

## Publications

The Trust has produced a number of pamphlets for the medical professions, these are:

- Dental aspects of Marfan syndrome
- ENT aspects of Marfan syndrome
- Growing older with Marfan syndrome
- Musculoskeletal problems with Marfan syndrome
- Pregnancy in Marfan syndrome
- Psychosocial aspects of Marfan syndrome

The Trust has also produced a 'Guide to Marfan syndrome' and 'Exercise in Marfan syndrome'.



In addition, the British Heart Foundation has produced 2 books about the condition. Although these books were published in 2002, they are still good background reading about the condition and the work that has been undertaken to prolong the life of sufferers.

- **Marfan syndrome**  
Information for people with Marfan syndrome, parents of children with Marfan syndrome and interested health professionals.
- **The Marfan syndrome**  
A clinical guide for doctors and consultants.

If you would like a copy of any of the above publications, please telephone the Charity Administrator on Tel no. **020 8725 1189** or e-mail: [hdydyk@sgul.ac.uk](mailto:hdydyk@sgul.ac.uk)

## Grace Barrand Design Centre

The Trust is very grateful to the Grace Barrand Design Centre for holding an exhibition of CD sized works of Art donated by local and national artists, celebrities, family and friends, the proceeds of which were donated to the Trust.

The Grace Barrand Design Centre located in Nutfield, Surrey has developed a reputation for promoting and selling the very best in contemporary design. The retail shop sells kitchen, glassware, furniture, lighting, jewellery, gifts & cards. The Gallery hosts up to six exhibitions a year, promoting the work of both new and established artists and makers. A licensed Café is on site.

The Grace Barrand Design Centre  
19 High Street, Nutfield,  
Surrey RH1 4HH  
Telephone: **01737 822865**

[www.gracebarrand.com](http://www.gracebarrand.com)

## Tall Clothing & Large Shoe Size Suppliers

A list of tall clothing and large shoe size suppliers for men, women and children is now available. If you would like a copy of this list, contact the Charity Administrator on

**020 8725 1189** or e-mail:  
[hdydyk@sgul.ac.uk](mailto:hdydyk@sgul.ac.uk).

## Charity Fun Day

The friends and colleagues of Jane Brogan, who died as a result of Marfan syndrome, held a charity fun day and raised **£440** for the Trust in memory of Jane. A big thank you to all those who took part and supported the event.

## Motability Reward Scheme

The Motability Scheme enables disabled people to use their government-funded mobility allowances to obtain a new car, powered wheelchair or scooter.

One of our supporters has advised us of a reward scheme operated by Motability, whereby members of this organisation who recommend a friend to join the scheme, receive a reward of £25, along with the new person joining the scheme. Our supporter very kindly donated his reward to the Marfan Trust.

Further details about the scheme are available on Motability's website (below), or by calling the Charity Administrator on **020 8725 1189**.

Motability –  
[www.motability.co.uk](http://www.motability.co.uk)

## RAFFLE

Enclosed with the newsletter you will find raffle tickets. Please support the work of the Trust by buying raffle tickets in order that our vital research can continue.

If you would like additional tickets, please contact the Charity Administrator on Tel No: **020 8725 1189** or e-mail [hdydyk@sgul.ac.uk](mailto:hdydyk@sgul.ac.uk). Please return tickets and unsold books in the pre-paid envelope by **27 June 2008**.

### RAFFLE PRIZES

**1st Prize - £200 cash**

**2nd Prize - £50 cash**

**3rd Prize - £25 cash**

**PLUS OTHER PRIZES**

SGUL ref: 9487

# MarfanTrust News

Spring/Summer 2008

PATRONS: SIR MAGDI YACOUB FRCS, MR ANTHONY LATTER MA

[www.marfantrust.org](http://www.marfantrust.org)

Registered Charity No: 328070

## Preimplantation Genetic Diagnosis (PGD) now available in the UK

For those couples who wish to be referred for consideration of the pros and cons of preimplantation genetic diagnosis to assure a pregnancy which is not affected with Marfan syndrome, a private London hospital has now been granted a license to offer this service.

