



**PUMPKIN SALE**  
A big thank you to Andy Sole who held a pumpkin sale and managed to raised £232 which was split between the Marfan Trust and a local childrens hospice in Kent.

Les Tippin, Chairman of the Marfan Trust being presented with a cheque by Phil Coles, Martyn Blake and Andrew Cherrett. Phil took part in the 44 mile hike last November from Inkpen Beacon in Berkshire to Eling Tide Mill in Hampshire. Phil's local scout movement also held a Carol concert and proceeds of this came to the Trust.



Andrew Cherrett, Phil Coles, Les Tippin (Chairman Marfan Trust) Martyn Blake.

## Make a Regular Donation by Standing Order

In 2010 our income from charities, foundations and companies was down by 34%. In fact the majority of the funds raised by the Trust last year came from individual donations, sponsorship money, the summer raffle and the sale of Christmas cards.

In light of the austerity measures being taken by the Government, 2011 is going to be a very difficult year not only for families and 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.

We know that times are hard for everyone but donating just £5 a month by standing order, will help us plan a

better future for Marfan syndrome sufferers.

Money that the Marfan Trust receives is spent on:

- **Research Salary funding in order that vital research studies can be carried out.**
- **Purchase of laboratory consumables required for the various research studies.**
- **Maintenance of essential equipment for the research projects.**
- **Printing of the Trust's newsletter and distribution to patients and donors.**

Setting up a standing order is easy. Inside this newsletter you will find a Standing Order form. Just complete this and return it in the pre-paid envelope enclosed.

**Thank you**

## 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, or prefer **not** to receive tickets in the future, please contact the Charity Administrator on:

Tel: **020 8725 1189** or  
Email: **hdydyk@sgul.ac.uk**

Please return tickets and unsold books in the pre-paid envelope by **27 June 2011**.

### RAFFLE PRIZES

- 1st Prize – £100 cash**
- 2nd Prize – £50 cash**
- 3rd Prize – £25 cash**
- PLUS 5 Marks & Spencers £10 Gift Cards**

## In Memory

Donations received in memory of  
**Jane Brogan**  
**Paul Newman**  
**Liam Gash**  
**Allan Price**  
**David Ramsden**  
and **Mr Robert Paul Jones**

## THANK YOU

The Marfan Trust is very grateful to Amanda Holmes and her friends for raising **£735.32** at their recent fundraising event in Cleveland.

# MarfanTrust News

Spring/Summer 2011

PATRONS: SIR MAGDI YACOUB FRCS, MR ANTHONY LATTER MA

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

Registered Charity No: 328070

## Research News

### AIMS Medication Trial

Patient recruitment for the medication trial (AIMS Trial) will commence in May 2011 for a 2 year period. Dr Child is the Principal Investigator for St George's Hospital, with a research nurse, Ms Helen Heath seconded to this project. Dr Anand Saggar will be referring patients from the Marfan syndrome diagnostic clinic, and is acting Geneticist to the team at the Brompton Harefield complex for the drug trial. The medication is prepared, together with the placebo, and both will be delivered to the 27 participating centres throughout the UK.

Patients at St George's Hospital will be recruited through the Marfan syndrome follow-up clinic on Monday and Wednesday afternoons. Dr Child has been granted a research registrar, Dr Sabiha Gati, as acting Cardiologist of this clinic for the duration of the medication trial. Each prospective patient who has already volunteered will be sent a letter of information about the trial, prior to their annual follow-up clinic. In the actual clinic, Ms Helen Heath will explain the project and recruit the patients.

Interested patients aged 6 – 40, with no cardiac surgery, should ask at their next clinic visit if they are suitable. More information is available on the AIMS website, at [www.rbht.nhs.uk/aims](http://www.rbht.nhs.uk/aims).

### Sonalee Laboratory

In the laboratory, Dr José Aragon-Martin has already commenced analysing FBN1 genes for patients who will be invited to join the medication trial. He will be responsible for analysing 100 samples per year from all the participating centres.

