

## In Memory of Liam Gash

Family and friends of Liam Gash held another walk in his memory in February in his home town of Sunderland. A total of £4,672 was raised for the Trust.

A big thank you to Lucy, Liam's sister for organising the event and to all those who very

kindly took part and sponsored the event.

Donations have also been received in memory of Liam, from the Lions Club of Sunderland, Boxing Day Dip and the North East Executive Sporting Club held a boxing match.



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### THANK YOU

To the customers of The Royal Oak Public House, Leatherhead, Surrey for their donations to the Marfan Trust collection box.

### Charity Fun Weekend

A charity fun weekend was held at the Unicorn public house in Luton the weekend of 23 – 25 May raising £1,400 for the Trust. Thank you to everyone who supported this event.

### In Memory

Donations received in memory of Trevor Bostock, Alan King, Nicola Elizabeth Maclean and Lisa-Marie Unwin. Special thanks to the family and friends of Dr Keith Reid who kindly donated £485 in his memory.

## A big thank you

to all those who adopted a duck in the Great British Duck Race, which was held on the 31 August 2008, raising £306 for the Trust.

**Overall winning duck number: 60595**

The remaining winning duck numbers:

196101; 69015; 203768; 214722; 189223; 235043;

198514; 203156; 68622; 94472;

44857; 189809; 189340; 209787;

205303; 48459; 204000; 173837;

72270; 50496; 80798; 68255;

209980; 62911; 57581; 75229;

198558; 173312; 229737; 189808



SGUL ref: 00288

# MarfanTrust News

Autumn/Winter 2008

PATRONS: SIR MAGDI YACOUB FRCS, MR ANTHONY LATTER MA

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

Registered Charity No: 328070

# Celebrating 20 years of Progress

In this our 20th year we celebrate the many magnificent achievements which have fulfilled our aims of providing research, education, and support for patients with Marfan syndrome and their families.

### Past Chairmen and Trustees

The charity was founded by patients and physicians who wished to discover the cause of, and cure for Marfan syndrome. Chairmen and Trustees have given generously of their time and energy to ensure the success of the charity. We are especially grateful to our Chairmen, Mr Brian Adams, Mr Anthony Latter, Mr Don Beer and currently Mr Les Tippin, for carrying the work forward.

Over the years the accounts have been kept immaculately by Miss Pauline Child, Mr Daniel Finkeltaub and more recently by Mr Roger Hill, and audited by Hazelwoods LLP.

The average number of 7 Trustees has been made up of people who are affected with Marfan syndrome or who have an immediate family member with

charitable Trusts, individuals and corporate organisations all of which have enabled us to increase our endeavours, beyond our expectations.

### Research Advances

The discovery of the Marfan syndrome gene, the mapping of over 200 mutations from UK patients and their families, family screening including prenatal diagnosis and pre-implantation genetic diagnosis, have all been made possible with the support of the Marfan Trust for the Sonalee Laboratory at St George's, University of London. The laboratory staff (Dr Paolo Comeglio and now Dr Gavin Arno) together with research assistants and medical students working on related projects, have been funded by the Trust. The Brian Adams Memorial Student Research Fellowship was set up and is awarded annually for this purpose.

### Raising Awareness

The Trust has produced a number of information pamphlets as a result of medical student projects regarding Psychosocial, Musculoskeletal, Ear, Nose and

Marfan syndrome, so that their first hand knowledge of the disease has spurred them to help decide how to raise funds, and how to apply them. Again the Trust is extremely grateful to these people who have given freely of their personal time, often travelling long distances to attend the quarterly meetings. Their guidance has been invaluable.

At present our Trustees are; Mr Alan Savage, Mr Roger Hill, Dr Michael Carr, Dr Caroline Carr, Ms Lucy Hyde and Mrs Victoria Stilliard.

### Sources of Funding

We are extremely grateful to all donors both large and small for their support, both financial and moral. Every penny raised has been used directly for one of our aims. In recent years we have been fortunate to receive several large donations from major

# Marfan Trust

## CHRISTMAS CARDS

are now on sale.  
Our old stock has been  
**reduced to £2**  
and our new cards are  
at the lower price of **£4**  
per pack of 10.

