



REGULAR FEATURES

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Chairman

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Special!

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SPECIAL FEATURES

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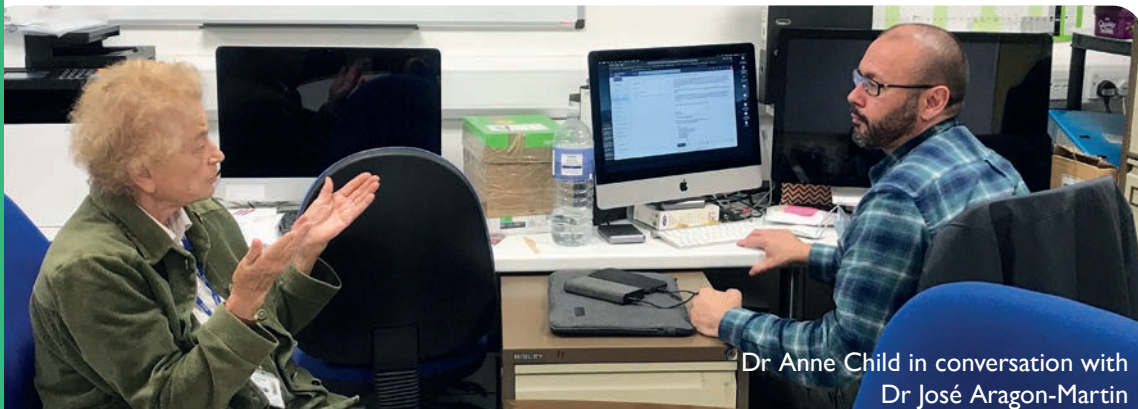
Marfan Trust
Information Day

Marfan Matters



Marfan Trust

Supporting Research into Inherited Aortic and Related Disorders



Dr Anne Child in conversation with
Dr José Aragon-Martin

Welcome to our Spring/Summer 2021 Edition

A dark protracted lockdown has given way to birdsong, blossom and hope. Spring has sprung! Life is unlocking, shops are filling, and the Marfan Trust is growing. Growing our community of supporters. We are still basking in the afterglow of a very successful **Marfan Awareness Month Campaign** when we made many new friends and spread the word nationwide! With your energetic engagement and creative support, we threw the spotlight on our syndrome and our **Search for the Missing 15,000** [page 5] is reaping results.

And, as we expand, we would like to make our friendship with you 'official', by inviting you to become members [page 11]. Be our best friend and you will have exclusive access to a bespoke trove of information on our **new, easier-to-navigate website** [page 10]. Finally, in our brave new world where masks remain relevant, we have launched the new face of fashion – **Marfan Trust face masks**. Reusable, they can be worn again and again, showing the world that **Marfan Matters!**



Medical Student Mohamed Abdelrazek initiated the COVID-19 study

Breaking News:

While researching the effect of COVID-19 on our unique Marfan community, an exciting discovery was made ... skip to page 7 for details!

A Remote Word from our Chairman, Michael Heath

I know that so many of us enjoy a conventional newsletter and it a real pleasure to be again writing to you in this, our spring 2021 edition. That said, have you seen our upgraded website? It's coming along terrifically and you can catch up with the fascinating news items that the Marfan Trust team have published, many of them from contributions you have made in response to the weekly Marfan Mondays and Dr Child's Casebook, bulletins. Wow, I feel the team are now packing a punch. This was really evident with the great success for the Trust with our online communications during February, the Marfan Awareness Month, with Victoria's video montage leading the way of involving you, our supporters, during the lockdown winter. On that note, whilst I am trying not to mention the pandemic too much I must suggest you visit the online shop on our website and check out the 'Marfan Trust Mask' surely a must for us all.

Unfortunately, my plans for consulting with you on what you want from the Marfan Trust are delayed but I do hope that we will soon be able to do this. However, as mentioned we are now rolling out our new website, and membership is arriving this summer on 22 June. Whilst we are maintaining a Board of Trustees as the Governing Body, having an inclusive membership will bond our Marfan family, ensure we can contact you and welcome your comments and contributions as well as being a proven and steady source of income for the charity.

We will soon be saying a fond farewell to our Treasurer Katherine Goodman after nearly five years of brilliant service during some challenging times. I am sure that I could not have got through them without her commitment and professionalism as our Trustee Treasurer. A huge thank you to Kat and her family for her service to the Trust; we wish her well in the future. If you are thinking how you might support the Trust we will soon be actively recruiting new trustees. We will set out the expertise needed and the 'job description'. You may well be surprised to find you have the skills we need and feel you can volunteer three years or more as a Trustee.

As mentioned I am thrilled that our staff have now gelled together to deliver an exciting Trust. I hope you agree that we are presenting a wide variety of relevant topics for us all who are affected by Marfan syndrome and the Trust continues to inspire your continued support. For it is only with your donations, individual or group fundraising activities, that the Marfan Trust will continue to provide support, research and education.



Farewell Katherine, and Thank You!

Calmly assuming the integral role of Trustee Treasurer in 2016, Katherine 'Kat' has since helped the Charity through momentous transitions, physical and structural. In our move from St George's Hospital to Imperial College, we became an employer for the first time, and Kat our de facto HR officer. And in merging with the Marfan Association, there were the attendant financial implications, all managed brilliantly by Kat. And all whilst managing over £1bn of costs for British Airways! But good things come to an end, and Kat is moving on in her career and in her life. At just 32 she's successfully balanced Trustee Treasurer responsibilities with a finance role at BA and, prior to that, a position in the City.

Kat has Marfan syndrome and her diagnosis was as sudden as it was surprising. It happened during her mid-twenties, in 2015. In preparation for a 3-month work secondment in Australia in 2014, Kat went for a routine GP appointment and mentioned heart pains, not knowing it was a prelude to a reality redefining revelation. While her friends were colonising precious tent space at Glastonbury, Kat went for the urgent echocardiogram at the local hospital, organised by her GP. When told that the Consultant would be called to look at the scan: "I knew it must be something more serious than I had anticipated. My aortic root was dilated to over 7cm and I was admitted immediately to hospital, transferred to St George's Hospital the next day and underwent open heart surgery the following morning. The operation was a success and the following year, through genetic sequencing and physical review, it

was confirmed that the cause was Marfan syndrome. This was both a shock and a relief.

