



RESEARCH

Research Grants

The Trust has awarded three research grants during 2007

Professor Robert Nussbaum, £50,000 Institute of California (2nd year Lowe research project).
 Dr Rudiger Woscholski at Imperial College London was awarded a £10,000 continuation grant
 Dr John Lucocq of Dundee University an additional £10,000 for continuation research.

CHICAGO MUSICAL STAR TONY HADLEY PRESENTS LOWE SYNDROME TRUST RESEARCH GRANT TO IMPERIAL COLLEGE, LONDON PRESS RELEASE

Star of the West End musical ‘Chicago’ and former Spandau Ballet singer, Tony Hadley, today joins Lorraine Thomas, Chair of the Lowe Syndrome Trust, to hand over a cheque for GBP £10,000 to Imperial College, London, for ongoing research into the Lowe Syndrome disorder. Imperial College Rector, Sir Richard Sykes, and Lowe Syndrome researcher, Dr Rudiger Woscholski are to receive the grant on behalf of the college; the grant is a continuation to that awarded by the Lowe Syndrome Trust in 2003.



Dr Michiyo Shima of Imperial College also announces that following the success of the research undertaken by Drs. Woscholski and Ramon Vilar Compte, the college is awarding a grant of GBP £87,000 for the continuation of Lowe Syndrome research.

Lowe Syndrome is a rare, incurable disorder that affects only boys and produces congenital cataracts in the lenses of both eyes, muscle weakness, weak bones, kidney and brain development problems, which explains rather short life expectancy. The disease was first recognised in 1952 by Dr Charles Lowe and is caused by a gene mutation which makes a defective version of an enzyme named OCRL1,



needed for normal function of tissues like the lens, brain and kidney, although the reasons for [the mutation?] are still quite unclear.

The Lowe Syndrome Trust (LST) was set up by Lorraine Thomas as a voluntary charity in June 2000 when her son, Oscar (then aged 5), was diagnosed with the disease. The trust supports researchers worldwide in their efforts to gain knowledge and tools to tackle this devastating disease.

In 2003, the LST awarded Drs Woscholski and Vilar at Imperial College London a studentship in order to develop chemical tools for the detection of the substrates of the OCRL1 enzyme. This work has generated chemical compounds that are able to recognise the OCRL1 substrate with some selectivity in conditions that mimic the cellular environment.

Drs Woscholski and Vilar have continued to work on the characterisation of these new compounds in living cells through funds received from the Chemical Biology Centre (www.chemicalbiology.ac.uk). Together with the funding provided today by the LST, they will be able to study the suitability of the receptors towards generating chemical tools for biomedical research and which may even provide the foundations of a future drug development programme to tackle the symptoms of Lowe Syndrome.

Mrs. Thomas, chair of the Trust, says: "We were devastated when Oscar was diagnosed with the syndrome at the age of 5. All of the children are partially sighted or blind due to cataracts and some never ever walk. Even Lowe children (boys only) who are doing quite well with the disease sadly deteriorate and most die in their teens. I am so grateful for the research being carried out by Drs Rudiger Woscholski, Ramon Vilar and their teams at Imperial College, aiding us in our aim to raise awareness and funding for research projects that will one day lead to treatments and some increased hope for these boys. We are thrilled that the initial seed funding from the Lowe Syndrome Trust has led to a substantial award to the research team from Imperial College and hope that all research aimed to elucidate Lowe syndrome will attract the attention of other funding bodies".

**(12 FEBRUARY 2007) RESEARCH INTO RARE DISEASE CONTINUES:
A £10,000 AWARD HAS BEEN GRANTED TO RESEARCHERS AT THE UNIVERSITY OF
DUNDEE WHO ARE INVESTIGATING THE CAUSE OF THE RARE DISEASE, LOWE
SYNDROME. [PRESS RELEASE]**



Lowe Syndrome is a rare genetic disorder that affects only boys and produces cataracts in the eyes, defects in brain development and kidney problems. Life expectancy of the boys is short due to the complications of the disease.

Dr John Lucocq, a Principal Investigator in the School of Life Sciences at the University of Dundee, was awarded a grant of nearly £50,000 in 2003 to conduct research into a key protein, Ocr11, which he believes is linked to the defects in kidney and nerve cell function.