Interested couples should initially contact Dr Child as genetic counselling and gene mutation identification are the first steps in the process. Preimplantation Genetic Diagnosis may become available through the NHS in the future. A contribution to

private PGD costs can sometimes be made available from the patients' local Primary Care Trust. Dr Child can be contacted on **020 8725 5248** or e-mail: [achild@sgul.ac.uk](mailto:achild@sgul.ac.uk)

## STOP PRESS!!

The Trust has been successful in its application for a BBC Radio 4 Charity Appeal, which will be broadcast on 26 October 2008.

The Radio 4 Appeal is broadcast weekly, across 3 transmissions, which reaches an estimated 2.5 million listeners.

## eBay for Charity

The Marfan Trust now has a charity account on eBay.

Any one wanting to sell items on eBay can now donate between 10% and 100% of the final selling price to the Trust.

For further details visit [www.ebay.co.uk](http://www.ebay.co.uk).

eBay for Charity -  
[www.ebay.co.uk/community/charity](http://www.ebay.co.uk/community/charity)

## Support the Marfan Trust by adopting a duck and you could win the first prize of £10,000

Not only did they smash the Guinness World Record for the 'World's Biggest Charity Duck Race,' previously held by Singapore, but also managed to raise hundreds of thousands of pounds for various good causes. This year's event will take place on Sunday, 31 August 2008 at Hampton Court Palace.

The Marfan Trust can share in the funds raised with a little help from our supporters. This is how it works; it costs £2 (plus a recommended donation of £3 to the Marfan Trust). Every duck entered has the chance to win a fantastic prize and the winning duck wins a massive £10,000.

All you need do is visit [www.thegreatbritishduckrace.co.uk](http://www.thegreatbritishduckrace.co.uk) and select the Marfan Trust as the benefiting charity for your duck. The Great British Duck Race will do the rest. You are

not restricted to one duck, buy as many as you like and tell your friends, family, colleagues and acquaintances....the more ducks we sell, the more money we make.

Alternatively, you can now buy your ducks direct from the Marfan Trust. Ducks cost £5 each. If you would like to purchase a duck(s), please complete the enclosed form. (Cheques made payable to the Marfan Trust).



Great British Duck Race - [www.thegreatbritishduckrace.co.uk](http://www.thegreatbritishduckrace.co.uk)

# A Difficult Year Ahead

Worries of recession, falling stock markets, global credit crunch, soaring food and oil prices and higher energy bills are all signs that 2008 is going to be a difficult year not only for individuals but also for smaller charities like the Marfan Trust.

We receive no government grants and rely entirely on donations and the generous help of our supporters. Any donations we receive, no matter how small, are crucial to the success of our work.

If you are able, please support us.

**DONATE ONLINE** via our website; [www.marfantrust.org](http://www.marfantrust.org). It's easy and secure.

**STANDING ORDER** Set up a regular donation by a standing order. Forms are available on our website or be calling the Charity Administrator on **020 8725 1189**.

**DONATE IN MEMORY** Make a donation in memory of a loved one.

**GIFT IN YOUR WILL** Leave a legacy to the Marfan Trust.

**DONATE BY POST** Make a gift by post. Please make cheques payable to the Marfan Trust.

## Fundraising

If you are not able to make a personal donation then please consider fundraising for us. The money you raise whether large or small will make a difference to the lives of many people and their families affected by Marfan syndrome.

You can make it as fun, creative or as challenging as you like and to help you on your way we have put together some fundraising ideas.

## GARDENS FOR

**THE MARFAN TRUST** – Why not open up your garden for the Marfan Trust? Whether it is a small corner-plot or country estate, it's a great way of fundraising. You could also have a plant sale, a book or cake stall.

**HOLD A JUMBLE SALE** – Get all of your friends and families to clear out all of their unwanted items and hold a jumble sale somewhere local. Remember one person's rubbish is another person's treasure!

**DINNER PARTY** – Cook a meal and invite your friends – for a price! You could also run a mini-affle or auction during dinner to provide additional entertainment and raise money.

These are just some of the things you can do. Every donation that we receive is vital to our research work.

# RESEARCH UP-DATE

## Tissue Doppler Study

Dr Anatoli Kiotsekoglou has now presented her ground-breaking echocardiogram work regarding new diagnostic criteria in adults with Marfan syndrome to the European Society of Cardiologists, the American College of Cardiologists, and in the spring will present to the UK Cardiologists. She has had 2 papers accepted for publication and is preparing a third and fourth.