I have many of the physical characteristics but had not been noticeably impacted from the syndrome prior to this event, having skydived in 2009, ran a half-marathon and played in sports teams throughout my life. In 2016 I underwent another open-heart surgery and during my recovery organised a charity ball, raising over £8,000 split between the Marfan Trust and the St George's Hospital Charity. I wanted to get more involved in the Marfan Trust and the stars were aligned - the previous Treasurer was looking to step down, and I promptly joined. However, having had an ischaemic stroke in 2020 I am stepping down to focus my spare time on my health and wellbeing, whilst also continuing my career." *Visit our website for full interview with Kat.*



A Word from our Trustee, Carol Gill

Since losing her partner Robert Clayton Turner over twenty years ago to Marfan syndrome, Carol has tirelessly and creatively campaigned for the Marfan Trust. At Robert's funeral, Carol requested that donations be given to the Marfan Association, raising over £3,000. And she has continued raising significant sums since then, for both the Association and the Marfan Trust, through her lucrative games of bridge. Around seven years ago Carol was invited by the Marfan Trust's then-fundraiser Shannah Adams to make her relationship with the charity official, by becoming Trustee. And over these past few years, Carol has been instrumental in the Trust's merger and current status as the only charity in the country dedicated to improving and saving the lives of those with Marfan syndrome. But with new status comes new responsibility and Carol feels that new blood is needed amongst the Trust's Board. "We need new niche knowledge to help the Trust continue to grow and make the right decisions.



We need to fill voids in the current board and are looking for specific skills. Please read on and wonder to yourself, do I have these skills and do I wish to join the Board?"

TRUSTEES NEEDED! JOIN US!

Poised for exciting times, the Marfan Trust is a small charity making a big difference, an indelible difference to the lives of those affected by Marfan syndrome. Founded in 1988 by its current Medical Director Dr Anne Child, the Trust has evolved through a series of distinguished accomplishments, from forming the consortium that identified the Marfan gene, and creating an internationally acclaimed laboratory, to establishing a helpline offering direct access to specialist knowledge. We are niche charity of great consequence with global clout. And we continue apace. Since our merger with the Marfan Association we are now uniquely placed as the only charity in the United Kingdom concentrating on the syndrome. We are also embarking on a new chapter, becoming a membership organisation and expanding our community of supporters.

With new exciting status comes new serious responsibilities. Our Board of Trustees has looked long and hard at itself, in doing so identifying several gaps in its pool of knowledge Gaps that must be filled in order to effectively support, steer and oversee this small and significant Trust. Specifically:

- A Fundraising Guru: can you open doors to prospective supporters and donors. With COVID-19 there are fewer than ever pools of money available. We receive no

government support but rely purely on the goodwill of our community. We need your powers of persuasion to develop relationships with commerce and grant-makers to help keep our laboratory and helpline alive.

- A Clinical Researcher: do you have the experience and expertise in the esoteric area of clinical research to help oversee the life-saving work of our precious laboratory?
- A Clinician: would you like to enhance and oversee the increasingly valuable medical advice dispensed by the Trust?
- A Treasurer: essential to any charity is the person overseeing its finances. Are you a chartered accountant with the acumen and ambition to become our trusty treasurer?

By filling these gaps, you will be guiding the Trust through our next new exciting chapter, making a tangible difference to an important community. You will be writing for our twice-year newsletter and attending our quarterly meetings. Your voice will be heard. Become our essential Trustee!

Visit the Vacancies Section on our website for further details.

Anecdotes and Antidotes: Supporters' Corner

Our gossipy new series, Anecdotes and Antidotes, discards the doctor's textbook and puts you, the supporter, in the consultant's chair. Your words of wisdom and gems of advice have recently been filling our helpline. We want to share and air this precious material publicly, for no one knows Marfan more intimately than you. We've gathered a trove of top tips which we'll dispense on the last Thursday

of every month. So, if you're feeling disconnected, literally (Marfan joints) or figuratively, step this way! Our inaugural episode is an antidote, a peaceful poem from **Val Greatorex**; offering words of solace when confronted by a world of Marfan medecalese. Let's get gossiping!

LIVING WITH MARFAN SYNDROME

So often we wonder what life has in store
The future is hazy, vague pictures we draw
Sometimes gloomy and hopeless, then hopeful, less dim
Yet always uncertain, not knowing is grim

We listen to stories and try to explore
All pathways of happenings to others, not sure
That perhaps indications might lead us to think
This could happen to us, so let's panic and shrink

Do stay open minded, let order prevail
Our syndrome can vary, not fixed on a trail
We are different, yet similar, this is the key
So let's trust in the future, and just wait and see



Val Greatorex

Val Greatorex

Marfan Awareness Month Campaign

by Victoria Hilton and Gurpreet Madan

In a cluttered world of competing causes and general noise, awareness can be stretched and diluted. February 2021 marked our new team's first Marfan Awareness Month and we were determined to focus the spotlight firmly on our syndrome. Our four-week campaign was fuelled by a sense of urgency, the urgent need to **find the Missing 15,000**. With 3,000 Marfan patients known to the charity, we estimate there are a further 15,000 in the United Kingdom unknown to us, and their condition unknown to some of them. There's a life-threatening gulf between early and late diagnosis, and this stark fact lit the fire of our awareness campaign.

Emblematic of the life-saving need for timely diagnosis were three supporter stories that resonated far beyond our community. We are immensely grateful to Christopher, Lewis, and Natasha for sharing their experiences. And thank you to Professors John Pepper and Graham Stuart whose clarion call for greater awareness was widely watched in our campaign film **The Professor Perspective**. Concluding the month was our 'film trilogy' starring our supporters. No one speaks more eloquently of Marfan syndrome than folk affected by the syndrome, and Christopher (again); Charlotte & Amiyah;

Joy; Helen & Laura; Lucy, and Michael gave compelling insight into life with the condition.