The trust is now awarding him a further £10,000 to continue his work. Dr Lucocq says, "This award will allow us to further investigate how nerve cell function and brain development are defective in boys with Lowe syndrome."

Lorraine Thomas established the Lowe Syndrome Trust in June 2000 after her son was diagnosed with the incurable syndrome in 1999. No Government support or UK research of the syndrome was available at that time, and for the last 7 years Lorraine has devoted her life to raising money for the charity.

Lorraine Thomas explained: "The Lowe Syndrome Trust is delighted to award a grant of £10,000 to the University of Dundee to further research into the rare disease called Lowe Syndrome."

"Sadly, due to lack of awareness and funding, many children only live until their teenage years due to the complications of the disease which causes partial sight, blindness, arthritis, rickets, mental impairment, speech and development delay, tooth and bone decay and kidney failure."

"The objective of the Trust is to fund medical research which will eventually lead to the development of drugs to better regulate the metabolic imbalance of the disease and eventually a cure of the syndrome."

Since starting the charity, Lorraine has persuaded many celebrities to back her cause, including Jonathan Ross. He says, "As a trustee of the Lowe Trust, I am delighted that we are able to fund another Dundee University research project which may result in better treatments and eventually a cure of Lowe Syndrome. We also hope that this research will entice more interest into the disease from research scientists worldwide".

The protein, Ocr11, is produced by the faulty gene and is thought to reside in the Golgi apparatus. The Golgi apparatus is responsible for the processing, sorting, packaging and distribution of proteins in cells to the right destinations within cells. Dr Lucocq believes that defects in kidney and nerve cell function are linked to problems of protein transport from Golgi to other parts of the cells.

PROFESSOR ROBERT NUSSBAUM AWARDED £50,000 FOR 2ND YEAR LOWE RESEARCH PROJECT.

The Trust awarded an additional £50,000 to Professor Robert Nussbaum at The Institute of California. Full details of the project can be found on www.lowetrust.com

Professor Robert Nussbaum found the gene responsible for Lowe Syndrome and has worked on this disease for nearly 20 years. "Although we have made much progress, much more needs to be done. I received a grant from the Lowe Syndrome trust to fund a two year project which represents the next small but significant step in what has been a very long journey- understanding how this disease comes about so we can intervene and treat it more effectively. It is very difficult to obtain funding for research in conditions like Lowe Syndrome so Charities such as the Lowe Syndrome Trust are absolutely vital to research teams such as mine...."



The Trust advertised a new “call for research” for the amount of £80,000 into Lowe Syndrome and is delighted to have received many applications which are currently being reviewed by the 1st Lowe Scientific Advisory Board. The board will meet mid November to discuss the reviews and if the projects should be funded by the 1st.

**CALL FOR RESEARCH PROPOSAL IN
LOWE SYNDROME**

You are invited to apply for research funding from the Lowe Syndrome Trust.

The genetic basis for Lowe Syndrome is a defective gene OCRL1 that results in the deficiency of an enzyme Phosphatidylinositol 4,5-bisphosphate-5-phosphatase (OCRL1).

Lowe’s oculocerebrorenal syndrome is a disorder affecting the brain, eyes, kidneys and bones. Research funds are available, £80,000 in the first instance, for funding a research studentship or assistant in understanding how the enzyme deficiency leads to observed phenotype.

Closing date of application is 31st August 2007.

For further information and Application Form please contact
Lorraine Thomas, Lowe Syndrome Trust
Telephone 0208 458 6791
(lowetrust@homechoice.co.uk) see lowetrust.com

New Research Project

Lorraine Thomas, Chair highlighted to the Lowe Scientific Board, the recent UK press announcement about a significant breakthrough in research in terms of a potential drug to treat two genetic disorders being Duchenne Muscular Dystrophy and Cystic Fibrosis

The treatment on offer is correcting a mutation and can be used apparently to cure affected organs and tissues.

Following various meetings with members of the Scientific Board and a Lowe research scientist, the Trust is now collaborating with the pharmaceutical company PTC Therapeutics in the USA on a joint Lowe project.

Enzyme Assay

The Trust met with the Lowe Scientific Board to discuss, the setting up of a Lowe Syndrome Trust enzyme diagnostic service within the UK. Children are diagnosed by DNA at Manchester Hospital, but the 100% conclusive test is done by a skin biopsy sent to the Baylor Lab in the USA. The Trust is working on a setting up this facility within the UK which will also help with future research.