## Arrhythmia in Children and Adults Study

The first 15 patients who wore Holter 48 hour recording machines have given results as follows:

12 were male and 3 female, with age range 16 – 63 years. 9 electrocardiograms were normal, 3 were slightly abnormal, and 3 were distinctly abnormal. The most common abnormality was Ectopic beats (extra heart beats) coming from the ventricles (lower heart chambers) or atria (upper heart chambers). The heart rate was low on average, which is a common finding, possibly due to the large heart size in tall patients. One female had frequent extra beats, and required medication to suppress these. One male had many pauses as well as extra beats, and was referred for consideration of medication and possible cardiac pacemaker implant.

This useful study continues, with preliminary results indicating that arrhythmias develop a bit earlier in the Marfan syndrome patient population, than in the normal population. Cardiologists should ask about arrhythmia, and patients should not hesitate to report palpitations. Extra heart beats should be taken into account during surgery for any reason. Occasionally, patients need care for their arrhythmia, even while we are watching the aortic root diameter to predict the need for future surgery.

This study is funded by the Foyle Foundation and donations for the medical equipment for this study were received from F H Muirhead and the Rosetrees Trust. A final report will be prepared in 2 years time. Patients who wish to participate should contact Dr Child directly.

## Summer Medical Student Project 2008

This year's project involves the eye in Marfan syndrome, which will involve using molecular genetic techniques, and other scientific techniques if necessary to study the eyes. The main ocular problem is dislocated lenses.

This affects 40% of patients with Marfan syndrome, and is a major cause of visual disability, requiring surgery to remove the lens and replace it with an anterior segment lens with fixed focal distance. This is not without risk, including infection in the eye, and detached retina as a result of the removal of the lens and its surrounding fluid.

Since only 45% of patients with dislocated lenses have mutations in the Marfan gene for fibrillin-1, we are curious as to what other causes can be discovered.

This project has been designed to look at the constituents of the ciliary zonular filaments which hold the lens in place. Genes controlling the production of ciliary zonules will then be screened for errors. Medical student Miss Dana Ahnood is pursuing this project which is funded by the Marfan Trust.

## Travel Insurance

If you are having difficulty in obtaining travel insurance, try a specialist medical insurer.

These include:-

- **Orbis** offers travel insurance for people with impaired lives. Tel No: **01424 220110**  
Website: [www.orbis-insure.co.uk](http://www.orbis-insure.co.uk)
- **Freedom Insurance**  
Freedom is a specialist travel insurance company, offering quality pre-existing medical condition travel insurance.  
Tel No: **01223 454290**  
Website: [www.freedominsure.co.uk](http://www.freedominsure.co.uk)
- **MediCover Travel Insurance** is a travel insurance policy that has been created by Inter Group Insurance Services Limited to provide travel insurance for travellers who have suffered from a majority of medical conditions. Tel No: **0870 735 3600**  
Website: [www.medi-cover.co.uk](http://www.medi-cover.co.uk)
- **Cover My Travel** offers travel insurance for many medical conditions that are often refused by other insurance companies. Tel No: **0800 917 7829**  
Website: [www.covermytravels.co.uk](http://www.covermytravels.co.uk)

Give your mouse  
a heart



Just by using Everyclick.com as your search engine, you raise money for the charity of your choice.

No charge. Just free giving.

[www.everyclick.com](http://www.everyclick.com)

Make Everyclick.com your homepage and raise money for THE MARFAN TRUST whenever you search the web.

[www.everyclick.com/marfan-trust](http://www.everyclick.com/marfan-trust)

## Les & Jenni Vince



Last year Les & Jenni Vince raised £9,400 bringing the total amount raised in 8 years to £40,000.

Les and Jenni Vince were asked to open the new mezzanine floor at their local Tesco Supermarket in Cleethorpes on 29 October 2007. Tesco very kindly donated £1,000 to the Marfan Trust.

*Thank you to Jim Vince for raising £236 on his fish round.*

## THANK YOU

Thank you to all those who bought Marfan Trust Christmas Cards last year. More cards will be on sale later in the year.

## In Memory

Donations received in memory of Richard Medd and Dr Keith S C Reid who passed away in 2003.