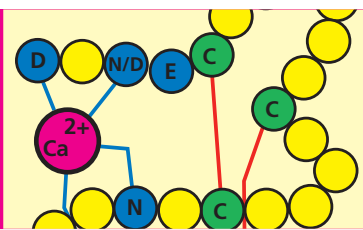


Research Update

All our studies have Ethical Committee Approval



Tissue Doppler Echocardiography

Our Research Fellow Dr Anatoli Kiotsekoglou has now performed this high resolution echocardiography for 75 Marfan syndrome patients and 30 normal volunteers, many of them St George's medical students. We are very grateful to all who have participated so patiently. These results are being analysed at present, and preliminary results should be available for the next newsletter. A fundraising drive is underway to purchase the ultrasound machine for Anatoli. The total cost of the machine is £110,000, and contributions are being sought from other charities. This machine will be used in the next 5 years in our drug trial. Further volunteers who have not had heart surgery are required, and anyone with Marfan syndrome interested in participating should contact Anatoli directly by **telephone on 0208 725 3480 or e-mail: anatoli9@hotmail.com**. The study involves a half day visit to the unit with expenses paid.

Arrhythmia (Irregular Heart Rhythm) Study

100 patients with arrhythmia, diminished left heart function, or signs of abnormal function on echocardiogram will be selected for this study. With electrocardiogram monitor equipment, attached painlessly to the chest for 24 hours, we hope to determine the proportion of patients suffering from irregular heart beat, and the exact type of palpitation. Clinicians concentrate so much on the aortic root diameter, they often forget to ask whether the patient has troublesome palpitations. This study should increase awareness amongst both doctors and patients, as to the importance of palpitations, and their treatment.



Research nurse Miss Kate Dale has been recruited from the Cardiac Ward at St George's Hospital and is now working half time on this research study. She is funded through the Marfan Trust by the Foyle

Foundation for 2 years, and the Holter Monitor equipment has kindly been donated by F H Muirhead and the Rosetree Trust. **Interested patients who wish to participate should contact her on telephone no: 020 8725 2591, or write to her in the Cardiac and Vascular Sciences Dept., St George's, University of London, Cranmer Terrace, London, SW17 0RE.**

Pilot Study of Losartan

Dr Kiotsekoglou has recruited 7 patients, but we need a further 15 volunteers with Marfan syndrome to try this new use for an old, familiar medicine, which doubles the life span in the Marfan syndrome mouse. We are doing a short trial to see how Losartan has this effect on human blood vessels, by measuring ultrasound waves in the neck, arm and leg. Patients need to be of either sex, aged 18 – 54, with no heart surgery. They can be on medication already. The study involves coming to St George's Hospital with travel expenses reimbursed, for the first visit, again at 6 weeks and at 12 weeks. The volunteer would take Losartan for 6 weeks, and placebo (an ineffective sugar pill) for 6 weeks. Neither the patient nor the doctor knows which is which. At the end of the study, we will break the code and see if Losartan has had any effect on the blood vessel wall.

This study is unique in the world. We feel that if we are going to offer Losartan to Marfan syndrome patients we need to know how it works in humans.

Interested volunteers should contact Dr Kiotsekoglou as mentioned above (echocardiography study). We must stress that Losartan is an old medicine that has been around for a long time, has very few side effects, and has been used safely for many years for high blood pressure. This is not a new drug, merely a new use for an old drug.

Our new website is now up and running. Donations can now be made by credit or debit card. If you would prefer to receive an electronic copy of the newsletter, just complete the e-newsletter subscription form and you will automatically be sent an electronic version of the newsletter. If you decide to receive an electronic version of the newsletter, please let the Charity Administrator know by **e-mailing, hdydyk@sgul.ac.uk**.

www.marfantrust.org



Marfan Trust News

AUTUMN/WINTER 2006

PATRONS: SIR MAGDI YACOUB FRCS, MR ANTHONY LATTER MA

www.marfantrust.org

Registered Charity No: 328070

Chairman's Report



By the time you receive this Newsletter it will be nearing the end of another successful year for the charity.

Steady progress is being made through the continued commitment of the team supported by the Charity. Studies, drug trials and further research are all underway, enabling the medical profession to not only diagnose the severity of the problems encountered, but also to be able to plan the correct medical treatment, in both the short and long term.

This Newsletter highlights 3 additional studies which the Trust has agreed to support in order to further understand the possible cumulative problems/occurrences of the syndrome. It also highlights a pilot study of a known drug that may have real beneficial effects for sufferers with Marfan syndrome.

I know it is a well worn line – but we “couldn't do it without you”. We would not be able to fund this additional research without the continual fund raising and support of those who generously donate their time and money. In this instance I would like to mention our charity administrator, Helga Dydyk. Her continual commitment, thinking up new ideas and sources of

funding has helped to maintain the Charity's financial liquidity. I would also like to acknowledge the efforts of our most prolific fundraiser Les Vince and his wife Jenni. They have raised a further £3,000 in this last year, bringing their total to £29,000 in 7 years. We were pleased to invite them to London to the July Trustees meeting. As reported earlier in the year we have up-dated the Charity's website, which is now fully operational. Visitors to the site now have the ability to donate on-line through a secure payment system – “PayPal”. Also for those who may be new to this Charity you may review past Newsletters and read about our research projects on line.

With Christmas almost upon us, I encourage you to purchase our Christmas cards. This year we have additional designs on offer for your consideration. Not only will your support add to the funds, it will also help to widen the public knowledge of Marfan Syndrome and the Trust.

With all good wishes for the forthcoming festive season.

**Les Tiffin
Chairman**

Christmas Cards 2006



Marfan Trust 2006 Christmas cards are now on sale. Please support the work of the Trust by buying our Christmas cards.