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

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



Throat, Dental, and Ageing Problems in Marfan syndrome. Also, the increased risk of aortic and cardiac problems in pregnancy for women affected with Marfan syndrome has been highlighted. Our Exercise in Marfan syndrome booklet makes specific recommendations. All pamphlets have been distributed to the relevant speciality, again funded by the Marfan Trust.

The Marfan Trust Research programme has made a major contribution to the International Consortium which is co-operating and collaborating to increase research production by increasing patient numbers available for study. Anonymised family pedigrees, clinical details, and mutations discovered have been contributed to the Marfan gene map held in Paris. We have contributed the second largest number of mutations of any country in the world. We could not have done this without the

enthusiastic co-operation of our patient population. In this way, UK families can help all Marfan syndrome families round the world by sharing clinical information about how they are affected, and what treatment is best.

### Future Plans

All the previous research is a precursor to our ultimate wish to find preventative medicine for Marfan Syndrome which will delay or stop the aortic root thinning and dilating in the stages prior to aortic dissection. Although we are very glad that expert cardiac surgeons can repair or replace weak areas in the aorta and heart, even the surgeons would be grateful if we could remove the need for surgery, with its small attendant risk.

The Marfan Trust has encouraged a nationwide medication trial. We hope that this major 5 year

drug trial which is due to commence in 2009, will be funded in the near future. A network of 21 collaborating centres, all of whom have Marfan syndrome clinics, has been recruited to help.

### Marfan Newsletter

All these advances could not have been made without patient support, and patient efforts in raising donations for which we are extremely grateful. We will continue to provide up-to-date news through the twice yearly distribution of this newsletter. We aim to be factual, informative, and encouraging. If you know of anyone else who would like to receive this newsletter please send their name and address (with their permission) to:

Helga Dydyk  
Tel no: 020 8725 1189 or email  
[hdydyk@sgul.ac.uk](mailto:hdydyk@sgul.ac.uk)

## BBC RADIO 4

Marfan Trust  
Supporting Research into Marfan Syndrome

## Charity Appeal for the Marfan Trust

### Sunday 26 October 2008

You may already know that we will be the featured charity for the BBC Radio 4 Appeal on Sunday 26 October 2008.

We are now delighted to announce that Lady Maryanna Tavener will be presenting the appeal on our behalf. We are very grateful to her for finding time in her busy life to record the broadcast.

The appeal will air on Sunday 26 October 2008 at 7.55 am and 9.26 pm, as well as the following Thursday at 3.27 pm on FM 92.4-94.6 and LW 198. Please put this date in your diaries and tell all your friends, family and work colleagues.

The appeal attracts an estimated 2.5 million listeners so this is an ideal opportunity to raise awareness of Marfan syndrome.



Lady Maryanna Tavener

**BBC Radio**

**Frequency: FM 92.4 – 94.6**

**LW 198**

**Tune in and support us!**

## 2008 Raffle Prize Winners

Thank you to everyone who bought tickets for our Summer Draw which raised £780 for the Trust.

The winners of the first 3 main prizes were:

<b>1st Prize</b>	<b>£200 cash</b>	<b>Mrs V Pakenham-Walsh</b>	★ DVD	R Adams
<b>2nd Prize</b>	<b>£50 cash</b>	<b>Sara Moses</b>	★ DVD	R Mead
<b>3rd Prize</b>	<b>£25 cash</b>	<b>Frances Villa</b>	★ DVD	E V Green
			★ DVD	F Burnel
			★ DVD	J Hammond
			★ DVD	O Power
			★ DVD	Mr Myers
			★ DVD	Mr P Deslandes
			★ DVD	Miss M Grasar
			★ DVD	Mrs H Braunton
			★ Pen	S Kull

Other Prize Winners:

£10 Marks & Spencer gift voucher	J Burnell
£10 Boots gift voucher	Mrs S Tippin
Photo frame/clock	Mrs M Sole
Laptop bag	Andy Sole
Laptop bag	Mrs Nohrin Doherty