Marfan Trust

Supporting Research into Inherited Aortic and Related Disorders

a guide for Young Adults with Marfan Syndrome

www.marfantrust.org
info@marfantrust.org
020 7594 1605
Registered charity number 328070

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the Marfan Forum

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Supporting Research into Inherited Aortic and Related Disorders

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www.justgiving.com/ntrgnlojhs

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Contents

The Marfan Trust needs your help to continue to provide support, research and educational literature to those affected by Marfan syndrome

A great way to get involved is to organise fundraisers as it doesn't just raise donations for the Trust but also increases awareness

Fundraising ideas don't have to be boring or unimaginative. They can be as creative as you like and can be based around your hobbies and passions. Why not try these:

- Sporting event watch party
- organising a clothing swap
- Pizza party
- Video game tournament
- Danceathon
- Create a sports tournament
- Sponsored event

With your support, together we can continue to improve the treatment of patients and increase awareness of this condition.

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Marfan Trust Hotline
020 7594 1605

Facebook - www.facebook.com/Marfan-Trust-102179834771903
Instagram - www.instagram.com/marfantrust
Twitter - www.twitter.com/MarfanTrust

the Marfan Forum

Marfan Forum UK

www.facebook.com/groups/marfanforum

Marfan Forum

www.facebook.com/groups/marfanforumuk

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www.marfantrust.org/shop

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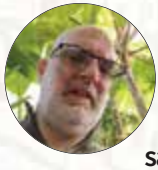
Introduction



My name is Darren McDean & I started the Facebook groups the Marfan Forum & the Marfan Forum UK back in 2009 & before that I had a website forum of the same name for a number of years. These type of groups have really grown in popularity with the explosion of social media over recent years.

I was first diagnosed with Marfans back in the early 80s. I've suffered mainly with heart & aortic issues, the first being aortic root replaced back in 1985. In 2016 I was diagnosed with a 55cm long aortic dissection running from the aortic arch down to My groin which is currently being controlled well with medication & I'm also awaiting mitral valve surgery. At close to 50 years old now, as I've aged more problems have become apparent. Over the years I've suffered with cataracts, retinal detachment, dural ectasia & numerous joint problems, but on the positive side most problems have been fixed.

I was approached by Dr Child from the Marfan Trust, with whom who I first had contact with back in 1985, to create this guide for Young Adults. Her vision was that the Marfan Trust & the Marfan forum members should come together to create this publication. The booklet is aimed at young adults from the 16-30 years age group.

The topics & questions within this publication have mainly been put forward by the young adult members of the groups, so hopefully there is some information here to help you more understand Marfan syndrome.

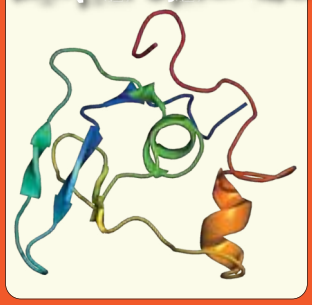
Please take the time to visit either of our Facebook groups; you'll find they're a friendly bunch who are always available to help or to chat with. I also would like to thank My fellow admin members Chez Monnie, Maya Brown-Zimmerman & Carolanne Martin for their ongoing help in keeping the groups going & also to the members who kindly submitted photos for this booklet.

What is Marfan Syndrome?

What does the Marfan Trust do?

www.youtube.com/watch?v=ZZUdNkhkuSc

Marfan Syndrome



...is caused by mutations in the FBN1 gene, which provides instructions for making a protein called fibrillin-1

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What is Marfan Syndrome?

Marfan Syndrome is an inherited disorder of the body's connective tissue that affects both men & women of any race or ethnic group.

Marfan syndrome affects the heart, eyes, lungs & skeleton. It can be disabling, painful & even cause death in some cases.

- Severity differs from person to person.
- In 75% of cases it is an inherited disorder; 25% occur as a result of a spontaneous mutation. Any child of an affected parent has a 50% chance of inheriting Marfans.
- It is caused by a mutation in the gene for fibrillin-1 on chromosome 15. It can affect both men & women from any race or ethnic group.
- Approximately 18,000 of the UK population are affected & 1 in 3,300 worldwide.
- Every year on average in the UK there are over 200 new cases of Marfan's diagnosed.
- About 50% of all sufferers remain undiagnosed.

What Causes Marfans?

