at the Marfan Trust. I am a student studying for my A-levels in hopes of pursuing a career in medicine in the future. My goal is to spread awareness about Marfan Syndrome and I am currently writing an essay for school on this topic.

In the meantime, I'm here to read some books. There are many fabulous insightful books which are a joy for both children and adults to read and which can help your child to cope with being different. Here are our favourites. Don't let the publisher's recommended age put you off – there is no upper age limit to loving these stories!



Elmer ★★★★★ £6.99 | Paperback: 32 pages

Publisher Recommended Age: 2+ | ISBN 9781842707319

Elmer is different from all the other elephants. He is patchwork, not grey. One day he tried to change to be the same, but the other elephants recognised he was special and celebrated this.

A wonderful, book with a happy, colourful elephant celebrating being different, guaranteed to brighten your day. More than 10 million copies sold. This is the first in a series of 29 books. Elmer even has his own day – May 28th!

The Colour Monster ★★★★ £6.99 | Paperback: 32 pages

Interest Age: 3+ | ISBN 9781783704231

Colour Monster's emotions were scattered all over the place. A little girl helps him collect his emotions into colours.

Fantastic book to teach children how to express and deal with feelings with the added fun of colour. This is a teacher's favourite. More than 5 million copies sold.

Ruby's Worry ★★★★ £6.99 | Paperback: 32 pages| Age: 3+

ISBN 9781408892152

Ruby was perfectly happy until she discovered a worry. It grew and grew until Ruby found a way to get rid of the worry.

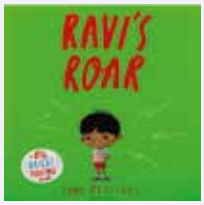
An uplifting story illustrating the importance of sharing feelings.

Perfectly Norman ★★★★ £6.99 | Paperback: 32 pages | Age: 4+

ISBN 9781408880975

Norman was perfectly normal until one day when he grew wings!

A lovely story encouraging children to be themselves and embrace who they are.



Ravi's Roar ★★★½ £6.99 | Paperback: 32 pages| Age: 4+

ISBN 9781408892183

One day Ravi did not control his temper, causing him to turn into a tiger! Being a tiger seems like a great idea at first, however, who wants to play with a growling, roaring, noisy, wild tiger?

Ravi's Roar is a clever book discussing temper tantrums also helping with bad days and noisy outbursts.

School Risk Assessment and Recommendations

Navigating the often-tribal path of adolescence is a hormone-fuelled rite of passage. It is a turbulent time of peer pressure and self-discovery, one that can be made harder when you stand out, literally, from the crowd, and have hampering physical issues. We were approached by the relative of a tall teenage student, B. B has Marfan syndrome. In response to B's difficulties in adjusting at school, the relative wrote a set of helpful recommendations, ones that will ease the path for 'B' to both study and socialise. This is an abridged version of the full document which can be found on our website: https://www.marfantrust.org/articles/school-risk-assessment-recommendations *Please do write in with any recommendations you may have of your own.*

Pupil specific proposed action plan to support school accessibility and attendance

This document could be used to feed into a formal School Education, Health and Care Plan.

Character description

B is a sensitive, kind, enthusiastic and highly intelligent young person. Focusing on and developing his strengths is likely to be the key to B's success at school. He also has Marfan Syndrome [definition]

B does not need an education support assistant but would benefit from a dedicated key coordinator.

The Marfan Trust has published a booklet for teachers. It is important for all B's teachers to read it https://www.marfantrust.org/pages/94-information-leaflets

Height, joint pain and vision:

Normal chairs and unsuitable desk heights do exacerbate discomfort.

Furniture tailored to suit B's needs in all his school rooms. Rise and fall desks and worktops might be one solution.

Because of poor vision and tall stature, he should sit near the front but at the side of the classroom.

Tiredness, headaches and pain

B is on permanent medication to reduce his blood pressure which increases tiredness and reduces stamina. **B would benefit from a discrete place to lie down and rest during the day when needed. He also needs** pain medication with him, in permitted quantities, to take discretely.

Digestion

B can sometimes experience discomfort from digestion and will benefit from eating more frequent, smaller meals designed to provide a balanced diet.

Psychosocial

B is having to come to terms with a host of issues affecting how he feels and functions, physically and mentally, as well as the prospect of future unknowns. At times B feels a need to withdraw from social contact when in a low mood and spend time alone.