The campaign reaped tangible results. Surges across our social media pages and the helpline kept the team extremely busy! Calls to the hotline increased by over 50%; Facebook page likes and followers by over 200%; tweets and tweet impressions by over 50% with an increase of over 100% in profile visits whilst website traffic soared exponentially with 3000 hits. On a pro bono basis we partnered with **prestigious PR gurus Freud's** who broadcast our campaign on 221 radio stations across the country, reaching an audience of over 24,000. **We spread the word!**

Opportunities to identify MFS exist everywhere in everyday life, from GPs and dentists to shoe shops and opticians. Help us #FindtheMissing1500: <https://www.marfantrust.org/articles/category/32-fundraising-campaigns>



Supporters' Video



Professor Perspective Video

Helpline ... A Lifeline

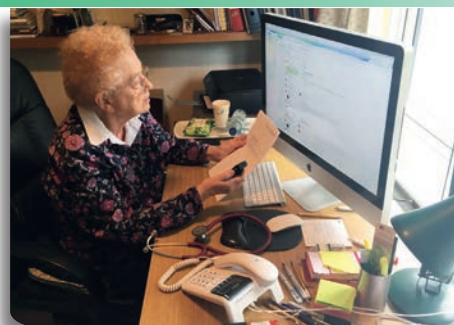
by Dr Anne Child & Victoria Hilton

Operating seamlessly and ceaselessly during the pandemic, our Helpline is a port in a storm. A readily available source of comfort, clarity and rarefied medical knowledge. Increasingly busy, it has received over 240 calls since June 2020; calls that were disparate in nature, reflecting the variability of Marfan syndrome. While largely from the UK, patients also contacted us from France, Sweden, The States, Pakistan and Iran, showing that we're a niche helpline with global reach! Amongst the assorted enquires one theme dominated, the need for a definitive diagnosis of MFS, or a similar connective tissue disorder. This continues the momentum of our awareness month campaign, edging us closer to finding the **Missing 15,000**.

Of the 240 calls, **18%** were from those seeking clarity on their condition and a diagnosis. COVID and vaccine-related worries constituted **10%** of enquiries whilst a further **10%** needed to discuss matters of the heart. Pectus chest abnormalities, scoliosis, metatarsalgia, dislocations and other skeletal manifestations of MFS were common problems whilst the paediatric care of Marfan syndrome also featured. Advice was sought on the eye and the intrinsic value of surgical intervention, and guidance was sought on pregnancy and the attendant aortic worry. It's good to talk and some patients simply wanted to do

that, discuss their condition in general terms. Medical advice sometimes gave way to practical tips when several supporters sought guidance on how to obtain insurance and mortgages.

Adapted every Wednesday into Dr Child's Casebook, our Helpline has started a **conversation between our supporters**. **Peer-to-peer support** is invaluable and something we hope to offer more regularly. **A recent Casebook Why Me? prompted a mutually beneficial encounter between two parents and their young daughters!**
Read on ...



Dr Anne Child



Victoria Hilton

Continued on page 6

J:

"I cannot tell you how wonderful it was yesterday for my daughter to connect with D's daughter. The girls chatted for 2.5 hours despite being 3 years apart in age, and I cannot tell you how happy it made A knowing there was someone out there in the world that is similar to her! It has also been great talking to another parent about our worries and concerns and again knowing what it is like and how best we can support each other.

It made me realise how powerful it can be for children and parents too to be connected and chat about how this syndrome makes them feel, I would love to try and help further with this area of connecting and chatting to people who might feel in need of support! If there is anything I can do please let me know, and in the meantime many thanks for connecting us!"

Research Report

by Dr José Aragon-Martin

Lockdown has meant 'heads down' for Drs Child and Aragon-Martin who have worked solidly during this global pandemic, setting the scene for future exciting projects while making an exciting discovery in the meantime.

News Flash

On 14th December our precious DNA samples collected over a 30-year period from willing volunteer patients, were at last delivered from St George's University of London, and installed in our new Sonalee lab at Guy Scadding Institute. We can now commence the several projects planned for our 2021 research programme which are based on these samples!

Research Update Research in Sonalee Lab

This academic year 2021-2022 we are going to supervise two Imperial College MSc student projects (June to September 2021) to analyse NGS (Next Generation Sequencing) data on TAAD (Thoracic Aortic Aneurysm and Dissection) and hEDS (hypermobile Ehlers-Danlos syndrome) to find genetic biomarkers that might be causing these conditions:

1. Qasim Mansoor Ashraf will be working on TAAD family 1
2. Lauren Lau will be working on TAAD family 2

This connective tissue condition shares clinical features with Marfan syndrome (MFS) and finding more about its genetic markers will allow us to understand better MFS.

We will be supervising Husnaa Fathima Ali Azamathullah Khan (Queen's University Belfast), for one of the summer studentships starting late in June 2021 with a project



Transporting Our
Precious Samples



title: "Review of the Genotype-Phenotype associations in Marfan syndrome". We are very excited to have a summer student working remotely on this topic that is just starting to expand, so we can understand better what is known so far in the relationship between genotype and phenotype in Marfan patients. We are speculating that not just the position of the amino acid in the FBN1 protein but the type of amino acid that has been exchanged is the cause for the difference in clinical features. This work will open a clear understanding for future research on this topic.

We are having a summer volunteer (1st year medical student Imperial College – Rohan Bhupal) starting in June 2021 to help us with bits and pieces in the lab. He will be a very much-needed pair of hands in the lab.

Research Manuscript Publications

Good news! The scoliosis paper has been granted publication status and it will be online very soon. The gene TTLL11 is the 2nd gene associated with scoliosis, hurray! A second paper on scoliosis is scheduled to be published by the end of 2021.

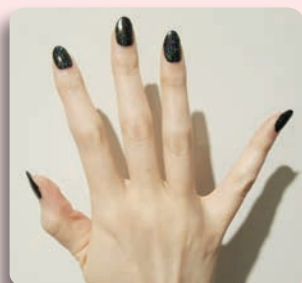
We are still working on the LMOD1 gene for the condition called TAAD, and we hope to publish it this year 2021. We hope it to be as successful as the recently published scoliosis paper.