A single abnormal (mutant) gene on Chromosome 15 causes the condition. This abnormal gene controls production of fibrillin, a very fine fibre in connective tissue throughout the body (the "glue & scaffolding of the body"). Most of the time this gene is inherited from a parent who is also affected. However, about 25% of the cases occur when the abnormal gene appears in an egg or sperm (a spontaneous "new" mutation) producing an affected child from two unaffected parents.

Marfan syndrome is inherited as an "autosomal dominant" condition. This means that someone with Marfan syndrome has a 50-50 chance that each offspring will inherit the condition, regardless of sex.

Diagnosis & Where to Obtain it

Marfan syndrome can be difficult to diagnose because signs of the condition vary greatly from one person to the next. Most affected people will not have all the signs & complications of Marfan syndrome.

long slender fingers (arachnodactyly)

In general, Marfan syndrome is diagnosed by careful physical examination, particularly focusing on the main systems involved; eyes, skeleton, heart & lungs. Certain tests, such as an echocardiogram (a soundwave picture of the heart) are useful in obtaining the diagnosis.

People with Marfan syndrome should have an initial diagnostic echocardiogram which is repeated at regular intervals. An Electrocardiogram (ECG) is not adequate screening. Skeletal X-rays (mainly chest & back) may be necessary & a careful eye examination using a slit lamp to detect lens dislocation is recommended. Also family history is important & needs to be taken into account.

positive thumb sign is helpful in diagnosis

Diagnosis can also be confirmed within a family by genetic testing. Mutations can be found in the fibrillin-1 gene in 97% of patients, assisting with screening of family members.

A Blood test demonstrating the abnormal gene is available through referral to a clinical geneticist. Prenatal diagnosis is now available for most families with this condition, where a mutation (change) in the fibrillin gene has been demonstrated.

Who Discovered Marfan Syndrome?

portrait by Henry Bataille

Marfan syndrome was first identified in 1896 by the French physician Antoine Marfan & the gene was discovered in 1991

www.en.wikipedia.org/wiki/Marfan_syndrome

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Clinical Features & Modern Management

Heart: The most serious life-threatening problems associated with Marfan syndrome involve the cardiovascular system. The two leaflets of the mitral valve may billow backwards when the heart contracts, a condition called "mitral valve prolapse". This feature may lead to heart failure or be associated with irregularities of the heart rhythm.

The aorta (the main artery carrying blood away from the heart) is generally wider & more fragile in people with Marfan syndrome. This widening is progressive & may result in leakage of the aortic valve or in the development of tears (dissection) in the wall of the aorta. When the aorta becomes widened, medications (eg beta-blockers to lower blood pressure, or Irbesartan to slow aortic enlargement), may be prescribed, thereby reducing strain on the aorta & regulating heart rhythm. This may be followed by surgical repair preferably when the aortic root widens to between 4.2 - 4.5cm diameter, & before it becomes torn.

Patients with Marfan syndrome are recognised to have a slightly increased morbidity & mortality risk associated with general anaesthesia. Preoperative assessment should include a thorough medical examination with a chest x-ray, electrocardiogram & echocardiogram. Any treatment must be carried out in conjunction with the patient's cardiologist. Antibiotics may be prescribed prior to dental, genito-urinary or other minor surgical procedures, to reduce the risk of infection (endocarditis) in people who experience mitral valve prolapse, or who have had aortic root surgery.

Lifestyle adaptations, such as the avoidance of strenuous exercise & contact sports, are often necessary to reduce the risk of injury to eyes & skeleton, as well as the aorta.

Heart Poll

What heart issues did You have by the time You got to 24 years old?

Mitral valve problems	33%
Aortic problems	16%
Aorta repair	15%
None until i was older	13%
Aortic valve problems	10%
Aortic valve repair	8%
Arrhythmia	4%
Mitral valve repair	3%

the Marfan Forum

Poll was taken by 176 members from the Marfan Forum Facebook group (June '20)

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Marfan Syndrome Diagnosis & Management

A video discussing all aspects of Marfan Syndrome by Dr Child

www.youtube.com/watch?v=szxN5yvG_8A

Hypermobile Joints

Joint hypermobility is often the cause of pain and stiffness from having very flexible joints

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Clinical Features & Modern Management

