

“Thank you to all our supporters of the Trust including attendees at the events, trustees, patrons, sponsors, friends and the Lowe Scientific Advisory Board for helping raise funding for research into the Lowe syndrome disease”. Lorraine Thomas, Chair, The Lowe Syndrome Trust

Searching for a cure

During 2003, thanks to successful fundraising events and support from sponsors and friends, the UK Lowe Syndrome Trust has raised a further £50,000 for medical research, bringing the total raised since our formation in June 2000 to almost £200,000.

This has enabled the Trust to make three substantial research grants this year, to **Dundee University’s** School of Life Sciences (£50,000), **Imperial College London** (£50,000) and **University College London** (£50,000), all to support three year studies into the defective ORCL1 gene which causes Lowe Syndrome. The Trust has also donated a further \$15,000, in addition to an earlier grant of \$10,000, towards two research projects in the USA coordinated by the Lowe Syndrome Association.



*Patron Jono Coleman presenting grant cheque to **Imperial College London** (right).*

*Dr John Lucocq of **Dundee University’s School of Life Sciences** receiving a cheque for £50,000 from Oscar and Lorraine Thomas (left).*



In October 2002 the Trust, together with the LSA supported the first international Lowe syndrome medical conference at the National Institutes of Health (NIH) in Bethesda, Washington USA. The Trust also awarded a £9,000 grant to William van’t Hoff at **Great Ormond Street** children’s hospital. This research has been successfully completed and Lowe children’s kidney cells have been cultured and available for the other research projects. Lowe Syndrome research is also underway at Manchester University under the guidance of Martin Lowe in the Lowe Laboratory.

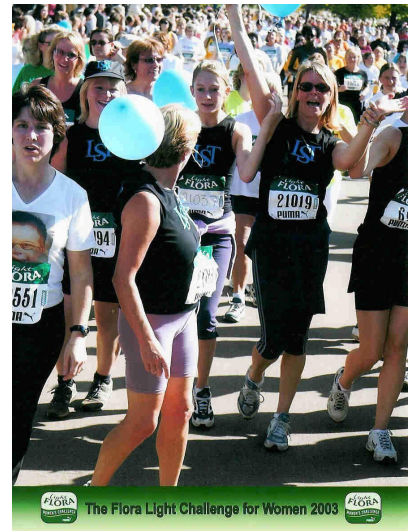
Nobel Laureate in Physiology of Medicine Dr Brenner has said “the real units of function in an organism are cells and not genes .. what is required to be discovered is the actions of the products of the genes”. To date, despite government announcements on genetic research there is no UK government support or funding into Lowe Syndrome, but Lorraine Thomas, chair of LST, will be meeting Peter Greenaway, Assistant Director of the NHS in January. This follows on from three earlier meetings with Sir John Pattison, Director of Research and Development at the NHS. Lorraine is also in communication with Lord Warner, Parliamentary Under Secretary of State.

Highlights of 2003

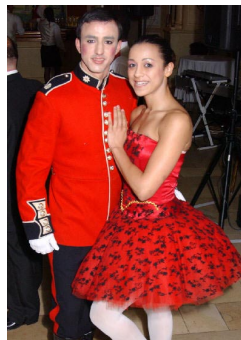
For the third year running friends and supporters ran in the **Flora Light Women's Challenge** (pictured right), a fun run in Hyde Park in September. Forty women donned LST t-shirts and raised £4,000. The Challenge is for women of all ages and abilities and we aim to have an even bigger team in 2004. Entry forms are published in the summer; please contact Lorraine Thomas if you are interested in taking part.

LST supporters also took part in the 10 km **Two Castles Race** in Kenilworth in June, raising £400.

A **BT Funday** raised £2,700, including a £1,000 contribution from **EMC Computer Systems** who have generously supported the Trust since its formation.



November's **Nutcracker Ball** was a fabulous event in Mayfair that raised £30,000 – the most raised at a single event yet. Charity patron Jono Coleman made a speech, fellow patron Tony Hadley drew the raffle, and Mark Lamarr conducted the auction for an amazing array of donated goods, including the most sought after item of the evening: an England World Cup rugby shirt signed by the team that fetched £6,000. 150 guests enjoyed a champagne reception, dinner and dancing to the Grand Funk Corporation Band.



Clockwise from top left: patron Jono Coleman and chair Lorraine Thomas; dressed up for the Nutcracker theme; dancing the night away; enjoying the dinner; Mark Lamarr gets the auction underway.