B is also conscious of being much taller than his peers and can sometimes read innocuous comments by others as negative, resulting in low self-esteem. Having an adult on hand to talk to when this happens may help him. Non-specific conversations by teachers with other pupils which deal with bullying/teasing and respect for, and celebration of differences may help his peers to be more sensitive without singling him out.

It should be up to B alone to choose whether to share or discuss his condition with anyone.

B's height and advanced verbal skills lead adults to see him as older than he is.

Hypermobility and writing

B's hypermobile hand joints make it difficult for him to write and his handwriting is shaky. It is unnecessary for anyone to comment on this. Typing may be a good option for exams, homework and lessons. Time allowance should be made and when it comes to tests and examinations & formal application during GCSE's may be required.

Sport

B is very keen on sport but is often unable to take part for long or to engage in high impact or contact sport. Distance or cross-country running is not advised. Enabling him to play for shorter periods during a game or to become the commentator, may help him to join in when he is able.

Time off School:

B has to take time off school for very frequent medical appointments or when feeling unwell.

Medical emergency at school:

All staff including non-teaching staff must be aware of procedures for emergency including the nearest casualty department during school outings. See our Booklet for Teachers.

TO CONCLUDE

B is a normal boy with normal prospects for the future and should be primarily seen as such. With sensitive informed management from all concerned he should lead a happy and fulfilled school life.

Summary of recommendations

1. Part time dedicated coordinator/ communicator to ensure B's needs are met each day.
2. Remember to treat B according to his age despite his seeming older due to his height and verbal skills
3. Adapted furniture /equipment and position in relation to the whiteboard, wherever needed.
4. All staff to read this report and the Marfan Trust Teacher booklet for schools to increase understanding.
5. Respect B's wishes for rest or retreat and a place to do so.
6. Maintain a low-key approach to any adaptations to protect B's self-esteem.
7. B to manage his own medication discretely.
8. Support his need to eat smaller meals more often, some of which he could bring.
9. Be aware of his perception of being bullied due to his height, conduct generalised discussions with pupils to mitigate this and ensure that no member of staff inadvertently teases him or comments upon his height.
10. Have some key person with whom he can talk about his feelings regarding any incident if needed.
11. Be aware that B is not always comfortable with transitions which need to be handled sensitively. This is likely to be due to fear of being able to cope.
12. Ensure everyone understands that writing neatly is difficult for him and may be slow; help him to learn to type instead.
13. Focus on and encourage his strengths and interests.
14. Adapt sports lessons to enable him to participate part of the time if necessary and ensure he is not asked to run too far or do contact sports.
15. Ensure everyone is aware of the rare potential for medical emergency and familiar with the symptoms and necessary action denoted above, and in the Booklet for Teachers.

Fundraising Update *by Gurpreet Madan*

Two years ago, we re-started engagement at The Marfan Trust, we developed a strategy of how we were going to slowly build up the Trust's reputation and credibility. We focused on building relationships with supporters, letting them know they can count on us, introducing a variety of content to answer burning questions, educating people on Marfan syndrome through conferences and webinars and also raising awareness through Marfan awareness month so that the signs and symptoms of Marfan syndrome become more recognisable. We are happy to share that stage one is now complete and we will now be focusing on more creative ideas and innovation to ensure the Trust thrives!

"Creativity is thinking up new things. Innovation is doing new things."
— Theodore Levitt

This is our focus going forward but before we get into that, let's first look at all that we've achieved in the first half of 2022.

Key Highlights:

- Facebook Page has over 1,000 followers and likes
- Since June 2021, over 300 supporters have signed up to receive our emails
- Over 150 people have signed up to be members (Best friends and Family friends)
- Marfan Awareness Month – Lots of supporters shared their stories, downloaded our PDF to take to their doctors, shared our stories on social media and made donations
- Following on from Marfan Awareness Month, we launched our first in-house fundraising campaign, "Stand Tall in April". We are thrilled to see so many people sign up to choose and complete an activity they are comfortable/passionate about whilst raising money for The Marfan Trust
- Launched our first webinar of 2022 - PEARS and secured over 28 sign-ups thus far see page 15.

Plans going forward:

- Survey is being conducted to understand our supporters views so that we can better help you (enclosed to this newsletter). The findings will be shared in the next newsletter
- Sending out trust and grant applications for funding
- Speaking to businesses about advertising in our Newsletter
- Planning for October 8 conference

Can you give us a hand?