Research Grant Applications

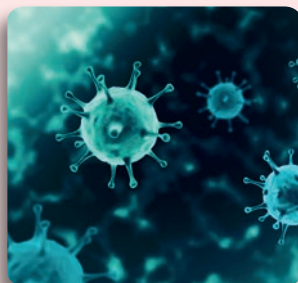
Although we are fully funded by Marfan Trust, we always continue to apply for outside funding to help ease the burden of funding the Sonalee Lab. We have applied

recently to FightForSight but we were not successful on this occasion. We will try again soon.

I just want to take this opportunity to say thank you, no, really, thank you very much. The generous donations to the Marfan Trust have helped us to educate students, volunteers and ourselves in these connective tissue disorders that would otherwise be much more difficult to manage.



Marfan Syndrome



Coronavirus (COVID-19)

STUDENT RESEARCH

The global pandemic is the catalyst for a fascinating discovery made by medical students Mohamed Abdelrazek & Thomas Whittaker, and Drs Aragon-Martin & Anne Child. Read on ...

Results of COVID-19 Pandemic Questionnaire

By Mohamed Abdelrazek, Thomas Whittaker, Dr José Aragon-Martin, Dr Anne Child

Thank you to all who responded regarding this questionnaire. People with Marfan syndrome (MFS) were asked to participate in a questionnaire distributed by email, post and social media to the Marfan Trust and Marfan Syndrome UK communities in November 2020. The results were analysed and reported by Mohammed Abdelrazek, our Cardiff University summer student.

104 individuals diagnosed with Marfan syndrome participated. Of these, 57% were female. The mean age was 51 years. The mean body mass index (BMI) was low, at 23.5 (normal range 12 – 49). Mean height was 180cm (range 136 – 208cm).

51% of the sample had pre-existing heart and lung conditions deemed to put them at increased risk of complications.

9 reported having COVID-19 confirmed by PCR nasal/throat swab. The median number of days they were ill was 16 (range 4 – 60), with a single case developing pneumonia that required hospital admission.

Discussion

Even though the majority of this MFS population presented with existing conditions linked to poorer COVID-19 outcomes, only a single case required hospital admission. This may provide evidence that MFS is a protective factor due to reduced adipose tissue (fat). The COVID-19 virus uses adipose tissue to replicate and when released, can overwhelm the body evading the immune response.

Patients reported increased breathing difficulties. They also presented much more with fatigue and muscle aches, and an increased prevalence of changes in taste, and vomiting. Patients with MFS are less likely to present with a fever.

Conclusions

Reassuringly, Marfan syndrome patients do not appear to be affected severely by COVID-19. The clinical pattern differs significantly from the normal population, with less fever, but more fatigue and muscle aches. Further work with a larger group is required to confirm the possible protective factors of Marfan syndrome, including the lack of obesity which may modify the severity of the disease.

This paper is being submitted for publication. Thank you to all participants.

José's Wish List

The Sonalee Laboratory Wish List for Summer 2021

The Sonalee Laboratory is sponsored solely by the Marfan Trust and relies purely on goodwill. Sometimes we urgently need to replace some of the equipment in the laboratory, and buy new instruments to broaden our research. We have created a list of those items we desperately need.

We are happy to meet with you and chat about this list further, so please do get in touch. You can reach us on 020 7594 1605 or email info@marfantrust.org. If you would like to purchase, or contribute towards, an item then let us know. Perhaps you would like to visit the Sonalee Laboratory, physically or virtually? If so, we can arrange a time!

CONSUMABLES

Whole Genome Sequencing (WGS) screening [£950 for 1 sample]

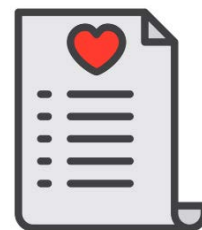
This will screen a patient's DNA in the latest technology available: whole genome sequencing (exons and introns).

We will look for mutations in the FBN1 gene (Marfan syndrome) and other connective tissue disorder genes (TAAD, EDS, EL, Scoliosis).

DISSEMINATION OF RESEARCH

Conference (yearly): American Society of Human Genetics (ASHG) USA [£2,500 for 1 attendee.]

The money will go towards membership fees (£145), conference fees (£245), ESTA fees (£10), flight,



Continued on page 8

accommodation, food and transportation at the conference location. It is very important for networking, training and scientific talks.

STAFF

Technician [£32,000 per year] - contributions toward This technician will help with the workload constantly present in Sonalee Laboratory as well as being trained in the latest technology for mutation screening. This post has the possibility in the future to be eligible for a PhD research study in Sonalee Laboratory.

Summer studentship [£2,000 per student/per summer] to host students who don't have any means to sustain themselves when they come for Marfan syndrome laboratory training during the summer.

EQUIPMENT

Laboratory glassware drying rack [£200] After washing our glassware, they need to dry in a proper environment to make sure they are completely dry, there is no dust or other residues that can build up inside the glassware. The lab uses glassware to measure and prepare solutions for experiments.

Laptop [£6,700] – contributions toward This will help with NGS data processing and analysis. The current laptop has been working overtime for the past 8 years and it is time to upgrade to a more helpful one.

Microwave [£60] (Microwave 800W) This is a crucial piece of lab equipment.

Undercounter Fridge [£500] This is a crucial piece of lab equipment. Our old fridge, known to Sonalee Lab since 2003, is not working properly (either too low or too high temperature even though the setting is in the right place) and we are in need of replacing.

Bench stands for bio-bin pipette upright waste boxes [£20 each box]
3x Bench stands for our bio-bin pipette upright boxes (£20 each, £60 all 3).

Thanks for the tremendous generosity of our sponsors. You still have time to make it to our wish list for the academic year 2021-2022:

Tall Tales!:

Interview with Mike Tunstall of The Tall Persons Club of Great Britain and Ireland

United by their 'height difference', the Tall Persons Club (TPC) is aiming to make the world a more height conscious place. Founded thirty years ago by living legend and bilateral lung transplantee Phil Heinrich, the Club educates and lobbies while providing a safe social exchange of information, advice and tips. All this to secure a fairer passage through life, practically and emotionally, for tall people. We met one of the Club's organisers, Mike Tunstall, on the ubiquitous technology that is Zoom to talk all things tall thinking this will be useful for Marfan folk who are often (but not always!), taller than average. At 6ft 7", Mike is a fraction above the Club's male median height and, as with other TPC staff, he is a volunteer, and an 'accidental expert' on matters from doorway dimensions to ergonomic desk design. He is also a past master on dodging and deflecting obstacles, literal and figurative. Read on for an engaging introduction to the TPC and for some handy tips on navigating life in the tall lane!

