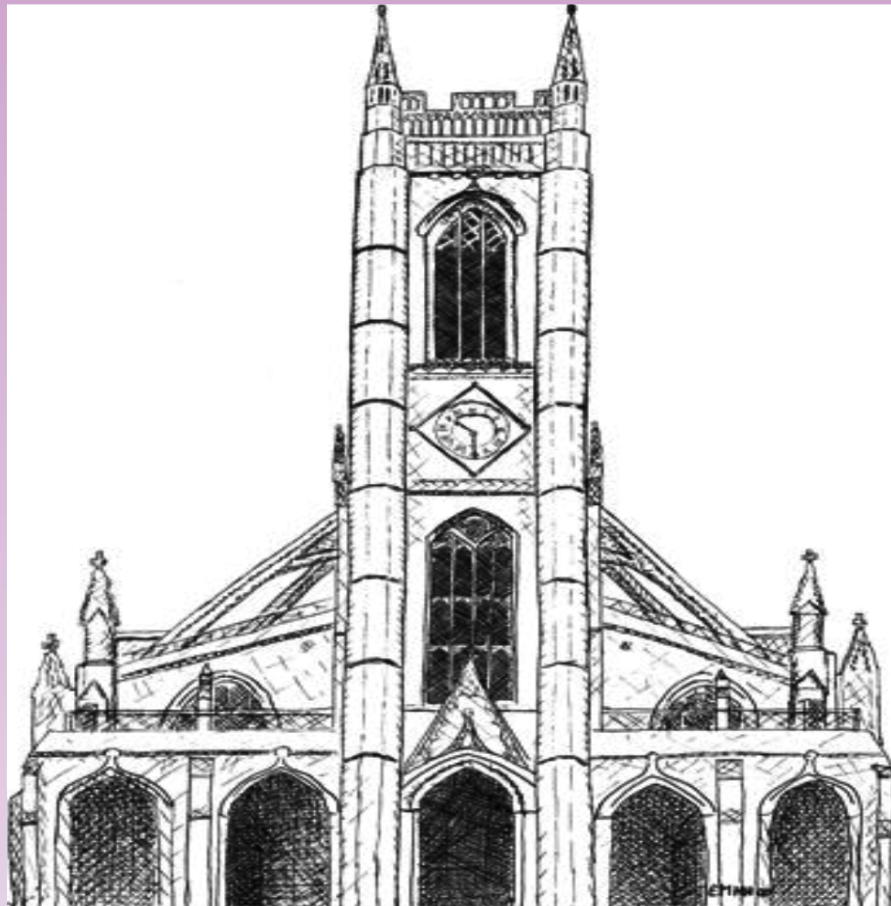


Handel's Messiah

St Luke's Church, Sydney Street, Chelsea, London
Saturday, 12 December 2009 at 7.30 pm



The Marfan Trust is sponsoring a performance of The Messiah as a celebration of 20 years of research into Marfan syndrome.

The concert will be held on Saturday, 12 December at 7.30pm.

Tickets are priced at £25, £20, £15, and £10 and are available from the Charity Administrator.

Please telephone **0208 725 1189** or e-mail: **hdydyk@sgul.ac.uk**.

We hope to see many of our supporters at this event.

In Memory

Donations received in memory of Mrs Beatrice Olive Sanderson, Keith Greenwood, Miss Elizabeth Ann Hardy, Pam Bury, Liam Gash and Jacob Long.

Music for MARFAN

Patrons: Sir John and Lady Maryanna Tavener

A series of concerts are being planned to raise funds towards the medication trial. The first concert will be held at **St Luke's Church, Chelsea, London on Saturday, 12 December.**



Miss Sultana Hasso, St George's Medical Student, using the PCR machine kindly donated by the family of Mr Daniel Finkletaub, in his memory. Dr Gavin Arno, PhD, supervises her successful BSc Biomed project.

SGUL ref: 01587

MarfanTrust News

Autumn/Winter 2009

PATRONS: SIR MAGDI YACOUB FRCS, MR ANTHONY LATTER MA

www.marfantrust.org

Registered Charity No: 328070

Research Progress

Completion of medical student and PhD projects by Sultana Hasso, Dana Ahnood and Dr Anatoli Kiotsekoglou has resulted in the following posters presented at a recent cardiovascular genetics research day here at St George's Hospital. This material is in preparation for publication.

- TGFB2 mutation analysis in Marfan and associated syndromes.
- The role of fibrillin-1 mutations in families with dominantly inherited ectopia lentis.
- Effects of genotype on biventricular function in adult patients with Marfan syndrome.

Two special research projects are still underway. In the first one, we are looking at other candidate genes to explain ectopia lentis (dislocated lenses) in patients who do not have mutations in the fibrillin-1 gene. This has uncovered the fact that a further identified gene and two other possible genes may well be involved. This helps to explain ectopia lentis patients who do not have full blown Marfan syndrome, and therefore need to be counselled quite differently. These patients often present in Marfan syndrome diagnostic clinics, and may be wrongly diagnosed as having Marfan syndrome unless molecular genetic tests

are done.