- **Attend our Events**
  Lend your support and partake in Marfan events – whether that's attending our seminars, conference or virtual events
- **Donate, donate and donate**
  Donate to the Marfan Trust– this can be a one off donation or a monthly standing order.
- **Endorsement**
  You can support us by tapping into your network by recommending us to your Company as their Charity of the Year partner or why not speak to your child's school about fundraising for us?
- **Ad space**
  Ask businesses to take out an ad space in our Marfan Matters magazine and website. For more information, email Gmadan@marfantrust.org
- **Help us spread the word**
  Post on your social media accounts with the hashtag #MarfanTrust or alternatively send stories/videos of how Marfan Trust has helped you to info@marfantrust.org

With your support, we could make a massive difference to the lives of those affected by Marfan syndrome and their families. Thank you for supporting The Marfan Trust.

Membership Update

"Once my foster daughter was diagnosed I didn't know where to turn but Marfan Trust have been invaluable in giving me factual accurate information and preparing me so that I am able to let her lead her best life and to live with Marfan." | *Jessica Hart*

If you are not yet a Best friend/Family Friend, why not consider becoming one? As a member, you will receive our fabulous content (weekly case studies, articles, blog posts), Bi –annual newsletters, 4 PDF versions to Marfan Trust's advice pamphlets and discounts on our events. You will get all of this and more for a small monthly donation of £3.

A year's membership fee, **£36** will enable us to respond to 2 additional calls received by the Helpline. Please sign up today to ensure those affected by Marfan syndrome receive the support and care they deserve.

Join our membership scheme to be part of a growing community of Marfan friends who will support each other and spread awareness. If you would like to register, please email Gurpreet Madan at Gmadan@marfantrust.org

In Memory

Jean Alexander

Jean was a long-standing, loyal and committed member of the Marfan Association and Trust. We were very sad to hear of her death earlier this year. Not only a well-liked member of our Trust Jean was also a very popular member of the Ladies Oxford Golf Club who have donated very generously in her memory. We offer condolences to all those who knew and loved her.

George Franks-Herbert | *by his parents, Diane and Peter*

George was diagnosed with Marfan Syndrome at birth due to his family's medical history. Both his sisters and his father have Marfan Syndrome, his father having undergone numerous successful operations to repair his aorta and heart valve. George was monitored carefully by the Cardiac team throughout his lifetime but sadly passed away suddenly and unexpectedly due to aortic dissection at the age of 18.

George enjoyed singing, acting and dancing and attended Stagecoach Theatre School in Bridgend since he was 4 years old. He starred as a body double in Casualty and alongside Eva Longoria, Jack Whitehall and David Suchet in the BBC production of Evelyn Waugh's 'Decline and Fall'.

He was passionate about football and supported Leicester City football team, like his father. He played for Pontypridd Town for many years.

George was in his second term at Bristol University studying Biochemistry. He was doing incredibly well and had achieved 1st class marks in his Pharmacology and Biochemistry exams, which he had worked hard for over Christmas. Unfortunately, he never got to find this out.

Aside from being incredibly intelligent, George was kind, caring and extremely thoughtful. He will be missed very much by all.

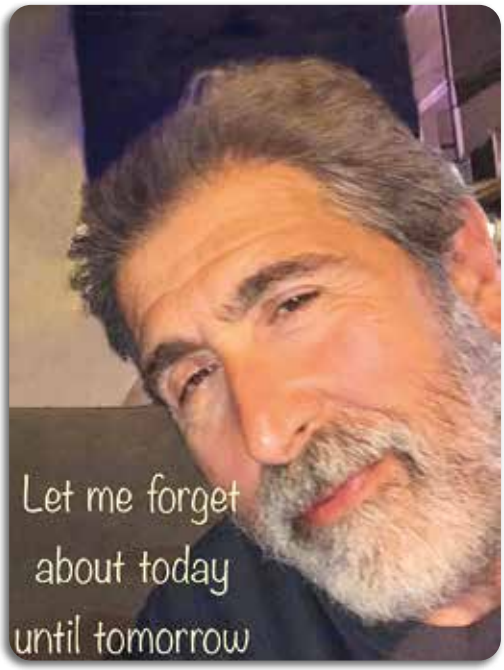
George's family have raised over £5,000 in their son's memory for our Trust. Thank you.