Lowe Syndrome Clinical Database

The UK has no official database of Lowe sufferers. Following various meetings with Government, the Trust is in the midst of setting up a UK database of children suffering with Lowe Syndrome. This is not as easy as one would believe as to commence we have to apply for ethical approval and Doctors are not allowed to communicate with the Trust as to patients they are treating. This project is underway with funding from the UK Big Lottery Fund.

The Trust will endeavour to find out sufferers worldwide to ascertain treatments in other countries.

LOWE SYNDROME TRUST VISITS THE ITALIAN LOWE ASSOCIATION

The LST and family were invited to the Italian [AISLO](#) (Associazione Italiana Sindrome di Lowe) that was initiated by Anna Maria Dinelli president of AISLO and organised and funded by the community of Formignana.



The meeting was held in the local theatre (*Teatro Comunale di Formignana*) and the families were also invited to a special mass at the church by cardinal Tonini with local dignitaries. Also invited to the meeting were Fabrice Riou, President of the [ASL \(L'Association du Syndrome de Lowe\)](#) France and Debbie Jacobs who is President of the [LSA](#) (Lowe Syndrome Association USA). The community had also organised translators, a creche for the children and a very social agenda. The families stayed at a hotel in nearby Copparo.

The LST, Lorraine, Andrew and Oscar Thomas would like to thank everyone involved and to say how overwhelmed we were by the welcome and hospitality, not mention the incredible generosity and organization.

LOWE SYNDROME CAMPAIGNS AND EVENTS

- Radio campaign with LBC March 2007
- Billboard Poster at UK Arsenal Football Ground April 2007



- Taxi tip up seat advert to be placed in Taxis in central London (July – September 2007) (see attachment)
- *Flora* Light Women Challenge a 5K race in Central London (September 2007) We had fewer runners this year but thanks to those who raised funds for the charity - £800 raised
- *Flora* 2012 Olympic half Marathon 2008- please enrol now, we have ten places (attached).
- Radio 4 interview (October 07) to discuss the difficulty of obtaining Marathon places unless we pay extortionate buy in places of £2,500 each
- Nick Ferrari radio interviews
- Hello! Magazine articles (two weeks of three pages) organised by Threes A Crowd events.

THE LOWE SYNDROME TRUST CHARITY EVENT

hosted by JONATHAN ROSS, with Russell Watson, Newton Faulkner, Beverley Knight, Tara Palmer-Tomkinson and Jean-Christophe Novelli (25th September 2007)



- A fantastic and fun fundraising event was organised by Tara Palmer Tomkinson's event and lifestyle company [Three's A Crowd](#). The event had a wide variety of sponsors/revellers including [Hello! Magazine](#), Play.com, EMC computers, [Network2supplies](#), [Generators now](#), KMPG, CapGemini, [Keanes](#), [Ingram Builders](#), to [Mystical Fairies](#) (I kid you not!). The event is featured in [Hello! Magazine Oct9th](#) who also ran a feature on Jonathan Ross's support for the charity on [Oct02](#).
- The party was held at Floridita in Soho (London UK) and was hosted by Charity Trustee [Jonathan Ross](#) with dancing to [Russell Watson](#) whose repertoire included "strangers in the night" <play [video](#)> and "that's life", [Newton Faulkner](#) and [Beverly Knight](#) <play [video](#)>. Revellers included "IT" girl Seville Bulpitt, TV stars [Tris Payne](#), [Louise Rednapp](#), producer [John McKenzie](#), Arsenal footballers [Alexander Hleb](#) & [Mathieu Flamini](#) (also charity patron) and charity patron [Tony Hadley](#).
- A champagne reception featuring the stunning street magician [Dynamo](#) started the night rolling, followed by a dinner by award-winning chef Jean Christophe Novelli, salsa dancers and comedy and an auction conducted by Tara Palmer Tomkinson and Johnathan Ross.
- The charity would like to say a massive THANKYOU to everybody, especially all the volunteer performers, auction prize donors and sponsors. Russell performed with a mini-orchestra, Newton actually flew from a tour in Germany especially for this event and Beverley Knight performed with band and backing singers. The evening raised almost £35,000.



PATRON PENNY LANCASTER and ROD STEWART

Penny and Rod supported the Trust yet once again by kindly donating a substantial amount to the charity from their wedding this year. The amount will fund the next Lowe Research Project. We cannot thank them enough for their support not only in highlighting the cause but also raising funds to support medical research. A huge thank you to Penny, Rod and Alastair!