Similarly, a research project is underway to examine mutations in messenger RNA for fibrillin-1, and other possible causative genes for familial ascending aortic aneurysm. Again, families present to Marfan syndrome clinics with similar aortic aneurysms, but no dislocated lenses, and often very few or no skeletal features of Marfan

syndrome. Mutations in further genes are being found and reported. This should enable us to again screen and counsel these families correctly.

Future projects planned include looking for modifier genes which can lessen the effects of the Marfan syndrome genes within families, explaining the variability of severity in close family members.

News of the medication trial of Irbesartan in Marfan syndrome, will be forthcoming in the near future once funding is confirmed.

Advice as to how and where to join in the planned trial will be widely circulated at that time.

Thank you to all those who kindly contributed towards the medication trial appeal.

Preimplantation Genetic Diagnosis for Marfan syndrome

Guy's Hospital will shortly become the first genetic centre to offer the above testing for couples with Marfan syndrome, funded through the NHS. At present, this service is only provided in a private hospital, but Guy's should have a licence within 6 months.

Any couple where one member has Marfan syndrome, and the couple wish to plan an unaffected pregnancy, is invited to contact Dr Child to discuss this possibility. This is a great step forward for those families who are seriously affected, and wish to avoid passing the gene onto their offspring.

TEL: 020 8725 5248 E-MAIL: achild@sgul.ac.uk

Downing Street Petition

The Trust has been contacted by members of the Marfan Forum who are seeking a more co-ordinated approach to Marfan syndrome recognition and treatment, especially for patients who live outside of London. The Marfan Forum has created an e-petition which has been approved by Downing Street. The petition reads: "We, the undersigned, petition the Prime Minister to improve the awareness, earlier diagnosis, and treatment of Marfan Syndrome and HCTDs. There is a great need to raise awareness of Marfan Syndrome, in particular of its variable manifestations. Earlier diagnosis and understanding would not only prevent tragic deaths, but fundamentally alter the

quality of life possible for those with the condition. In this country a system does not exist where one can see a Marfan specialist about all the combining aspects of this difficult condition that affects many different systems in the body simultaneously. We need less departmentalisation. In France and the US there are Marfan centres. Please could we have a similar arrangement here." A minimum of 500 signatures are required.

Deadline to sign up by: 27 January 2010 – Signatures received so far: 209

If anyone would like to support the petition created by the Marfan Forum, the website address is:-

<http://petitions.number10.gov.uk/marfan/>



It was a proud day in June when two successful St George's PHD students who have worked in the Sonalee Laboratory, graduated. Dr José Aragon-Martin studied the causes of Glaucoma, which affects 8% of Marfan Syndrome patients. Dr Louise Ocaka identified two scoliosis gene locations. Scoliosis affects 70% of Marfan Syndrome patients. Congratulations to both on their success. Their publications are read internationally.

Marfan Trust CHRISTMAS CARDS



are now on sale. All our old stock has been

reduced to £2

per pack of 10 cards.

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. Alternatively, you can order Christmas Cards via our website, www.marfantrust.org.

Please support the work of the Trust by buying our Christmas cards

"Growing pains" – A 25 minute film on Marfan Syndrome



The film was premiered at the Whitgift Film Theatre in Cleethorpes, Dr Michael Carr attending on behalf of the Marfan Trust. From left, Les Vince, Nigel Dunwell, Aaron Naveran, Steven Vince, Jenni Vince, Jim Vince, Dr Michael Carr; seated, from left, Alan Broodryk, with Stuart Hall of Hallway Media, Director of the DVD and Laura Gray, Producer of the DVD.

Mr Les Vince who has Marfan syndrome and has lost close family members to the condition has made a short film for release to Community TV Channels, which has been part-funded by the Marfan Trust.

The documentary also features the Gash family who lost their son Liam, at the age of 22 to Marfan syndrome. The Trust's Medical Director, Dr Anne Child, who is one of the leading specialists on Marfan syndrome in the UK, is also featured in the DVD.

If you would like a copy of the DVD, telephone or e-mail the Charity Administrator and consider sending a minimum donation of £5 to cover postage and production costs. Tel: 020 8725 1189, e-mail: hdydyk@sgul.ac.uk.

Les has had a good response to the sale of the DVD and would like to thank all those who have very kindly bought a copy.

Tel No: 020 8725 1189
e-mail: hdydyk@sgul.ac.uk

2009 Raffle Prize Winners

The winners of the first three main prizes were:

1st Prize	£100 cash	Mrs E Deslandes
2nd Prize	£50 cash	Frances Johnson
3rd Prize	£25 cash	T Myers

Winners of the £10 Marks & Spencer Gift Voucher:

Janice Hamilton
Mr R Towne
A Dobin
Mrs S Englert
Mrs Holly Chapman

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