Skeleton: Musculo-skeletal problems are common & troublesome in Marfan syndrome. Indeed, recognition by a rheumatologist could be the first vital step towards diagnosis of the underlying condition. Involvement of the skeleton includes curvature of the spine (scoliosis/kyphosis/ lordosis), abnormally shaped chest ("pectus" deformity), tall stature, & loose jointedness (often causing joint pain & dislocation). Physiotherapy, pain clinics & bracing may be helpful. GP referral to orthopaedic surgeon, rheumatologist, growth clinic may provide the team necessary for management. In certain instances, surgery is indicated. Careful monitoring is needed, especially during childhood & adolescence. Arch supports (orthotics) may help the affected child. Weak ankles may require lace-up shoes with ankle support.

Eyes: People with Marfan syndrome are generally near-sighted (myopic). In addition, some have dislocation of the ocular lens, & retinal detachment. Glasses &/or contact lenses may be prescribed to correct visual defects. Surgery is now available, if required for removal & replacement of lens(es) & reattachment of retinas.

Lungs: Spontaneous pneumothorax (collapse of the lungs) is thought to occur in approximately 5% of patients & requires hospital treatment. Those affected should not smoke and winter flu vaccinations are highly recommended to protect the lungs. Sports involving sudden changes of pressure (parachute jumps, scuba diving) are not recommended.

Bowel symptoms: A significant proportion of patients with Marfan syndrome have gastrointestinal disturbances constituting irritable bowel syndrome (IBS), with abdominal pain, bloating, constipation and diarrhoea. Dietician advice and specific medications are helpful. In the general population, IBS commonly first develops in young adults and teenagers.

Relationships & Sex

Sexual relationships are very important to people with Marfans. There are lots of questions that arise within social media groups regarding this subject and there's no denying that it can be difficult to find a partner, or to have the confidence to put yourself in a position to achieve this.

Once you have found yourself a partner or even before this person has become your partner, you may feel the need to tell them about your having Marfan syndrome. You may choose not to tell them, nobody should judge whether You should or not. But when & if you choose to tell your partner about Marfans, you will know when the time is right. If you do choose to tell them, be honest, let them know how it affects you & try & make time to answer any questions they have. Invite your partner to accompany you to your next specialist visit so you can both ask questions and hear the answers together.

Regarding having sex, have sex, but do be aware of any limitations you may have. Some positions & acts are easier on the body than others & if your not aware of this your body will tell you.

Starting a family can be a very personal decision that should be made solely by the prospective parents, but only after acknowledging & understanding the potential risks, especially if the female partner is affected with Marfans. If the aortic root measurement is greater than 4.0cm, you can be at risk of aortic dissection; this can happen in 10% of pregnant females with Marfans. Aortic root replacement prior to pregnancy is an option, ensuring safe pregnancy for both mother & child. It is advised that pre-pregnancy genetic counselling should be undertaken before starting a family. Each pregnancy should be planned. If a DNA blood test has revealed a causative mutation, preimplantation genetic diagnosis (PGD) can ensure an unaffected baby is born, thus eliminating the gene from the next generation of your family.

Relationship Poll

Thinking back to when You were between 16-24. How easy did You find starting intimate relationships?

Really Hard	55%
Similar to My Peers	23%
Very Easy	22%

Poll was taken by members from the Marfan Forum Facebook group (June '20)

Clothing Group

Buy/sell/swap clothing & equipment

www.facebook.com/groups/1009287712861413

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Mental Health

Thinking back to when You were between 16-24 years old. Did You experience any sort of mental illness during this time?

Yes	64%
No	34%
Not Sure	2%

Poll was taken by members from the Marfan Forum Facebook group (June '20)

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Relationships & Sex

Ensuring safe pregnancy for mother and child, an echocardiogram should be performed before pregancy, each trimester during pregnancy, and after delivery. Warfarin should be stopped and Heparin used during the pregnancy, to avoid malformations in the baby. If low back pain becomes a problem, a maternity back support for the abdomen can be safely worn. Doctor can refer you & your partner to your assisted conception unit, through your regional genetics clinic.

Mental health problems

Young people with Marfan syndrome may feel that they look different & often find restrictions imposed on them in their daily life due to their poor eyesight, painful joints & cardiac problems. You might also find that people treat you differently too because of the way you look, sometimes in a negative way which can leave you feeling down or excluded.