ESPORTA HEALTH CLUB CHARITY EVENING (6 SEPTEMBER 2007)

Thanks to those who supported us raising £1250

The Trust with the support Esporta Health Club, organized a Lowe charity party at the Finchley Road Club on the 6th September. Thanks to Waitrose for their very kind generosity in donating the wine for the evening. TV Producer and celebrity David Guest volunteered to host the Lowe Syndrome Charity auction and announced the raffle with Charity Patron and Arsenal midfielder Mathieu Flamini. A magician also provided entertainment and the charity supporters and volunteers danced and sang to/with Soul Star Melissa Bell of Explosive Entertainment.



CHICAGO CHARITY EVENT

Other events this year have included an evening at **Chicago** in which Trust Patron **Tony Hadley** appeared. This was followed by a private champagne reception with Tony and the cast of Chicago. The Trust would like to take this opportunity of thanking Tony for his continued support to the charity which has helped enormously in raising the profile of the disease and funding to support research.



LST
The Lowe Syndrome Trust
Chicago Charity Event
Thursday 29th March 2007

Tony is currently playing one of the lead roles in the smash hit West End musical "Chicago". Tony plays the part of lawyer Billy Flynn who represents both main characters Roxie Hart and Velma Kelly. Tony will perform alongside Aoiife Mulholland as Roxie, Annette McLaughlin as Velma Kelly, Julian Sims as Amos Hart and Brenda Edwards as Mamma Morton.

Lowe Syndrome Trust Patron, Tony Hadley, invites you to attend Chicago on the 29th March at the Cambridge Theatre London. The show will be followed by a champagne reception with Tony. There are limited tickets for this event, which will raise funds to support medical research into Lowe Syndrome, an incurable children's disease.

The Lowe Syndrome Trust is a small UK charity.
Visit www.lowetrust.com
or call 0208 458 6791/07958 444020

£50 per Ticket
8.00pm Show 10.30 Champagne reception

THE OLD CRANLEIGHAN LOWE SYNDROME TRUST CHARITY BALL

(OCTOBER 2007)



The Old Cranleighan Ball was held in Madame Tussauds, London on 27th October 2007 with the Lowe Syndrome Trust, sponsored by BGC systems.

The evening was hosted by Eamonn Holmes.

Guests were greeted with a taxi ride through the history of London to a champagne reception, surrounded by celebrities from Tara Palmer Tomkinson, the Beatles to Hollywood stars like Tom Cruise to the Royal Family. The partygoers were greeted by Old Cranleighan Society chairman Rick Johnson and television presenter Eamonn Holmes who kindly hosted the evening.

The dinner was followed by the auction, champagne diamond with dancing to Heather Small and Charity Patron Tony Hadley. The School Headmaster also appeared, firstly to thank the old schoolboys, especially Rick Johnson, the committee and guests, who also made other appearance to restore order amongst the assembly.

The evening was a tremendous success raising funds to support a new medical research project into the disease.

PREMIER LEAGUE CASH BOOST FOR LOCAL CHARITY/GOOD CAUSE



The Lowe Syndrome Trust in London has received a boost of £2000 to its funds from the Premier League, as part of the League's flagship community programme 'Creating Chances'.

The trust is one of only 20 runners-up selected by **Arsenal Football Club** in the 'Places for Players' initiative and will receive £2,000 from the Premier League.

'Places for Players' is the core element of the Premier League's Creating Chances programme. It will involve 200 Premier League players supporting charities and good causes in September with £1,000,000 to be distributed by the Premier League to help raise awareness of the charities' and good causes' work as well as creating fundraising opportunities.

In total, over 500 good causes will benefit from the Places for Players initiative either by players getting involved or from a £2,000 cash donation direct from the Premier League.

Richard Scudamore, Chief Executive of the Premier League, said: "Creating Chances highlights the Premier League and our clubs' continued and increasing commitment to local communities. We wanted to help as many good causes as possible through the 'Places for Players' initiative, and so I hope the £2,000 donation for our runners-up will help them to continue their fantastic work and in many cases provide a springboard for charities and good causes to achieve their goals."