Mike, Introduce Us to life at the Tall Persons Club

The Tall Persons Club is a place where you are never out of place, height-wise. The tallest in the group is currently 7ft 5" and the shortest 5ft 10". There's always someone taller than you except for one person! You can stand tall together, which is good for your posture. At our height 20-odd years ago, we were a 2000-strong membership but now stand at 200+- and our Facebook site has



Mike Tunstall

approximately 1000 followers. The aims of the Group are three-fold. We **educate** the world on issues and problems encountered by tall people. We **lobby** legislatures, manufacturers and designers to create an environment that copes with tall people which means it will be a good inclusive environment for all. There are often protections omitted in legislative activity. We had to remind the Health & Safety Executive under the Shop and Safety Act the height of a shop sign should be a minimum of 6ft 6". We've also done training with British Airways. We are a **safe and friendly information exchange** where people can meet, share experiences safely trade tips on subjects from measuring feet to countering unwarranted attention in the street from passers-by who feel compelled to crack jokes on one's extraordinary height.

How Sociable is Your Club?

We are a diverse, motley group of individuals with extra height in common! Amongst our ranks are a violin teacher, a virologist, a cab driver, a Wookie, a shot-putter and several members of the burgeoning British Rowing Team. There are also people with Marfan syndrome! We exist in meetings, on Facebook and email, and we send a newsletter each month which is read by about 400. We currently have one "last Friday" social every month in London at the Thornbury Castle near Marylebone and are trying to establish regional gatherings. This year on Friday 25 June, the day before Tall Persons Day, we are having a UK-wide Tall Persons meet-up, pandemic willing!

Once a year we host an 'Annual Doo' on the last Bank Holiday of the year with about 30-100 in attendance. It involves a dinner dance, some exploration, a lot of entertainment and events such as go-kart racing – a truly silly thing for tall types to do! We also celebrate with an annual Christmas Dinner in December or January! And we meet our international cousins in Europe and The States, most recently in New Jersey, causing mayhem locally!!! It's nice to go with these people and not be asked how tall you are! It also is great fun to walk into a pub with fellow Group members. Last time there was me at 6ft 7", the lady with me at 6ft 4", followed in hot pursuit by Chris Greener, who at 7ft 6" was once the tallest man in Britain. The entire pub fell silent.

Do you have many experts, accidental or otherwise, within your ranks?

We do! We share a lot of information about clothing and daily issues faced by tall people. Apart from "Accidental Experts", amongst our ranks are experts in several areas, happy to answer questions on shoes and measuring feet for example. The owner of the **Walk Tall** company will give advice in a non-partisan manner and he incidentally also runs **Magnus Shoes**. We have people who can talk to you about cars too! We also work with **TallAlternative Retail**. A good network. We have disability advisors and clothing manufacturers.

There have been 10 or 11 (lasting!) marriages within the Club and children born amongst our ranks too! With the children outstripping their parents height-wise, and now joining in their own right as members.

What Tips and Techniques Can You Offer to Self-Conscious Teenagers?

We are welcoming an influx of 'Inbetweeners' as we call them. Youngsters who are relieved to meet someone of their age just as tall if not taller than them! We give co-support, and someone is always on hand to help and counsel because we've all been there ourselves at one time or other. One 14-year-old who stood at 6ft 2" with size 11 feet was dubbed 'Big Foot' by her peers. We helped build her confidence to the point where she was able to retaliate with "If my feet weren't so big I'd topple over and crush you". She loved it!



Mike in Context

When we all assemble to have a photo taken the new members are used to walking to the back of the photo where they would normally look over everyone. Their surprise and pleasure is palpable when they are then asked to stand at the front, as amongst the shortest.

One of our team has had to speak to a head teacher (at the behest of a tall teenager) to help them understand the teenager's issue with being different. We advised that the first comment from a teacher should not always be around their difference as it amplifies their sense of isolation. A small learning point, but an important one for any difference.

Most of us who are tall are regularly asked in the street "Do you play basketball" and a classic response is: "No do you play miniature golf?". In fact we are creating a t-shirt with some standard replies to these everyday Tall questions.

For the full interview go to: www.marfantrust.org/

Big Thing Coming....

By Gurpreet Madan and Moira Taylor

We Did It! We have launched our new website and are launching our membership scheme imminently, on 22 June 2021! Keep your eyes peeled for our exciting communications where we will discuss in detail our plans for the membership scheme and the benefits you will receive from it. To make sure you receive these, sign up to our e-news here: <https://www.marfantrust.org/pages/13-subscribe> We hope to see many of you joining us.

New Website for the Marfan Trust

As well as the exciting membership news, the Marfan Trust has been busy launching its new website <https://www.marfantrust.org/>. The new website is easier to navigate than the old one and importantly contains lots of useful information on Marfan syndrome and how to manage it. So, supporters can now do the following online via the site:

1. **Donate online.** Both one-off and regular donations can be made directly at <https://www.marfantrust.org/pages/12-donate>;
2. **Download all our information leaflets** at <https://www.marfantrust.org/pages/94-information-leaflets>; and
3. **View lots of useful resources to help manage Marfan syndrome** at <https://www.marfantrust.org/pages/84-resources>;
4. **Find links to Marfan specific social media support groups** which you can join at <https://www.marfantrust.org/resources/6-useful-information-other>;
5. **Buy items more easily from our new online shop** at <https://www.marfantrust.org/pages/32-shop>, including our new Marfan Face Masks, greetings cards and our Emergency Alert Card to quickly alert paramedics and hospitals in case of sudden medical emergencies.

A lot of time and effort went into it and we hope you – our amazing wonderful supporters – are finding it easier and friendlier to use. If you have any ideas or if you've noticed any mistakes, please drop an email to Gurpreet Madan at Gmadan@marfantrust.org.