**Dr Gavin Arno** is writing his paper about fibrillin-1 mutation negative patients with ascending aortic aneurysms, indicating what proportion have mutations in other causative genes including TGFBR2 and ACTA2. He is also collaborating with Mr David Charteris' research fellow **Mr Aman Chandra** from Moorfields Eye Hospital, in the laboratory to look at new genes for dislocated lenses and study patients' eyes to see how the effect of the new genes compares with the effect of the Marfan gene.

We thank all participating patients for their help.

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## Calling All Internet Users

If you regularly search the internet, instead of using Google, please use Everyclick. It will not cost you anything and every time you use this search engine, the Marfan Trust gets 1p.

To-date this site has raised **£1,740,892.10** for charities.

The Marfan Trust has earned **£93.82** from that amount.

**1p** does not sound much, but in this difficult financial climate, as

a certain large supermarket says **"Every Little Helps!"**

Please make Everyclick your homepage.

**Remember every click you make on this site, gives the Marfan Trust 1p.**

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)

Medical student, **Miss Emily Gibson**, has completed a project regarding scoliosis in Marfan syndrome. Is the scoliosis caused by rapid pubertal growth spurt, and early puberty? Can these predisposing characteristics also explain adolescent scoliosis in non-Marfan patients? This material was presented in March at the Phillip Zorab symposium in London regarding scoliosis causes and treatment. We are hoping that her data can be correlated with Gavin's data on genotype. Are there certain mutations which can predict severe scoliosis?

Student **Stephanie Harris**, supervised by José, has been studying the role of ACTA2 mutations in fibrillin-1 mutation negative aneurysm patients. Mutations have been found, helping to explain aneurysms in patients who do not have classical Marfan syndrome.

A collaborative project with Miss Marjan Jahangiri, our Marfan aortic

surgeon at St George's Hospital, has seen her fellow, **Dr Nada Adbulkareem**, working on the genetics of bicuspid aortic valve. Nada is studying the role of fibrillin-1, TGFBR2, and newer genes.

**Dr Anatoli Kiotsekoglou**, echocardiologist, has successfully completed her PhD thesis on echo and MRI studies in Marfan syndrome. Congratulations to her, and thank you to all participating patients.

#### New Research Projects in 2011

**The Brian Adams Memorial Studentship** will involve a medical student in assessing Marfan syndrome patients using the Ghent criteria, and reporting them to the French International database to swell numbers for analysis and collaborative publications.

**New Research Studentship – The Daniel Finkleaub Memorial Studentship** will be granted to a medical student to perform a postal questionnaire survey of Chronic

Fatigue Syndrome in Marfan syndrome. This mysterious debilitating complication needs highlighting, and treatment offered to avoid a major effect on quality of life for young and old alike.

#### Publications

ARAGON-MARTIN, J.A., AHNOOD, D., CHARTERIS, D.G., SAGGAR, A., NISCHAL, K. K., COMEGLIO, P., CHANDRA, A., CHILD, A. H., and ARNO, G. Role of ADAMTSL4 mutations in FBN1 mutation-negative ectopia lentis patients. Human Mutation, 2010 31:E1622-E1631. doi:10.1002/humu.21305

DETAINT D, FAIVRE L, COLLOD-BEROUD G, CHILD A. H., LOEYS B L., BINQUET C, GAUTIER E, ARBUSTINI E, MAYER K, ARSLAN-KICHNER M, STHENEUR C, HALLIDAY D, BEROUD C, BONITHON-KOPP C, CLAUSTRES M, PLAUCHU H, ROBINSON P.N., KIOTSEKOGLOU A, DE BACKER J, ADES L, FRANCKE U, DE PAEPE A, BOILEAU C, JONDEAU G. Cardiovascular manifestations in men and women carrying a FBN1 mutation. European Heart Journal Advance Access. August, 2010

#### Accepted for Publication

KIOTSEKOGLOU, A, CHILD, A.H. Impaired biventricular deformation in Marfan syndrome: a strain and strain rate study in adult unoperated patients. Echocardiography Journal.

## COME & SING DAY WITH JOHN RUTTER

On the 16 October 2010 a Come & Sing Day with John Rutter, the famous choral composer was held at the historic Magdalen College in Oxford, in aid of the Marfan Trust.