LOWE CYCLE RIDE

Mick Fennings who has been a tremendous support to the charity, again organised a Lowe cycle ride – this time flying over to France then cycling/drinking!!! I know how gruelling the cycle challenge was (from **Montpellier to Monaco**) so our thanks go out to the team. I am pleased to announce that Mick Fennings has become a Lowe Charity Patron. Mick is in the midst of organizing Italian Lowe ride 2008, see www.lowetrust.com

Lowe Charity Bike Ride - Tuscany June 2008 - Da Pisa (Lucca) ad Assisi (Perugia): Gara Ciclistica

The 2008 cycle tour is being planned by Mike Fennings to raise money for the [Lowe Syndrome Trust](http://www.lowetrust.com) for medical research into Lowe Syndrome an incurable children's disease who suffer from cataracts (blindness and glucoma), arthritis, Kidney disease and autism. Classic Bike Tours will be managing the actual event on our behalf which will include lead rider, support vehicle, a Doctor and lead car to set up refreshment stops.

The adventure begins again!!!!

After 3 annual bike rides to raise funds for the Lowes Syndrome Trust and having a great time, the planning has now started for the 2008 Lowe Syndrome Bike Ride which will take place in Tuscany around the end of May beginning of June (exact dates TBC) .

The bike ride will be over a distance of around 250-300 miles and will be over a 4 day period. The plan is to fly out on a Sunday , and cycle from Monday - Thursday . I am then looking to get the option for people to stay onto Sunday perhaps with their families.

The planned start is from Lucca , a provincial town which is a jewel of Northern Tuscany , going down into Pisa , whilst passing Pienza (English Patient fame) , San Gimignano and a few other places before we finish in Montepulciano .

MELANIE BLATT OF ALL SAINTS AND MATHIEU FLAMINI OF ARSENAL

We were delighted to announce that **Melanie Blatt** of **All Saints** and **Mathieu Flamini** of **Arsenal** have both become charity patrons to help highlight the disease.

SKATEBOARDING ACROSS UK /AUSTRALIA AND NEW ZEALAND

Dave Cornthwaite has continued his support – in addition to **skateboarding across the UK and then Australia** for the charity (is he mad!!), he is now raising funds by other skateboarding events – thanks Dave we cannot thank you enough for the time and effort you have put into this!

Dave's efforts have spurred on a 31 year old primary teacher called **Natalie to skate across New Zealand 1500 miles**. See <http://www.ncdsa.com/52/Skate-Across-America.htm>
Donations can be given via the www.lowetrust.com website

LOWE SYNDROME MEDICAL SYMPOSIUM AT THE ROYAL SOCIETY (LONDON)



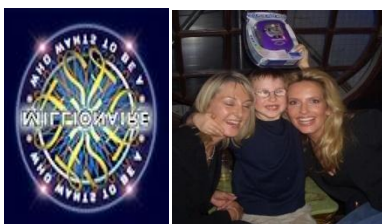
Funded and organised by the charity, the second international conference on Lowe Syndrome was held on 7th December 2007 at The Royal Society, Pall Mall, London, followed by a dinner at the RAC club. This historical event brought together over 50 international researchers, medical professionals and parents to present and discuss the disease, current research underway and ideas for future projects.

The outcome of the research on the mutations of Dents disease and Lowe syndrome confirmed that the clinical syndromes as they are described in the medical literature are not simply accounted by a single or multiple gene defects, the need for a focus on the enzyme deficiency for detection and potential therapies, the need for animal/fish models and clinical databases, and sharing of discoveries (and cells samples) and collaboration between researchers.

The meeting was chaired by Prof. Robert Unwin (UCL), followed by the plenary lecture by Prof. Nussbaum who discovered the Lowe's syndrome gene on the X-chromosome and has been instrumental in Lowe Syndrome research.

Presenters included Dr Martin Lowe, University of Manchester, Dr Andrew Wallace, National Genetics Reference Laboratory, Manchester; Prof Pietro De Camilli, Yale University USA; Prof. J Lunardi, Laboratoire de Biochimie de l'ADN, Grenoble, France, Prof. Michael Ludwig, Clinical Biochemistry, University of Bonn, Germany, Prof. Arend Bokenkamp, Department of Paediatrics, Amsterdam; Rudiger Woscholski, Division Cell & Molecular Biology, Imperial College, Dr Helen Cross, Institute of Child Health (UCL), Dr Tim Levine, Department of Cell Biology, Institute of Ophthalmology (UCL) and Prof. Steve Scheinman, Upstate Medical University, USA .