Fundraising in Tricky Times

As supporters, we're certain you are keen to hear how our fundraising efforts have been going, particularly given the challenges the pandemic has thrown at us. Unsurprisingly, the start of the year has been slow and we've got lots more funding to secure. We are tackling this by:

- Applying to Trusts and Foundations. If you know of any that align to the Marfan Trust's objectives and aims, please email Gmadan@marfantrust.org;
- Introducing new items for our store like our fabulous Marfan Masks;
- Taking part in the Captain Tom 100 Challenge;
- Organising a Raffle for you to participate in and share

with family and friends;

- Planning a Fundraising Virtual event – details to be shared soon;
- Coordinating a Pregnancy seminar; and
- Launching our Membership scheme.

How can you help? You can:

- **Attend our Events**
Lend your support and come to Marfan Trust events – whether that's attending our seminars, conference or virtual events;
- **Donate, donate and.... donate some more**
Donate to the Marfan Trust– this can be a one off donation or a monthly standing order. All donations can now be made via our website at <https://www.marfantrust.org/pages/12-donate>. Every bit helps and takes us that much closer to ensuring we continue to improve treatment of Marfan syndrome and increase awareness of this condition;
- **Keep things interesting and entertaining by setting up a Fundraiser**
How about doing: a quiz, a live stream of you cooking a family recipe, sharing a unique skill that you might have like yoga, dance, arts and crafts or if you are up to it, or why not take on some fun challenges? We've got two here to get you started:
 1. **A physical challenge:** For every £10 raised, you commit to climbing flights of stairs, doing a number of push-ups, planks, dancing for a set period of time, or some other physical feat; or
 2. **A "Dare" challenge:** For every £10 raised, you commit to doing something that a friend dares you to do. Be creative and get in touch for more ideas!
- **Endorse us**
You can support us by tapping into your network by



Gurpreet Madan, Fundraising Manager



Moira Taylor, Marketing Consultant

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. With your support, we could make a massive difference to the lives of those affected by Marfan syndrome and their families;

- **Join our membership scheme**

Keep an eye out for our communications and decide if being a Marfan Trust member excites you. If you've enjoyed our content over the last year then support us by putting aside the cost of one coffee per month to the Trust. £3 will go a long way in ensuring we continue to provide high level, interesting content to you and your family. Subscribe here <https://www.marfantrust.org/pages/13-subscribe> to receive all our communications on our activities, Marfan syndrome and how to manage it; and

- **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.

WHY YOU SHOULD BE A MEMBER?
Marfan Trust

CONNECTED
Join a growing community of Marfan Warriors keen to support one another

EDUCATE
Receive educational literature, case studies, newsletters, blog posts and articles that will answer your burning questions and put your worries to ease

EMPOWERED
"Knowledge is Power" The most current findings will be shared so that you are empowered to make the right decisions for yourself and your family

SUPPORT
Being a member provides the Marfan Trust with a small monthly donation which secures its future and ensures it will remain for years to come

Marfan Trust
Email Gurpreet Madan: Gmadan@marfantrust.org

Become A Member

Support, Educate and Empower those affected by Marfan syndrome

"Appreciate reading your newsletters and emails and wish to support your work".

Quote from a Marfan Association member

It's been well over a year since we merged with the Marfan Association. How time flies! As the Marfan Association was a membership organisation which enabled it to remain financially viable for many years and better able to serve supporters, the Trust too has decided to take a similar step to better secure its future. We are launching our membership scheme in June 2021 and hope you would consider being a part of it.

With Covid-19 and the fact that we receive no government funding, we've unfortunately experienced a drop in our finances. We are hoping that by launching our membership scheme, we will be able to bridge the gap and support the Marfan community better.

All supporters will be enrolled into our membership scheme, which will have 3 tiers. In particular, Premium members will receive our fabulous premium content (weekly case studies, regular articles and blog posts), our bi-annual Marfan Matters Magazine and 4 free PDF versions of Marfan Trust's advice pamphlets (worth £20). You will get all of this and more for a small monthly donation of £3. A year's membership cost of £36 will enable us to respond to 2 additional enquiries received by the Helpline. Please sign up as soon as we launch the scheme 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 your interest, please email us: Gurpreet Madan at gmadan@marfantrust.org. To find out more about the membership scheme, make sure you are signed up to receive our e-news. Register to receive our e-news here: <https://www.marfantrust.org/pages/13-subscribe>.

Last but not least, don't forget feel-good shopping at smile.amazon.co.uk! Shop with Amazon and donate to the Marfan Trust at no cost to you!

In Memory

Don Beer

The chairman, trustees and staff of the Marfan Trust would like to offer condolences to Mrs Sue Beer, and their son, Mr Nick Beer and family. The Marfan Trust is extremely grateful to Don, for taking on the chairmanship at a critical time, and dealing wisely and calmly with all problems. Our long-term success owes a great deal to his early efforts. Besides this, he was a great friend.

Our success story has culminated in 2020, with the amalgamation of the Marfan Association and the Marfan Trust. We now have 3000 supporters, a twice-yearly newsletter and education pamphlets, and an annual Marfan Information Day for patients and doctors. In addition, our patient helpline has grown tremendously especially during the Covid pandemic.

We are confident of our survival, and our continued need to support, educate and provide research of internationally acclaimed excellence.

Thank you Don. You are well remembered.

On behalf of the Marfan Trust,

Micah Gillings by his mother, Natasha

"My son, Micah, died suddenly and unexpectedly on July 23rd, 2020. He was 19 years old, fit and healthy. He had no medical problems that I was aware of. It's hard to put in words what Micah was like. To me as his mum he was a bright, chatty, caring, kind, thoughtful, clever, active, friendly lovely child who grew up to be an amazing young man with the world at his feet. It wasn't until he died that I discovered so many other people felt the same way about him.



Micah with his mother, Natasha



Micah



Micah with his girlfriend Nia, and friends Plami & Max

The night Micah died it was the second day of the summer holidays. He was at home cooking dinner for him and his girlfriend, my daughter and I were having dinner at a local restaurant with friends. I got a phone call from Micah's phone, it was his girlfriend telling me to get home asap, I could hear she was in tears and frantic I could also hear a female voice telling her how to CPR. I remember I just kept saying "don't stop, please don't stop". It took me about 40 minutes to get home. Some time later the clinician in charge came down and told me there was nothing else they could do, Micah was dead.