David Wilford

David Wilford | *by his son, Paul*

Our much-loved dad, husband and grandad, David Wilford, sadly passed away from Marfan syndrome on Saturday 9th April 2022. Dad has waged war against the disease since the 1990s - and defied the odds by surging way into his 70s - successfully battling through several epic operations along the way. Despite the many challenges Marfan Syndrome presented, Dad didn't let it stop him leading a happy and healthy life for the majority of the time!

In memory of his father, Paul has raised over £700 for our Trust, and wears his Marfan Trust t-shirt with pride (pictured).



Giuseppe Mare, 16 September 1956 - 1 July 2020

by his wife, Giusy

Giuseppe completed his accounting studies in Italy with honours.

A comrade, he engaged at a very young age in the socio-political struggle of the 1970s in the Italian area where he was born. Then, for a multitude of reasons, he emigrated to London in 1983 where he lived for the last 37 years of his life, while always remaining true to his principles and his political belief, which have always been on the side of the needy in society.

For all those who knew him, he was a cultured, clean and sincere man who has proudly devoted himself to standing up for the rights of the less well off.

Giuseppe was a diligent and very present partner in life, or even, often demanding and difficult, but always and in any case loyal. Being with him meant knowing where you stood. He has been precocious in life for many respects, as he has been in his death.

He had a health process that was nothing short of 'challenging', when I think about it I realise how many times he risked his life, but he always faced everything with irony and a pinch of unconsciousness because he had to. During life, Giuseppe had four eye operations to replace his dislocated lenses; he had a prolapse of vocal cords, hernias and a couple more operation. I remember the time when, waking up from another anaesthesia, the nurse asked him if he needed something and with his typical joking tone, he said 'can I have a glass of champagne please'.

Unfortunately, life reserved a cruel joke for him, taking it away too soon. He was affected by the Marfan syndrome unknowingly for a long time, Marfan was only discovered when he was around the age of 40 and after a few episodes of 'faintness', doctors found he had a Mitral valve prolapse, an enlargement of the aortic artery and a bicuspid aortic valve. He underwent open-heart surgery in 2008, the largest operation so far; for the next 12 years' his heart deteriorated progressively until he gave up fighting in July 2020.

He was interested in everything: from classical culture (he read his copy of the Peloponnesian Wars so much that the cover is completely ruined) to pop culture (you could see him watch the Vampire Diaries!). He cited Dante as much as TV advertisements. A carousel of knowledge, he sang Mozart's 'Figaro' to his daughter and they argued over mathematics and laughed while playing cards.

Having spent the last ten years working for a non-profit organization, he tirelessly fought for the rights of the most disadvantaged in society to ensure they were not trampled on, by an increasingly unfair system that is defrauding the people of essential rights. Proud of defending 'his clients' in court, where he was able to win all the disputes he brought on - honour to him. A large number of his 'customers' showered me with floral tributes and 'cards' with comments of praise about him that moved me to tears. It is clear from their comments, the person he projected with them.

He was in love with Bob Dylan and his motto *"Let me forget about today until tomorrow"* from Mr Tambourine Man I have inscribed on my favourite photo of him…

Feats Of Fundraising

Whether testing the limits of stamina and spirit, climbing Wales' highest mountain, crocheting for a cause, or fishing in fancy dress, the following fundraisers have achieved fantastic feats for the Marfan Trust. Celebrated here are just a few of our amazing supporters. Please send your fundraising story to info@marfantrust.org and we will gladly celebrate you.

Lucy's Lucrative Raffle

Eternally creative, Lucy Atkinson is an indispensable member of our Trust. She contributes in so many ways, from her treat-filled raffles to her candid popular blogs on everyday life with Marfan syndrome. Lucy also contributed her hands to our Awareness Month Campaign, demonstrating so helpfully the classic signs of Marfan syndrome. *Lucy's recent raffle made nearly £100 for the Trust.*

Sam the Superhero

Weaving superheroes into the fabric of her everyday life, Sam Glover has been crocheting for a cause. She has created blanket after blanket (pictured) as raffle prizes with money going to the Marfan Trust. Sam is 31 years old with two cats and a zest for life. She crochets in her spare time and has recently raised over £200 for us. Thank you so much!

Ladies Night!