Many organisations chose LST as their official charity in 2003, including **Golders Hill School**, which raised £3,000, **Abbotts Hill School**, £500, **Bertrum House School**, £143.64 and **Highgate Pre Prep School** who raised £1000. **Woolworths** Finchley Road have nominated the Trust as their charity of the year as did **Marks & Spencer** Temple Fortune who asked Lowe Syndrome sufferer Oscar Thomas to open up their new styled store in December, presenting a cheque to the Trust for £150.00. Please note that due to the urgency of trying to get the newsletter out highlighting events, we will compile a list of sponsors and donators for the next Newsletter.

Other continual fund raising activity continues such as **Trust letter writing** to various charities and we have produced a **Jonathan Ross Lowe Appeal poster** which is being used on two Heathrow Airport buses to raise awareness and hopefully funding.

So a great year with just one disappointment. Although we had a terrific line up of professionals and celebrities including **Bruce Forsyth, Rory Bremner, Robert Powell, Dennis Waterman, Trevor Harris, Tim Brooke Taylor, Ron Atkinson, Trevor Eve, Willie Thorn, Sasha Upton, Richard Boxall, Ruud Gullit, and Andy Gray**, the **Golf Day** at Wentworth planned for 1st July, fell victim to the Gulf War as many companies cut back on client entertainment during the summer. But with all the contacts we made in the golf world we hope to resurrect a pro-celeb golf day in the future.

Another supporter of the trust is **NW magazine**. Cathy Levy, Editor, met with chair Lorraine Thomas and subsequently printed a one page article in the magazine highlighting the trust and its endeavours to raise awareness and funding for research. The magazine has been an enormous support by printing a few articles over the past year including the cheque donation to Great Ormond Street and pictures of the Nutcracker Ball.

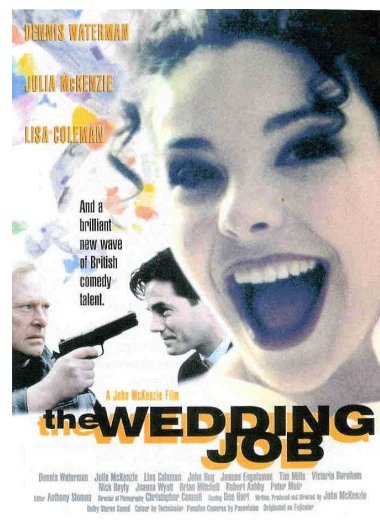
Looking forward to 2004

2004 looks set to be another busy fund-raising year with many exciting events already lined up:

- **Radio 4 Appeal** on 21 April with actor Tom Conti explaining to listeners why LST deserves their donations.
- **JONATHAN ROSS Film Quiz Evening**. **Jonathan will confirm date of this event by week ending 7 February when invitations will be issued.**
- **Ladies who lunch** in March, date and venue to be confirmed.
- **Brent Cross Shopping Centre collection day** on Sunday 21 March – we need eight volunteers to persuade shoppers to dig deep into their pockets.
- **New York Marathon** on 7 November – places are available for fit volunteers who can guarantee to raise a minimum £1000. The Trust will pay for your return flight and entry fee and can arrange (but not pay for) accommodation (full information attached). For those interested in participating in the **London Marathon 2005** please contact Lorraine (we cannot get group places but can apply individually).
- The first **UK Lowe Syndrome Work Shop will take place in December 2004**. This workshop will allow all the current researchers, Lowe Syndrome Trust Scientific Advisory Board and Trustees to convene and discuss the projects underway.
- The First **UK Lowe Syndrome Symposium** is being planned for 2005 when Research teams from both America and Europe will be invited to convene in London to discuss worldwide research projects.
- A champagne reception at the **House of Lords**- 7th July 2004.
- A summer **wine tasting** evening in Mayfair – June 2004.
- **“A Question of Sport”**, Knightsbridge, London

ANOTHER FUNDRAISING IDEA!

Film producer John McKenzie will donate 50% of the proceeds from any film license distribution deals that LST negotiates for “*The Wedding Job*” in the UK, USA, Canada and France. A comedy starring Dennis Waterman and Julia McKenzie, it tells the story of Samantha, 90 minutes away from her wedding, and the chaos that ensues when three armed gangsters led by Denis Waterman, on the run from the police, take refuge in the brides’ house and get sucked into the pre-wedding tension and family hysteria.



What is Lowe Syndrome?