Self portrait by Kirsty Latoya

It has been reported that in some cases, young people may also display behavioural, or emotional problems & suffer from low self-esteem. They may keep their worries & thoughts to themselves, resulting in withdrawal, physical complaints, anxiety & depression.

You can help yourself by trying to Identify your strengths, whether creative or academic. These skills should be encouraged & developed to help improve self confidence & social interaction. Psychological counselling may also be helpful to improve a young person's self-image & confidence.

Mental health problems

Another contributing factor to psychological problems can be prolonged periods of dependency on parents or guardians due to difficulties in finding employment hindered by visual problems that could prevent driving, also easy fatigability which can limit occupational choices.

The more you get to know Marfans the more questions you may have. Take a pamphlet about Marfan syndrome to your family doctor who may not be familiar with the condition. Ask for referral to specialists who will form a team to care for you optimally. Your GP remains in charge of the team, since all reports go back to the surgery.

Psychosocial Aspects

Children & adolescents with Marfan syndrome look & feel different and restrictions are imposed on them because of their poor eyesight, lax painful joints and cardiac problems. School absence may be frequent because of hospital appointments and corrective surgery for skeletal, ocular or cardiac problems. In addition, other affected members of their family may have been acutely or chronically ill, required heart, spinal or ocular surgery, or even died suddenly & unexpectedly, possibly at an early age.

Despite normal intellectual and gross motor development, children fail to perform to the best of their ability because of physical limitations: short-sightedness & clumsiness (due to lax joints & a long thin body build) are the main problems. Nevertheless, most children are able to attend a mainstream school, albeit often with special help (from statementing) in the classroom.

In the Marfan Trust (feb '02) survey of 101 children aged 4-16 years with Marfan syndrome the following results emerged:

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Virgin moneygiving

Help Stop Life Saving Research being put to an end by donating to the Marfan Trust with Virgin money

www.shorturl.at/nyDU1

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Psychosocial Aspects

- Children and young people with Marfan syndrome have significantly more behavioural problems & tend to internalise their worries, resulting in withdrawal, physical complaints, anxiety & depression.

- Children with Marfan syndrome have low self-esteem with respect to social & physical competence, & general self-worth. They feel they are not liked by others & are not sure of themselves (Harter Self-esteem Questionnaire).

- During the pubertal growth spurt, which typically starts & finishes earlier than in the normal population, features of Marfan syndrome may appear or worsen. Affected children realise more acutely that they are different & have difficulty with their body image. Not surprisingly they may be teased or bullied at school & tend to have fewer friends than their

Questions & Answers

Q: Do I need to declare Myself to the DVLA?

A: Yes, You do as Marfan syndrome is listed in the medical declaration section - www.gov.uk/health-conditions-and-driving Not declaring Your medical conditions could result in your insurance being void and maybe the loss of Your li-

Travel Insurance

Travel Insurance 4 Medical **Specialise in cover for people with medical conditions.**
www.travelinsurance4medical.co.uk

Orbis **Insurance for people with impaired lives.**
01424 215315
www.orbis.com

Freedom Insurance **Pre-existing medical conditions.** 01223 446913
www.insurewithfreedom.co.uk

All Clear Travel **Conditions including heart problems.**
01708 339295
www.allcleartravel.co.uk

Insurance With **Covers many medical conditions.**
020 3582 4598
www.insurancewith.com

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Questions & Answers

Can I get travel insurance?

A Many people may unwittingly embark on their holidays thinking that the EHIC (European Health Insurance Card) is all that they need if they fall ill when travelling in Europe. Speaking from experience, having travel medical insurance on top of the EHIC is essential for people with Marfan syndrome. Not having comprehensive travel insurance can make foreign medical bills and alternative travel arrangements very costly and stressful.

When travelling within Europe, the EHIC still allows you access to healthcare in your visiting country at a reduced cost or free of charge until 31 December 2020, and under certain circumstances from 1 January 2021.

There are many different travel insurance providers out there so it is always good to shop around (see suggested companies in column on the left). However, having now gone through the process, I now understand and appreciate the importance of being comprehensively covered in case of emergencies.

Your doctor can provide a letter stating whether you are mildly or moderately affected. This may reduce the cost of the insurance.

Can I get Life Insurance?

A It is not a legal requirement to have life insurance to get a mortgage but many mortgage providers do ask for it.
The only legally required insurance for procuring a mortgage is building insurance (which should be unaffected by Having Marfan syndrome. Doing a Google search for life insurance with medical or...

