



Lowe Syndrome Trust
Raffle

Please fill in pink raffle slips at £5 each to win one of the following prizes

Harrods Hamper

Champagne

Esporta Swiss Cottage day pass to use all facilities including £50 Beauty Spa Treatment

Lunch for Two at Base Hampstead

Years subscription to Country Illustrated

*Willow Hairdressers Highgate
£100 voucher**

**Terms and Conditions apply*

Care today ... cure tomorrow"

We have designer handbags and jewellery on sale – the Charity will receive 10% of any items sold !



Lowe Syndrome Trust
Silent Bid

*Place your bids on silent bid slips provided and winner to be notified 3.00pm
Meal for two at Rhodes Twenty Four with wines to be chosen by our Sommelier*

Terence Conran Watch

Dinner for Two One Aldwych

Jonathan Ross suit and shirt!

Debeers leather and diamond choker value £700

Skateboard signed by Joss Stone

Versace shoes owned by Elizabeth Hurley signed

Arsenal football shirt signed by Pires

Chelsea Football signed by team

Bailiffscourt Hotel & Spa West Sussex

One night stay Superior Room inc DB&B

Tony Hadley Biography signed

Matthew Pinsent book signed

Ivo Ventur Knightsbridge hairdressing voucher £100

Dinner for two with Wine Bull & Bush Hampstead

Caci non surgical face lift voucher value £55

Ivo Venturi start pack Laser Hair removal value £210

Pink Floyd "The Division Bell" signed by Nick Mason

"Peace" Eurhythmics signed by Annie Lennox

George Michael signed photograph

Paul Newman signed "Shameless Exploitation"

Harry Potter and the Philosopher's Stone

7 CDs special edition signed by J K Rowling & Stephen Fry

Beautytek Body Shaping 4 treatments value £200

Rory Bremner "You are here" signed

Joseph Koniak Hair Cut & Style Hampstead

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**LOWE SYNDROME TRUST SCRIPT BBC4 RADIO 4 APPEAL
11 APRIL 2004 PRESENTER: TOM CONTI**

Oscar is a cheeky, loveable little boy. A 10-year-old who loves to watch TV, play video games, listen to music – typical of a boy his age. Except that when Oscar was almost six, doctors told his parents that he was unlikely to make it to his seventh birthday. He was diagnosed with Lowe syndrome, an incurable genetic disease that strikes only boys affecting their brain, eyes, kidneys, bones and muscles, leaving the lives of its families drastically changed forever.

One mother whose child died from the complications of the disease summed up her feelings: “I hate Lowe syndrome”. I will never forget the moment my husband said those words, on that most horrible of days – the day our beloved son died. I couldn’t have said it better myself. What do you do, what do you say, after you have just seen the cold and still body of the child you have loved and tended for twenty years placed in a body bag and carried away.”

*Struggling to come to terms with the diagnosis and the limited knowledge available, Oscar’s mother, Lorraine, decided to set up a UK Lowe Syndrome Research Trust, of which I am proud to be a patron. The good news is that since forming in June 2000, the Trust has raised £200,000 and awarded research grants to Imperial College London, Dundee University, University College London, and Great Ormond Street Children’s Hospital **

Another mother, whose son Conor was born with the disease, is so excited that Lorraine has set up the Trust, hoping that the research will help her son live a longer, healthier life. Conor is blind and already has had an eye removed and cannot walk unaided due to the symptoms of the disease including arthritis and swelling of the joints. Sadly Conor is suffering another condition of Lowe which is severe seizures, sometimes having to endure four seizures or more within an hour, which is a most frightening experience.

Lorraine spends every waking moment campaigning. Doctors feel certain a cure can be found, or better treatment at least, if only their research is supported. It only takes relatively small amounts of funding to continue that research and make a world of difference to Lowe children

**Since this broadcast, the charity has awarded funding to support four additional research projects at UCL London, Institute of Ophthalmology, Addenbrooke’s Cambridge and Professor Robert Nussbaum who was responsible for finding Lowe to be caused by ORL1 missing enzyme.*



Ladies who Lunch

Charity Luncheon

Friday 12th May 2006

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All Proceeds to:
Lowe Syndrome Trust
“Care Today ...cure
Tomorrow”
www.lowetrust.com
Tel 0208 458 6791

Reg Charity 1081241

Trustees JONATHAN ROSS, LORRAINE THOMAS,
CATHERINE McNAUGHT, CAROLYN MITCHELL
& PENNY BIZIOU