Lowe Syndrome is a gene disorder that affects boys and can occur with no family history. Its symptoms include multiple physical and mental handicaps including **cataracts in both eyes (with glaucoma and partial sight or blindness)**, **muscle weakness (hypotonia or floppy baby syndrome)**, **brittle bones (some children develop rickets)**, **kidney problems (leaking kidneys causing metabolic imbalance)**, **arthritis**, **cysts can be found on gums of teeth, in the brain, on kidneys and body**, **poor growth**, **mental impairment (autistic spectrum disorder) and epilepsy (sometimes with severe seizures)**. There is no known cure, hence the urgent need for research. Sadly, most children do not survive into adulthood due to the severe complications of the disease.

The **Lowe Syndrome Trust** is a UK small charity formed in June 2000 run by volunteers from home. The aim of the Trust is to raise funds to encourage medical research into Lowe Syndrome in the UK and internationally. Entirely funded by donations and fundraising events, 100 per cent of the money raised is spent on medical research. In addition to having **Jonathan Ross** as a Trustee of the charity, we are also supported by **Tony Hadley** and **Jono Coleman** who are the Trust Patrons. We are delighted to announce that **Tris Payne** (TV Presenter) and **Richard Park** (Fame Academy/Radio Presenter) have also joined the trust as Patrons lending tremendous support and awareness to the cause.

The Trust has established a **UK Medical and Scientific Advisory Board** which advises on research issues and research proposals received. Meetings are held twice yearly at Great Ormond St Hospital.

- **Dr William van't Hoff, Consultant Nephrologist, Great Ormond Street Hospital (GOSH)**
- **Professor Robert Unwin, Professor of Nephrology & Physiology, University College London**
- **Professor Shamshad Cockcroft, Lipid Signalling Group, Department of Physiology, University College London.**
- **Dr Philip Beales, Hon Consultant in Clinical Genetics, Institute of Child Health (ICH)**
- **Professor Bruce Caterson, Professor of Research in Orthopaedics and Biochemistry, Cardiff University.**
- **Dr Anthony Norden, Clinical Biochemistry, Addenbrooke's Hospital, Cambridge.**
- **Professor Peter Cullen, Professor in Inositol Signalling and Lister Institute Research Fellow, Department of Biochemistry, University of Bristol.**

The Lowe Syndrome Trust Medical Advisors are:

- **Mike Harrison, Honorary Consultant in Pediatric Dentistry, Guys Hospital**
- **Dr David Taylor, Ophthalmic Surgeon, GOSH.**

How can you help?

Become a Friend

Please help our work by becoming a Friend of LST. Pledge £100 per annum and receive 10% discount and priority booking for Trust event tickets as well as regular news updates. Just complete the attached form.

Gift Aid

Make a donation and let us reclaim the tax. The Charity is registered with the Inland Revenue and CAF for tax deductible contributions. If you are a UK taxpayer please use the Gift Aid form attached (also downloadable from our web site) and send with your cheque or postal order made out to "Lowe Syndrome Trust" to Fundraising Dept, Lowe Syndrome Trust, 77 West Heath Road London, NW3 7TH. You can also make a will leaving cash or assets to the Trust.

Previous Donations

If you have previously donated money to the trust, please can you complete the attached gift aid form to enable the trust to reclaim an additional 28pence for every £1 donated.

Get in touch

If you would like to find out more about Lowe Syndrome and the work of LST, if you would like to make a donation, become a "friend" or volunteer to help us, contact Lorraine Thomas at:

Lowe Syndrome Trust
77 West Heath Road
London NW3 7TH
Telephone: 020 8458 6791 or 07958 444020
Email: lthomas@care4free.net
www.lowetrust.com

Registered Address 77 West Heath Road, London NW3 7TH

Telephone 020 8458 6791

www.lowetrust.com

Registered Charity 1081241

Trustees: Jonathan Ross, Lorraine Thomas, Catherine McNaught, Carolyn Mitchell, Undine Reidy

Patrons: Tony Hadley, Jono Coleman, Tris Payne & Richard Park



Low Syndrome Trust
“Care today ... cure tomorrow”

**LOWE SYNDROME TRUST
BECOME A FRIEND?**

Become a friend of the Trust and be eligible for priority information and tickets on all events, a 10% discount off your ticket price (applies to each member individually and not guests) and receive a twice yearly newsletter.

Your donation of £100 to become a Friend will help enable more research into the incurable disease Lowe Syndrome.

Please complete and return to Lorraine Thomas, 77 West Heath Road, London NW3 7TH

I would like to become a Friend of The Lowe Syndrome Trust and enclose a cheque for the sum of £100.00 made payable to The Lowe Syndrome Trust.

Name _____

Address _____

Telephone Number _____ Mobile _____

Email Address _____

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