Life Insurance

Life Cover For All British Heart Foundation recommended
www.lifecoverforall.co.uk

Moneysworth also BHF recommended
www.shorturl.at/aipwP

Beagle Street discovered via Google
www.shorturl.at/jIJRW

The Insurance Surgery (specifically designed to cover mortgages)
www.shorturl.at/vAZ37

Links by Jack Ronayne

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Questions & Answers

...heart conditions will return a lot of providers who specialise in plans for people with such conditions as well as providers who do not specialise but who do still provide coverage to people with medical conditions.
The British Heart Foundation website suggests the following two life insurance providers:
Life Cover For All & Moneysworth.
Two other reputable providers specializing in life insurance for people with medical conditions include Beagle Street. On the the Insurance Surgery it is advised to get 'decreasing life insurance' as this type of cover is specifically designed to cover mortgages, and has cheaper premiums.
The Cardiac Risk in the Young website have one page answering a FAQ in which they say that if cardiac abnormalities are found, it would increase insurance premiums and potentially jeopardise mortgage applications.
Cardiomyopathy UK has a page dedicated to explaining life insurance and the impacts of having a heart condition on it. The page is very informative about life insurance but offers little help in getting it.

To make applying for insurance easier it is advised that people have all their medical records available since these are likely to be asked for.

If possible, you can use your partner's life insurance as a basis for a mortgage. You can also ask your physician for a letter indicating that you are mildly or moderately affected, and that a normal lifespan is expected, if this is the case.

The doctor can ask that you not be weighted unduly for insurance. It is best to fasten this letter to your first application.

Sonalee Laboratory

The Sonalee Laboratory is sponsored by the Marfan Trust. We urgently need to replace some of the equipment in the laboratory and buy new instruments to broaden our research.
To donate contact 020 7594 1605 or email info@marfantrust.org

www.shorturl.at/pvGZ6

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Questions & Answers

Which sports can i take part in?

A The following are recommended by the Marfan Trust, but not to be carried out at high level competition: Swimming, Archery, Cycling (on the level), Hockey, Shot-put, Badminton, Discus, Javelin, Skating, Bowls, Fencing, Netball, Canoeing, Football (no heading) , Table Tennis, Cricket, Golf, Sailing, Tennis, Yoga, Walking/jog-walking, Dancing & Light weight-lifting.

What Kind of Career Advice Can You Give Me?

A Higher Education is important, since relative weakness of muscles, and easy fatigability are problems which make physical jobs unrealistic.

For this reason, joining the Armed Forces, Police, or planning a professional sports career are not realistic. When studying, try and live close to your centre of higher learning to avoid fatigue due to travelling. The first year on campus can be spent in university accommodation, if you make an application early enough. If purchasing a car, an automatic model is best to save joint stress. Also, there are kits available to lower the car seat so your head does not touch the car roof.

If a relatively sedentary job can be obtained, this will save energy to be made available for after-hours pursuits, and family life. Regular gentle exercise should always be built into your routine. Many people with Marfan syndrome end up in positions of authority, partly due to their height. Always plan if possible, to have a second career or to work part-time if possible, after the age of 50.

Famous people with Marfans

Peter Mayhew who played the character of Chewbacca in Starwars

Emergency Alert Card

Designed for all those with Marfan syndrome and related disorders

www.marfantrust.org/shop

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Questions & Answers

This is because many people suffer from easy fatigability as they grow older. Study your pension arrangement carefully, as you may have to apply for early retirement on grounds of ill health, even if this is only due to fatigability. Make the most of your natural talents in choosing a career.

What should I do in an emergency?

A The Marfan Trust has a card (see left column) which you can carry in your wallet explaining Marfan syndrome. The most important emergency is sudden acute chest pain, very severe in nature, which may indicate an aortic dissection. It is important to explain to the ambulance crew that you have Marfan syndrome and that you may be dissecting. They should take you to the nearest casualty where urgent assessment, not with a chest x-ray which is inadequate, but with an echocardiogram or CT scan, or MRI study (whichever is available) should be performed by the cardiologist on duty. Staff are available even in the middle of the night, and it must be explained that this is very urgent. If a problem is revealed, you should be taken immediately to the nearest cardiac surgery unit. This will avoid the high mortality risk in the first 24 hours.