Not only will your donation be supporting research into the cause and possible prevention of Marfan Syndrome, it will also raise the profile of the condition with the majority of people who have never heard of it.

If you would like to order any cards, please complete the enclosed order form and return it to the Charity Administrator in the pre-paid envelope or you can order on-line by visiting the Marfan Trust website at www.marfantrust.org

Update on Exercise in Marfan Syndrome Study

There has been a good response to the questionnaire that was sent out on 'Exercise in Marfan syndrome'. The main points that have come out at this stage seem to be that:-

- over 90% of respondents do some form of exercise every week and 65% do over 2 hours. By far the most popular activity was walking, followed by the gym, swimming and cycling.

- 72% of respondents said that having Marfan Syndrome affected their exercise habits; mainly in terms of choice of activity, the intensity of exercise, and not being able to participate competitively.

- less than half of the respondents (44%) have received information about suitable exercise activity.

- many respondents would like more information about ways in which they can improve fitness safely, without just being told what they can't do.

- many felt that the information

they had received was very general and not tailored to their specific needs, and also that there should be a greater awareness among paramedical professionals (including physiotherapists, occupational therapists and nurses) and gym/fitness instructors about Marfan Syndrome and its particular requirements in terms of exercise.

- 25 of the respondents had had heart surgery; of these only half were offered cardiac rehab. Of those who had cardiac rehab, some reported positive experiences, but most found that they were joining in classes with patients who were having rehab following heart attacks – so classes weren't always suitable and the other members of the class tended to be more elderly.

Now the study has been completed, a leaflet is being produced on the results and is available on request, as well as being sent out to the medical profession and gym/fitness instructors.

Celebrity Support from Rory Bremner



"I am pleased to be associated with the Marfan Trust and their research work in helping those affected by Marfan syndrome and their families".

BUPA Great Run South

Thank you to all those who ran for the Trust in this year's event. We hope to have places available again for next year. If you know someone who would like to run for the Trust, please contact the Charity Administrator on 020 8725 1189 or e-mail hdydyk@sgul.ac.uk.

In Memory

Donations received in memory of Bryan Orrell and Steven Grantham.



Liam Gash died aged 22 on the 13 August 2006 whilst backpacking in Australia.

His parents never knew that Liam had Marfan syndrome and were very shocked that it had not been identified sooner.

His parents feel that if they had known about his condition, they would have placed many restrictions on him but that would have been very difficult as he was a lively young man, running a football team and playing football.

When Liam took ill in Australia, his parents managed to travel out there and be with him whilst he underwent major surgery. Unfortunately 3 days later Liam suffered a seizure and after a further 9 hours of surgery, sadly he died. Liam's parents are devastated by his death and want to do as much as they can to raise awareness about the condition, and anything that will help to educate others, is a comfort to them.

Thank You

The Trust has received a donation of £2,500 from the Freemasons' Grand Charity.

Fantastic News... ICAP Selection

The Marfan Trust has been selected as one of the charities for ICAP's annual global Charity Day which will take place in December 2006.

ICAP is the world's largest voice and electronic interdealer stocks and bonds broker, with offices around the world. Since the beginning, ICAP has always given money to charity on an ad hoc basis. In 1993, when the firm had grown to around 100 people in London, it was decided to do something on a larger and more innovative scale which would make a significant difference to charities. The idea of the ICAP Charity Day was born, a day on which all revenues and commissions would be given away to just a few charities.

The project ICAP will be supporting is the Drug Trial. In this study patients with proven Marfan syndrome will test the efficacy of Losartan in normalising of the measured aortic wall, and limitation or prevention of aortic aneurysm and dissection which is the commonest cause of early death in patients. If our trial is successful, it should lead to further trials in the paediatric population under the age of 10, where the preventive potential is even greater.

The Trust is very grateful to ICAP for choosing us as one of their charities for this year's event.



Les & Jenni Vince presenting Les Tiffin, Chairman of the Marfan Trust with a cheque for £1,000. To-date Les & Jenni have raised a total of £29,000 for the Trust.

Left to right: Les Tiffin, Dr Child, Les Vince, Jenni Vince, Lucy Hyde and Dr Micheal Carr (Trustees).

Alexandra Rose Day

Thank you to all those who helped out with this year's Alexandra Rose National Flag Day, enabling the Marfan Trust to raise worthwhile funds for our research work.



Raffle Prize Winners



Left to right: Miss Helga Dydyk, Charity Administrator, Miss Louise Ocaka, PhD Student, Miss Bethan Davies, Medical Student, Mrs Manwai Lam Secretary to Dr Child, pulling out the winning tickets for the Raffle.

Thank you to everyone who bought tickets for our Summer Draw which raised £845 for the Trust.

The winners of the first 4 prizes were:

1st Prize £200 cash
Linda Gibbens

2nd Prize Weekend Voucher for 2 at a Hilton Hotel
Aiden Merrett

3rd Prize £50 cash
J Rufus

4th Prize Wallace & Gromit poster signed by Nick Park
Sarah Bowdin



Left to right: Les Tiffin with Linda Gibbens, 1st prize winner.

Other Prize Winners:

Ben Child
Frances Johnson
G Maclean
Jo Child
M Arichi
Mr A Latter
Mr Dahlhoff
Mrs C Allen
Mrs C Lee
Mrs H Braunton
Mrs J Glynn
Mrs M Grasar
P Dobson
P Evron
P G O'Reilly
P Pinnock
P Sharratt
P Timmins
R Adams
R Berry
S Goldrup
Sue Tiffin
Teresa Thompson
Mrs Wijetunge.

STOP PRESS

We will be holding a raffle again next year. If anyone would like to donate a prize, please contact the Charity Administrator on **020 8725 1189** or e-mail hdydyk@sgul.ac.uk