I had never heard of Marfan syndrome before, it was only when Micah's autopsy report came through that I first heard of it. He ultimately died of a dissected aorta and faulty heart valves. I'm left with a great big emptiness that was previously filled with laughter, fun and love and an amazing son. A group of Micah's friends got together and set up a just giving page to raise money for Marfan Trust in Micah's name, so far they have raised £4,000 just through social media sharing. Genetic conditions need to be talked about to help with the public and professional knowledge and understanding."

This is an extract from Natasha's Story. For the full story please go to: <https://www.marfantrust.org/articles/149-natasha-s-story-marfan-awareness-month>

Micah's girlfriend Nia, and friends including Max and Romeo, have raised over £4,000 for the Marfan Trust. We are immensely grateful to them, and terribly sorry for their unspeakable loss.

Raymond Moses

We are so sad to report the death of Raymond Moses. With his wife Pauline, Raymond turned old stamps into money for the Marfan Association and subsequently the Trust for years, raising a small fortune. He continued collecting old stamps during his illness and we are so grateful for his loyalty and tenacity. We will miss him greatly and offer our condolences to Pauline. Raymond and Pauline's son, Peter, died from complications of Marfan syndrome and



Pauline herself lives with the condition. If you are able to cut and collect used stamps please send them to Pauline. Keep Raymond's legacy alive:

Mrs R Moses, The Waves, Coast Drive, St Mary's Bay, Romney Marsh, Kent TN29 0HN

Leslie Vince

The death of Les Vince on 2 December 2020 prompted an outpouring of tributes to the 'kind-hearted' man who dedicated his life to fundraising. Les stopped working at the age of 21, owing to the debilitating effects of Marfan syndrome, which claimed the lives of his mother and older brother. Thereafter he devoted his time to raising money – over £70,000! - for the Marfan Association and Trust, while also raising desperately needed awareness of the syndrome. He himself was not diagnosed with the condition until his early thirties. Les's unstinting efforts saw him receive an MBE from the Queen. Although he was a wheelchair user since 2010 and spent much time in hospital, it did not stop his zeal and zest for life: "He had a wicked sense of humour and would always do his best to entertain his carers. He was a very kind-hearted man" said his wife Jenni who raised over £700 for the Trust at her husband's funeral. Jenni and Les were able to celebrate their 30th wedding anniversary shortly before his death. We offer Jenni our sincerest condolences, and our gratitude for all that she and Les have done for those with MFS.



Mrs David Holmes

Also fondly remembered are :

David Anthony Horton

Feats of Fundraising

Lockdown in its various guises has not stopped our unstoppable supporters!

Adam's Golf Odyssey



We conclude the story of **Adam Furneaux** and his Captain's Drive In, first covered in our 2020 spring newsletter. Ascending to the position of Junior Captain of the Churston Golf Club in January 2020, Adam nominated the Marfan Trust as its appointed charity. While his captaincy has since been impeded by the stop-start nature of the coronavirus restrictions, he has still raised a magnificent sum of £882.35 for the Trust. Thank you, Adam! Not only has Adam had lockdown to contend with, but also lensectomies and detached retinas. This has not stopped him playing golf, a game he has loved since the age of 6. Nor has it hindered him from going off to University, where he is destined this September. Good luck!

MarFriends TeamWorkers Charlotte & Lucy



Charlotte Nason



Charlotte's daughter, Amiyah

"She's my drive. I'm her voice". Since her daughter Amiyah was diagnosed with Marfan syndrome at just 18 months of age, **Charlotte Nason** has tirelessly raised money for the Trust and awareness of the condition. A condition of which she became first aware only with Amiyah's diagnosis. Amiyah has since undergone serious surgery - mitral valve replacement - and is now wearing a brace to correct scoliosis. From running around her neighbourhood close and collecting £600, to raising £300 and counting through raffles, partnerships with a local beautician and stands at her local supermarkets, Charlotte is a dynamo of creative ideas and activity. Everyone in her local area of Eastleigh has now probably heard of Marfan

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Continued from page 13

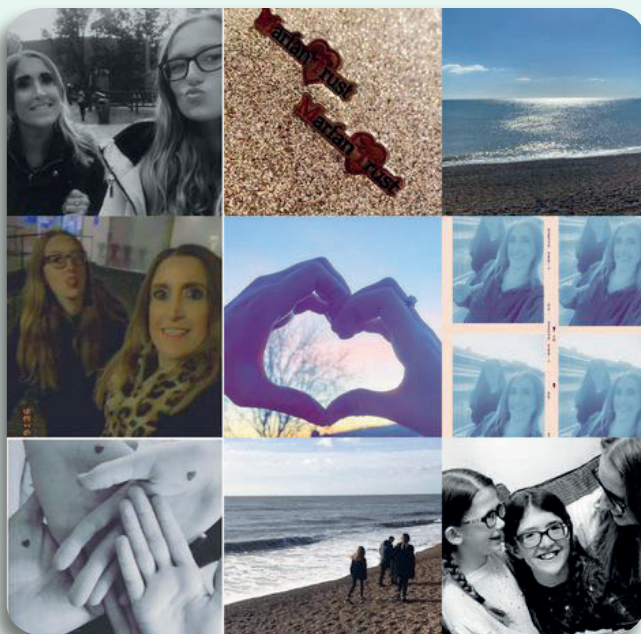
syndrome. And her daughter is following suit. For Amiyah kindly gave away her toys asking that, if inclined, people donate to our Charity, raising £23!



Lucy Atkinson

Working in close collaboration with Charlotte is **Lucy Atkinson** and together they form the @Marfriends_ teamworkers on Instagram! Lucy met Charlotte only recently through social media and they quickly became a formidable team, spreading the digital word on Marfan syndrome. Meantime Lucy is a long-standing friend of our Trust and frequently holds raffles, last month raising £75 through her luxury trove of chocolates, pink gin and candles. But the Trust is just as grateful for Lucy's blogs which she contributes to our social media sites. Chronicling her life with the syndrome, Lucy writes honestly and amusingly in a style that captivates many. Thank you, Lucy!!!