Another type of emergency involves the eyes. If a lens dislocates, vision will be blurred, and you may have pain in your eye. Or if a retina detaches, you may see a curtain coming down, or lose vision completely in one eye. You should go to the nearest ophthalmology hospital emergency unit, since glaucoma may result in loss of vision if not treated immediately. Emergency reattachment of the retina can also be performed, to save vision.

Weight poll

As we all know a lot of people with Marfans have the question of whether they will ever put weight on. So what was Your weight like between 16-30 years?

I was underweight during this period	52%
I was within normal weight during this time	30%
I was overweight during this time	18%

Part 2 of the Poll - How did your weight change after this age?

I was underweight growing up, but i gained weight as i became an adult	70%
I was underweight growing up and as an adult im still under weight	19%
My weight growing up was in the normal range and still is	11%

the Marfan Forum

Poll was taken by the members of the Marfan forum in July '20. Part 1 by 61 & Part 2 by 101 members

Marfan Trust Hotline

020 7594 1605

Questions & Answers

Pneumothorax (air in the chest outside the lung) can also produce sudden severe chest pain and shortness of breath. Again, admission to the nearest Accident and Emergency department should lead to an urgent chest x-ray to locate the pneumothorax, and admission for observation and treatment. Please present your emergency card to indicate that pneumothorax is a recognised complication of Marfan syndrome.

? Why Me?

A This question is most often asked by people who are the first members affected in a family. Everyone carries, on average, three major gene mutations. It is very difficult to make a perfect human being! Most of these mutations do not cause trouble, however the fibrillin-1 gene is a very important one, as fibrillin is a protein which holds us together in every system. Therefore, someone who has a mutation in this important gene may well show some signs.

Although we can diagnosis this condition nowadays, we do not have a magic cure. However, due to 30 years of research, improved medication and surgery has lengthened the average life span into the normal range, so early literature which suggests a very early age at death is no longer correct. Therefore, make a life plan and get started on it. If you look after yourself, and attend your medical appointments on a regular basis, you will be looked after by experts.

We do not know why spontaneous mutations occur in human beings. They are not the result of anything we do, or do not do. They occur purely by chance.

Clothing, Shoes & Bed Links

www.shorturl.at/klnvZ
Facebook group selling used clothes.

www.shorturl.at/fhkJR
Boohoo women's tall clothes

www.shorturl.at/aqBHT
Dorothy perkins tall womens clothing

www.shorturl.at/pwK15
Burtons menswear

www.shorturl.at/euCK4
Asos tall mens clothing

www.bigsize.co.uk
Mens shoes 12-19

www.longbeds.com
Long beds up to 7ft 3"

www.bigclothing4u.co.uk/tall
Mens BC4U

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Questions & Answers

The fibrillin-1 gene is made up of 65,000 small messages. It is a large gene, and therefore prone to hits, possibly from radiation, which can make the whole message distorted or ineffective. This occurs in every cell in the body, so is difficult to replace. However, with early diagnosis and lifelong management, every aspect of Marfan syndrome is treatable. You are not alone. We now realise how very common this condition is, affecting at least 1 in 3000 people worldwide. With your family doctor you can create a team to care for you through the NHS, supplemented by private medicine if you wish this, and can afford it. Please take a pamphlet to your family doctor who will know how best to care for you.

? Clothing & shoes - where can i find them?

A Shopping online makes modern choice much more available. For ladies, Booho & Dorothy Perkins provide clothing for tall ladies. High and Mighty specialises in clothing for men. For children, buying clothes for an age group several years in advance of the child's age may provide suitable sizing. Long narrow shoes are difficult to find, but a lace-up Oxford style shoe is best for growing feet to provide support around the arch. Flat shoes or low heels are recommended to prevent strain on joints. Clothes may be made to fit, and shoes can be made by specialist makers. The tallest people in Europe live in Scandinavia, Germany and The Netherlands. Holidays to these regions may provide shopping opportunities. Often, sports shoes are the most comfortable, and can be made to fit by wearing thick socks and padding the tongue with felt. Joining the Tall Club UK and Ireland (www.tallclub.co.uk) may bring benefits. They provide a catalogue of companies which supply tall people, including 7 foot beds with matching duvets. You may meet other Marfan syndrome people if you join this club.