This day was held in honour of Sir John Tavener, and to raise funds for the Marfan Trust medication trial which commences this year, in an attempt to find improved medical treatment to prevent aortic aneurysm in Marfan syndrome.

Marfan syndrome has affected Sir John Tavener throughout his life. Modern treatment has gained him approximately 30 extra years of life, but John Rutter reminisced about their time together at Highgate School, when he was always jealous of John Tavener, since John Tavener was excused games because of his heart involvement. The rest of the school had to run across frozen marshes in the dead of winter, wearing only light sports gear! John Rutter has never forgiven John Tavener for this ability to avoid games! He offered to hold this choral workshop, since "I would do anything to get John better".

The event started with 'Amazing



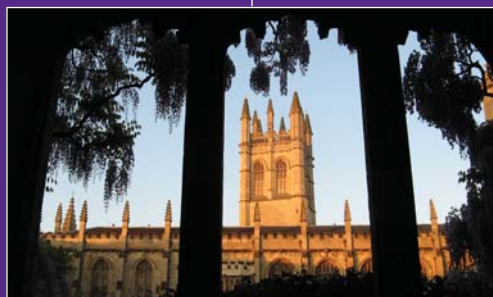
Grace' as warm up song which was sung three times, the last time at maximum volume to determine the acoustics, and fire the soul! The roof was literally raised.

The event was a huge success and a long standing ovation for both Mr John Rutter and Mr Daniel Hyde (organist, pianist and accompanist), expressed the audience's thanks for this uplifting day which everyone enjoyed tremendously. Much of the music and many CDs were purchased, and John kindly autographed many of the works.

The Marfan Trust Trustees are all extremely grateful for his sharing his precious time and knowledge with choral singers from all over the county (some from Wiltshire, Hampshire also one lady from France), and for sharing his knowledge and experience in this master class.

We would also like to express our sincere thanks to Daniel Hyde, Director of Chapel Music at Magdalen College, Oxford, for getting permission for us to use the chapel and for organising the event.

We are hoping to organize a similar event later this year.



## Fundraising through Virgin money giving

We have 5 people who are doing sponsored events for the Marfan Trust so far this year.



#### Sal Kiamil

##### London Marathon, 17 April 2011

Sal is taking part in the London Marathon on Sunday, 17 April. He is running for 2 charities, the Marfan Trust being one of them as a close friend of his passed away last year at the age of 30, as a result of the condition.

You can sponsor Sal by visiting his page on Virgin Money Giving:-

<http://uk.virginmoneygiving.com/salkiamil>



#### Pheobe Brown

##### Annual British 10K Run, 10 July 2011

Pheobe has taken part in a number of sponsored runs for different charities. This year she has decided to run for the Marfan Trust.

You can sponsor Pheobe by visiting her page on Virgin Money Giving:-

<http://uk.virginmoneygiving.com/phoebebrown>



#### Lucy Gash

##### Edinburgh Marathon, 22 May 2011

Lucy is taking part in the Edinburgh Marathon on the 22 May 2011 and is running for the Trust. Lucy's brother, Liam, died at the age of 22, from Marfan syndrome, whilst backpacking in Australia.

You can sponsor Lucy by visiting her page at:

<http://uk.virginmoneygiving.com/team/mackemovers>



#### Suzanne Scott

##### Sponsored Pyjama Walk, 3 July 2011

Suzanne, along with her friends, have organised a sponsored pyjama walk in Beveridge Park, Kirkcaldy in aid of the Marfan Trust.

You can sponsor Suzanne by visiting her page on Virgin Money Giving:

<http://uk.virginmoneygiving.com/team/suzannescott>

#### Dawn Barber, British Gas Big Swim, 2 July 2011

Dawn will be taking part in the British Gas Big Swim in London, swimming a mile down the Thames. Marfan syndrome was first discovered in Dawn's family when her aunt and cousin died suddenly within a year of each other. Since then various other members of Dawn's family have been diagnosed with Marfan syndrome.

You can sponsor Dawn by visiting her page on Virgin Money Giving:

<http://uk.virginmoneygiving.com/DawnBarber>

**Virgin Money Giving**