A Step Up



Leanne and Daughters

Earlier this year, **Leanne Pocock** took 358,846 steps in the right direction for the Marfan Trust, wearing her Marfan badge with pride and raising £300. Leanne was joined by her daughter Olivia who managed fewer but a still fantastic 313,154 steps. Leanne, her daughter, brother, father and niece all have Marfan syndrome and making these strides was no mean feat. As Leanne said, "it's easy

for some but not for us". This makes their act all the more special. Thank you!

A Beloved Brother



Phil (centre) with Friends

By **Phil Coles** "My brother passed away unexpectedly from Marfan syndrome which was undiagnosed. He was aged just 27 and died in 2009. I have completed three sponsored walks now, 2010, 2014, and this latest one, raising a fair amount of money. This time we walked from Christchurch to Salisbury along the Avon Valley Path (30 miles) and then the next day Salisbury to Winchester (23 miles). I completed it with my brother-in-law (to be), Patrick Noble, and my brother's best friend, Tim Jackson. I have attached a photo. It was wet, muddy and hard going on day one! Day two was more pleasant weather but the first day had taken its toll." Thank you, Phil!

Through a Child's Eyes



A belated but heartfelt thank you to the **Schools** in **Southport** for raising an incredible £6,452.16 for our charity last February. Southport Learning Partnership schools stage a 'Love My Community' every February, giving variously to muscular dystrophy, local foodbanks and a nearby hospice. In 2020 the schools appointed the Marfan Trust as their charity of choice, for personal reasons: "Linaker Primary School has a family who have to deal with Marfan Syndrome every day and we all wanted to show our support." The schoolchildren all wore civvies for the day and added funky sunglasses to the mix, with every child giving £1 to participate.

In Memory of Matthew



By **Helen Syms** "The Marfan Trust team have totally impressed me with their energy, ideas and creativity following the merger with the Marfan Association UK, and their handling of the challenges of COVID has been inspirational. It's great to see fresh impetus to the communications, education and fundraising initiatives as well as continued good progress on the research. For

anyone thinking to try a fundraiser I totally recommend a wing walk! It is exactly as it sounds, and I thoroughly enjoyed mine whilst raising a good sum for the Marfan Association at the time. I did this in memory of my son Matthew Cross who died in October 2017, aged 17, from complications following heart surgery. He's in my thoughts and in my heart every day, and he brought out the best in everyone who met him.

I'm pleased to support the Marfan Trust, it's a great team doing great work."



Marfan Information Day

Save the Date 9th October 2021

A virtual one-day conference for families with Marfan Syndrome as well as interested physicians has been planned for Saturday 9th October 2021, 9.30 am to 16.30 pm.

If you are interested please see the programme described below, and register your interest by emailing info@marfantrust.org. If you don't have access to email then please call +44 (0) 207 594 1605 to register.

Please check our website <http://www.marfantrust.org> for updates. Please do register early. We will not ask for any funding until autumn, so we do need your contact details.

Conference Programme

Updates on aortic surgery, children's eyes, scoliosis management, psychological support and prenatal genetic diagnosis are planned. Student research projects will be reported, followed by an update on Marfan Trust activities including helpline and fundraising.

Opportunities for breakout chat rooms will be provided and lots of question times has been built into the programme

"It was a first-class line-up with great use of technology and excellent time management"

[supporter talking of our 2020 conference, our most highly attended]

As society reopens for business, our raffle is a treasure trove of possibilities! From tickets to a sensory feast of music at the Royal Albert Hall to walking with goats, there's something for everyone. Enclosed you will find one book of 10 tickets for you, your family and friends. More are available if you wish; simply email info@marfantrust.org or purchase online through our webshop.

MARFAN TRUST
Registered Charity Number: 328079
Promoter: Marfan Trust, Guy Scadding Building, Dovehouse Street,
SW3 6LY

SUMMER RAFFLE 2021

1st Prize: Classical Spectacular Royal Albert Hall
(sound and light) 2 people
2nd Prize: £50 Amazon Voucher
3rd Prize: £25 National Garden token
4th Prize: Buttercup Goat Sanctuary Voucher
Runner up - box of Hotel Chocolat

Draw will take place on 30th July 2021

Registration details: Registered with London Borough of Kensington and Chelsea
QuickPrint(UK) Ltd, 23 Prince William Road, Belton Park, Loughborough, Leics. LE11 5QU Tel: 01509 236987 www.quickprintuk.com

TICKETS
£1
EACH

Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders

SHOP



Robin on a Snowy Branch



Christmas Wreath



Marfan Trust Face Mask, Red



Three Kings of Orient



Snow on the South Bank



All Occasions Card

Welcome to
Our Shop
www.marfantrust.org



A Guide for Young Adults with Marfan Syndrome

Response Slip (this can be photocopied)

Please return the response slip to the Marfan Trust, Guy Scadding Building, Imperial College, Dovehouse Street, London, SW3 6LY. Please make cheque payable to the Marfan Trust. Thank you for your support!

Name..... Address.....

Postcode.....

Email.....

Please tick relevant box and insert number of packs required in the dashed line (Greetings Cards supplied in packs of 10)

- ☐ ***New* Marfan Trust Face Masks Black and Red £10.00** (inc. p&p) No: [please specify black or red]
- ☐ **Robin on a Snowy Branch £4.00** (plus £3.00 p&p): No: ☐ **Snow on the Southbank £4.00** (plus £3.00 p&p): No:
- ☐ **Christmas Wreath £4.00** (plus £3.00 p&p): No: ☐ **In the Stable £4.00** (plus £3.00 p&p): No:
- ☐ **Three Kings of Orient £4.00** (plus £3.00 p&p): No: ☐ **All Occasions Card £4.00** (plus £3.00 p&p): No:
- ☐ **A Guide for Young Adults with Marfan Syndrome £5** (plus £3.00 p&p): No:
- ☐ **Marfan Trust Emergency Card: £2.00** per card (plus £1.00 p&p): No:
- ☐ **Marfan Trust Wristbands: £2.00** per wristband (plus £1.00 p&p): No:
- ☐ **Marfan Trust T-shirts: £5.50** each (plus £3.00 p&p): Small Medium Large XL
- ☐ I am eligible for Gift Aid: Please give your name and address above:

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

Registered Charity Number:328070



STAFF

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