Eyes - Dislocation of lenses, short-sightedness, retinal detachment, glaucoma

Skeleton - Excessive height with long limbs and fingers, flat feet, protruding or indented chest bone, loose joints, scoliosis, early osteoarthritis

Heart - Ballooning and potentially fatal tearing of the aorta, backward billowing of the heart's valves

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About the Marfan Trust

Founded in 1988 to fund research into the cause, treatment and possible prevention of Marfan syndrome, the Marfan Trust is the only Marfan charity in the UK. It funds its own laboratory, the Sonalee Laboratory, undertaking medical and analytical research so that more is known about Marfan syndrome and its management. The results of its internationally recognised research enable doctors and surgeons to provide better treatment for patients in the short and long term.

Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders

The Trust is also committed to supporting those with Marfan syndrome and their families and raising awareness of the condition, so that more people recognise the signs and more diagnoses are made in good time. This is crucial as over 18,000 people are affected by Marfan syndrome in the UK, with many anticipated to be living with the condition undiagnosed.

The Marfan Trust's three main objectives are to:

1. Provide support and medical guidance to those with Marfan syndrome and their families;

2. Fund medical research projects that aim to aid the diagnosis and treatment of Marfan syndrome patients; and

3. Provide educational literature on Marfan syndrome and all its aspects to the medical profession and the general public, thus raising awareness of the condition.

Our website includes information on the medical aspects of Marfan syndrome; advice and guidance on living with Marfan syndrome; updates on our latest research projects and publications and ways to support the Trust's important work.

www.marfantrust.org

Marfan Trust
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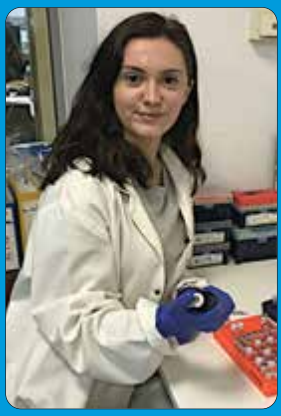
Donate online with JustGiving™



Help Stop Life Saving Research being put to an end by donating to Us. We fund medical research to aid diagnosis & treatment

www.justgiving.com/ntrgnlojhs

Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders

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Credits

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Marfan Trust Information Leaflets

Find out more about the charity Marfan Trust Leaflet
Marfan Trust Guide to Marfan syndrome
Marfan Trust Dental Guide to Marfan syndrome
Marfan Trust Exercise Guide to Marfan syndrome
Marfan Trust Bowel Symptoms in Marfan syndrome
Marfan Trust Care of Symptomatic Hypermobile Joints
Marfan Trust ENT Aspects of Marfan Syndrome
Marfan Trust Growing Older with Marfan Syndrome
Marfan Trust Musculoskeletal Problems in Marfan syndrome
Marfan Trust Pregnancy in Marfan syndrome
Marfan Trust Paediatric Guide
Marfan Trust Psychosocial Aspects of Marfan Syndrome
Marfan Trust Dural Ectasia

www.marfantrust.org

Useful Websites

Marfan Genetic Testing UK www.shorturl.at/vCP48
NHS Genetic Services www.shorturl.at/iFJR8
Marfan Foundation USA website www.marfan.org
The Marfan Trust www.marfantrust.org
Teen Heart BHF (13-18 year olds) www.shorturl.at/bpCK7
One beat BHF (18-30 year olds) www.shorturl.at/knvOQ
Marfan Forum Facebook Group www.shorturl.at/gwxA5
Marfan Forum UK Facebook Group www.shorturl.at/otBI6

By donating to the Marfan Trust you can contribute to an ever-growing body of knowledge on the condition, allowing more doctors and medical specialists to deliver the best possible treatment to patients affected by Marfan syndrome.

Any amount you donate, no matter how big or small, will make a massive difference to the lives of families affected.

You can donate via Bank Transfer
You can make a donation by bank transfer for any amount.
Our bank details are as follows:

BANK: Charities Aid Foundation (CAF)
ACCOUNT NAME: The Marfan Trust
SORT CODE: 40-52-40
ACCOUNT NUMBER: 00017677
REFERENCE: Your Name Here

Or alternatively you can make a donation via:

Just Giving - www.shorturl.at/gwABX

Virgin Money - www.shorturl.at/gCG496

Thank you for supporting us and the work we do

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Marfan Trust Hotline
020 7594 1605

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