A loyal member of our Trust, Marfan patient Derek Goodger regularly donates to the cause through creative initiatives at his local Masonic Lodge. Recently, and ironically, the Lodge staged a Ladies Night in aid of the Marfan Trust. Tables were adorned with our leaflets and Derek and his wife wore our t-shirts as they educated their large audience on Marfan syndrome, spreading the word far and wide. Over £1000 was gathered for the Trust. Thank you, Derek and Doris.

Sean Hershaw is Unbreakable!

Testing the limits of his spirit and stamina, Sean has emerged unconquerable from the Spartan Challenge, undertaken for our Trust! The Spartan Race is essentially an obstacle race, and it is not for the fainthearted. Sean has completed all four of his challenges, muddied but triumphant whilst his exploits have been followed by many on social media. As he was nearing the finishing line, Sean said:

-"I can't put into words how grateful I am for people's generosity and support. Today we reached £1000 raised for **@MarfanTrust** through **#Spartans4Marfans** this coupled with £122 gift aid, and a £250 company fund match to be approved, gives a total of just under £1400.
- The first 2/4 **#Spartans** 4 **#Marfans** completed for my fundraiser for **@MarfanTrust** were smashed this weekend! Top 50% in the **#SpartanBeast** and top 20% for the **#SpartanSuper!**

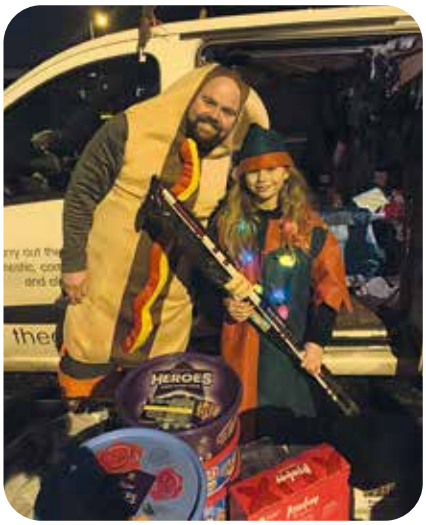
Offline donations yet to come in but nearing £1000!" Sean does not have Marfan syndrome but someone he cares about does. We are eternally grateful to him.

Feats Of Fundraising

Sharon Braved the Shave!

Sharon Johnson braved the shave for the Marfan Trust, losing her lovely red locks and baring her head to raise much-needed awareness of our condition, and gratefully received funds for our Charity. Thank you so much, Sharon! You're a star and you rock a shaved head.

Sharon's hair-cut raised over £800!



A Festive Fish-Off! | *by Karl Nicholls*

My wife has Marfan syndrome, as does my little girl. My wife recently had open open-heart surgery at Broad Green Liverpool so I thought how can I raise a bit of money for the Marfan Trust. I am a big angler and I organised fishing matches. On the 30th December 2021 I organised a charity match at Wirral Beach Angling Association called Santa Fish-Off where everyone had to fish in festive fancy dress for the Trust. I am proud to say we have raised £750!

Minchinhampton Charity Day | *by Alistair Thompson*

My granddaughter aged eight has Marfan syndrome and is undergoing continual investigations and treatment. If it wasn't for her, I wouldn't be aware of the condition.

Minchinhampton is one of the largest (by membership) golf clubs in the country with three courses and over 1700 members. The Old Course was opened in 1889 and two new courses which were created in 1974 and 1995 respectively.

Minchinhampton was one of six clubs which met in 1892 to set up the English Ladies Golf Union. A link to the club website is www.minchinhamptongolfclub.co.uk

In 2021 I was appointed Club Captain and chose Marfan as my Captain's Day Charity which was extremely well supported, as the money raised (£2,000) indicates. There were some smaller events and I chose to gift a number of raffle prizes and on the day gifts which is how my own contribution was included.

Climbing for a Cause | *by George Wallace*

I'm George, I'm 13 years old and I am going to be climbing Mount Snowdon in the hope to raise lots of money for the Marfan Trust! I enjoy playing football, Lego, and Star Wars. I suffer with travel sickness, I'm scared of heights and don't like long walks, WHY AM CLIMBING A MOUNTAIN? Because it's for such a worthwhile cause, and I wanted to do something that I wouldn't necessarily enjoy but would really challenge me. I have a 12-year-old cousin who is funny, kind and super bright, she has Marfan Syndrome. The way she copes with living with Marfan every day is absolutely amazing! She's had to have operations and goes to so many hospital appointments and still remains happy, upbeat and generally pretty cool. I moan about going to the doctors! Seeing how strong she is and her courageous attitude has inspired me to want to raise as much money as I can to support and raise awareness for the Marfan Trust.

