Marfan Trust Charity
Find out more today
www.marfantrust.org
Registered charity number 328070
Marfan syndrome is a genetic disorder of the body's connective tissue that affects men and women of any race or ethnic group, with an incidence of 1 in 3,300 worldwide. The syndrome can be inherited, but can also occur spontaneously with no family history. Currently only 9,000 patients are diagnosed in the UK, although researchers fear there could be thousands of undiagnosed cases owing to a lack of awareness of the condition.

Marfan syndrome was identified in 1896 by a French physician, Antoine Marfan and is known to affect the body in the following ways:

**Eyes** - dislocation of lenses, retinal detachment, short sightedness, 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.

All aspects of this condition are treatable. Undiagnosed and severe heart problems can lead to complications which can cause death at an early age. In many instances medical and surgical intervention can considerably reduce this risk.
Marfan syndrome can be difficult to diagnose because signs of the condition vary greatly from person to person. Most affected people will not have all the signs and complications of Marfan syndrome.

The most common feature is excessive height and long limbs, fingers and toes. This may be accompanied by a protruding or concave chest bone. Other signs include dislocated lenses, short-sightedness, a high-arched palate, crowded teeth and orthodontic problems.

Diagnosis can be confirmed by a blood test demonstrating the abnormal gene. These tests are available through referral to a clinical geneticist. Each child of an affected parent has a 50% chance of inheriting Marfan syndrome. Prenatal diagnosis is now available for most families with this condition, where a mutation in the fibrillin-1 gene has been found in a parent.

In general, Marfan syndrome is diagnosed after careful physical examination, particularly focusing on the main aspects involved; eyes, skeleton and heart. Major involvement in two out of three of these is required for a clinical diagnosis.
The Marfan Trust was founded in 1988 to fund research into the cause, treatment and possible prevention of Marfan syndrome. The results of our internationally recognised research have been used to educate patients and doctors about treating Marfan syndrome in the short and long term. The Trust is also committed to raising awareness of the condition, so that more people recognise the signs and more diagnoses are made in good time.

Over the past 25 years the Marfan Trust has funded a number of ground-breaking projects including:

- The running of the Sonalee Laboratory at St George’s Hospital; a lab dedicated to research into Marfan syndrome.
- A research fellow who made a major contribution to the discovery of the gene for fibrillin-1, responsible for this condition.
- A researcher who worked on pregnancy associated risks in Marfan syndrome patients.
- 15 medical students who have helped to discover and analyse gene mutations in UK patients.
- The production of information pamphlets regarding psychosocial, dental, rheumatological, prenatal and ageing problems in Marfan syndrome.
- The AIMS trial: a national drug trial, co-funded by the British Heart Foundation, assessing the effects of Irbesartan on preserving the aortic wall and prolonging lifespan in Marfan patients.
How to help...

If we could raise enough funding, we could start to lift the shadow of Marfan syndrome from the estimated 18,000 affected people in the UK. All funds raised go towards research which will help to treat and support patients affected by Marfan syndrome. Every contribution is most welcome and will help us to achieve our goals.

You can make a donation online through our website using secure payment methods www.marfantrust.org/make-a-donation/

If you would like to donate regularly through standing order with your bank please email us to find out more marfantrust@sgul.ac.uk

If you would like to fundraise for the Marfan Trust please email marfantrust@sgul.ac.uk we do not have a limit on how much you can raise for us we are so grateful for any money raised, so please get in touch.

Postal donations (cheques) can be sent to the address below, please include your full name and address so that we are able to thank you for your kind donation. Please also download our Gift Aid form and send in with your donation please. Please make all cheques payable to ‘The Marfan Trust’. Thank you.

Marfan Trust Charity
Guy Scadding Building
Dovehouse Street, London, SW3 6LY
Raising Awareness….

Many people affected by Marfan syndrome, mostly children, remain undiagnosed due to symptoms not being recognised by doctors and family members. We are campaigning to raise awareness of Marfan syndrome and its signs so more people can be diagnosed and get their treatment programme commenced as quickly as possible.

The Marfan Trust distributes pamphlets so that doctors, dentists and opticians recognise the signs caused by Marfan syndrome and refer their patients accordingly. We also issue newsletters twice yearly.

We need your help to spread the word about Marfan syndrome. By holding a fundraising event, talking to your family doctor, paediatrician, dentist, optician and/or by helping to distribute our literature you can be part of our campaign to lift the shadow of Marfan syndrome.

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