Thank you!

Professor John Pepper is a long-time supporter of the Marfan Trust, and we are extremely grateful to him for helping us find a new direction and stability after leaving St George's University of London in 2019. It was due to his influence that we found accommodation in the Guy Scadding Building, beside the Royal Brompton Hospital. He has also introduced us to his network of clinicians and research-workers at the Royal Brompton and Harefield Hospitals.

Professor Pepper is the Interim Director of Research and a Consultant Cardiac Surgeon based at the Royal Brompton Hospital. He trained at Cambridge University and Guy's Hospital, followed by training in cardio-thoracic surgery at the National Heart Hospital, London Chest Hospital and Guy's Hospital. He was a Consultant Cardio-Thoracic Surgeon at London Chest Hospital and St George's Hospital before moving to Royal Brompton Hospital.

In 2015 he was awarded an OBE for services to heart and lung surgery, in Her Majesty the Queen's Birthday Honours. His current research activities are focused on the development and promotion of an external support, specific to the individual patient with Marfan syndrome, known as the PEARS (personalised external aortic root support). He has travelled the world teaching this technique and has lectured to the Marfan Patient Support Group at our Annual Patient Information Conference on this topic.

Professor Pepper has always been accessible to us, for answers to questions from our patients through our helpline. His enthusiasm for teaching and supporting patients, and the Marfan Trust, has no bounds. We hope to continue working with him for many years.

Professor Edwin Chilvers is Professor of Medicine and Head of the National Heart and Lung Institute (NHLI) at Imperial College London. When we left St George's University of London in 2019, he very kindly offered to host us, both office and laboratory, at the Guy Scadding Building, Dovehouse Street which is directly opposite the Royal Brompton Hospital. COVID struck, and our one-year planned tenancy stretched to two and a half years. We are very grateful to Professor Chilvers for giving us this opportunity to consolidate the Marfan Trust, hire new staff, expand our membership, plan future grant applications and write research papers. We are now moving to new facilities, but are very grateful to Professor Chilvers, his staff and the reception at the Guy Scadding Building which made us feel we belonged during that period.

The Girdler's Charitable Company

Once again, we are grateful to the Girdlers' Charitable Company for responding to our request for funding towards the bridging salary of our molecular geneticist, Dr José Aragon-Martin. As he moves his laboratory to the Institute of Ophthalmology, he had a salary gap which needed to be filled to enable him to continue working during this period. A donation of £3000 to the Marfan Trust from the Girdlers' Charitable Trust, the Jock French Charitable Fund was voted on the suggestion of our good friend Major General Sir Sebastian Roberts KCVO, OBE, their Master Girdler.

We continue to be very grateful for their continued support and will acknowledge their support in present and future publications as well as presenting them with a copy. Without their help our research programme would not be the success it is today.

Questionnaire Alert

Since our merger with the Marfan Association in 2019, the Trust has been busily evolving. Uniquely placed as the only charity in the UK devoted to Marfan syndrome, we have been growing our community of supporters and expanding our newly introduced membership. And as we continue to evolve at an exciting rate, we want to be sure we are heading the right direction! Hence our first ever survey which gives you, our supporters, a voice and a say in the future steps our Trust will take. It will help us to help you. Please do participate if you can. We enclose a paper version for those who prefer the tactile nature of paper and post. Or, more simply, you can scan the QR code above and be swept immediately into the survey.

Marfan Key Rings!

Enlivening our webshop with her crochet, Dominique McDean has been making practical pretty by creating keyrings in our emblematic heart. Order yours now! They cost just £3.50 and proceeds go to the Marfan Trust. See back page for details.

Dominique originally started this enterprise for Ukraine. It proved so popular she spent hours frantically replenishing her fast disappearing collection, while expanding it for the Marfan Trust. Dominique's husband Darren has Marfan syndrome and she crocheted a worry worm for him as he underwent surgery last year. These cute little wiggly worms are on sale too for anyone who needs something tactile to cling to when worrying.

Thank you, Dominique!

A Zest For Life

To Whet Your Appetite!

Before he died at 23 of undiagnosed Marfan syndrome, Wayne Johnston was a professional chef. He left behind a wonderful son, a gorgeous family, and many tantalising recipes. Containing a trove of his most delicious dishes, A Zest for Life is a tribute to Wayne, capturing his natural ebullience and exuberance through his flair for food. Blending economy with creativity, this is the perfect cookbook for those who love taste on a budget, with proceeds going to the Marfan Trust. All hail our culinary adventure (see back page to order).

PEARS Webinar

Getting to the heart of the matter, PEARS pioneer Tal Golesworthy discussed his revolutionary invention in an illuminating lunchtime webinar on Thursday 12 May. Tal also took questions. It was a lively event with much discussion and debate.

PEARS (personalised aortic root support) is a new approach to the surgical management of the dilated aorta and arose from Tal's own need for the device when his aorta was expanding dangerously in the early 2000s. The first patient to be implanted with his invention, Tal can happily report that over 500 patients have subsequently and successfully benefited from his ExoVasc Aortic Root Support.

The webinar is on sale for £5.00

https://www.marfantrust.org/pages/32-shop

Marfan Information Day: Saturday 8 October 9.30am – 4.30pm

Informed by our Helpline, this year's Information Day emphasises children's needs and the management of pain. More than ever, parents are asking us to help their children navigate problems at school and our special speaker will give tangible tips based on lived experience. Meanwhile, we have invited Mr Marios Papadopoulos to discuss the management of dural ectasia, surely the most painful of Marfan syndrome manifestations.

Tickets on sale: https://www.marfantrust.org/events/marfan-information-day

Highlights from our Provisional Programme Include:

Update of PEARS Procedure from Worldwide Experience: Tal Golesworthy, Engineer & Inventor

Management of Dural Ectasia: Mr Marios Papadopoulos, Consultant Neurosurgeon, St George's University Hospital London

Management of Pain: Dr Fairiborz Neirami, Consultant in Pain Medicine, King's College Hospital London

Orthotic Management of Ankle/Feet: Dr Paul Stodart, Orthotist

Children With Marfan Syndrome: How to Navigate School: Speaker tbc

Turn Old Postage Stamps into New Money

Pauline Moses continues to sell used postage stamps to dealers, in doing so raising money for the Marfan Trust. Pauline and her husband, the late Raymond Moses, have made a veritable fortune for the Marfan Association and Trust through their initiative. If you are able to cut out and collect used stamps from envelopes, please send them to:

Mrs Pauline Moses
The Waves
Coast Drive, St Mary's Bay
Romney Marsh
KENT TN29 OHN

Shop | www.marfantrust.org

Welcome to our Webshop, newly adorned with our Zest for Life Cookbook and Crocheted Key Rings.

A Zest for Life Cookbook


Heart Keyring


Worry Worm Keyring

Marfan Trust Emergency Card


Marfan Trust Wristband

Marfan Trust Pin Badge


Marfan Trust T-shirts


Marfan Trust All Occasions Card


Christmas Card Robin on a Snowy Branch


Christmas Card Three Kings of Orient


Christmas Card Song of the Angels


Christmas Card Snow on the South Bank

Response Slip (this can be photocopied)

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

Name..... **Address**.....

..... **Postcode**.....

Email.....

Please include cost of postage (a flat rate of £3) in sum total. Christmas cards - Robin on a Snowy Branch, Three Kings of Orient, Song of the Angels, Snow on the Southbank - and All Occasions cards are in packs of 10.

Item	Price	Quantity	Total Cost
A Zest for Life Cookbook	£6.00		
Heart Keyring	£3.50		
Worry Worm Keyring	£3.50		
Marfan Trust Emergency Card	£2.00		
Marfan Trust Wristband	£2.00		
Marfan Trust Pin Badge	£2.00		
Marfan Trust T-shirts	£5.50 (each)	S..... M..... L..... XL.....	
Marfan Trust All Occasions Card	£4.00		
Robin on a Snowy Branch Card	£4.00		
Three Kings of Orient Card	£4.00		
Song of the Angels Card	£4.00		
Snow on the South Bank Card	£4.00		
Postage cost	£3.00		
SUM TOTAL (including postage)			

☐ I am eligible for Gift Aid:
(please tick if relevant and leave name and address above) **Signed**..... **Date**.....

And don't forget feel-good shopping! Shop at smile.amazon.co.uk and donate to the Marfan Trust at no cost to you. Get started!

amazon

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Registered Charity Number:328070

Marfan Trust, 24 Oakfield Lane, Keston, Kent, BR2 6BY **E: info@marfantrust.org**