WHO WANTS TO BE A MILLIONAIRE WITH PENNY LANCASTER



The charity would like to thank Penny Lancaster and Ian Waite for appearing on Who Wants to be a Millionaire shown on ITV on New Year's Day. £10,000 was raised for the Lowe Syndrome Trust which enabled the charity to award a new grant to Imperial College London for £80,000.

LOWE SYNDROME TRUST AWARDS A NEW RESEARCH GRANT TO IMPERIAL COLLEGE LONDON. This grant is the third award to Rudiger Woscholski and his team who hope to produce a drug to emulate the missing enzyme causing Lowe syndrome.

January 2008, the Lowe Syndrome Trust was delighted following scientific reviews, the third Lowe research grant to Imperial College London. A press release will be announced shortly regarding the project.

Previous award : 2003

DJ Jono Coleman presents genetic research grant to Imperial College Scientists

Jono Coleman, breakfast DJ on London's Heart 106.2 radio station will today meet scientists at Imperial College London who are tackling a rare genetic disease thanks to funds from the charity the Lowe Syndrome Trust.

Mr Coleman, Patron of the Charity, will hand over a cheque for £49,785 to Dr Ramon Vilar-Compte and Dr. Rudiger Woscholski, which will fund three years of research at Imperial into Lowe Syndrome.

Lowe Syndrome is a genetic disorder that affects only boys and produces bilateral cataracts, muscle weakness, kidney and brain development problems. It is a rare X chromosome-linked disease, thought to affect up to 10 per million male births.

The disease was first recognised in 1952 by Dr Charles Lowe, and is caused by a gene (Ocr1) mutation which makes a defective version of an enzyme named OCRL.



The money will support research into a chemical test for signs of the Lowe enzyme, hopefully leading to a fast, user-friendly and reliable method to help doctors diagnose and treat the Syndrome. Currently only expensive and unreliable DNA testing is available in the UK for Lowe Syndrome.

THE LOWE SYNDROME TRUST AWARDS GRANT OF £72,000 TO MANCHESTER UNIVERSITY JANUARY 2008

LOWE SYNDROME PRESS RELEASE - 2008

MANCHESTER UNIVERSITY LOWE SYNDROME TRUST RESEARCH GRANT AWARD

A £72,000 award has been granted to Senior Research Fellow and Honorary Reader, Martin Lowe at the University of Manchester who will be investigating the cause of the rare disease, Lowe Syndrome.

Lowe Syndrome is a rare genetic disorder that affects only boys and produces cataracts in the eyes, defects in brain development and kidney problems. Life expectancy of the boys is short due to the complications of the disease.

The project entitled "Zebrafish as a model organism to study Lowe Syndrome" will utilise zebrafish as a model organism for investigating OCRL1 function and the mechanisms by which its loss leads to Lowe syndrome.

Lowe syndrome is an inherited disorder affecting the brain, kidney and eyes. Lowe syndrome arises from mutation of a single gene, called OCRL1, which is found on the X-chromosome. The protein encoded by the OCRL1 gene can degrade a specific type of lipid which is localised to membranes inside the cells that make up our bodies. Although significant progress has been made in identifying where inside cells the OCRL1 protein is localised and the other proteins it binds to, we still do not fully understand what processes OCRL1 regulates, either at the level of individual cells or entire animals. Furthermore, we cannot explain how loss of OCRL1 brings about the physical changes associated with Lowe syndrome. Currently a major drawback in Lowe syndrome research is the lack of an appropriate model system in which the mechanisms underlying the disease can be explored.

Martin Lowe explained that Zebrafish offer a number of advantages over other model systems and are currently being used by many investigators to model a wide variety of human diseases. In a pilot study we have found that OCRL1 is expressed in a similar manner in zebrafish to that in humans, that it is enriched in the brain, and that ablation of OCRL1 expression results in a defect in early brain development. We plan to extend this analysis using a number of complementary approaches to further analyse the role of OCRL1 in development, focussing initially on the brain but also examining the other tissues affected in Lowe syndrome. In the long term it is hoped that zebrafish will serve as a model system for high throughput screening of small molecules that suppress the symptoms of Lowe syndrome.

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Lorraine Thomas established the Lowe Syndrome Trust in June 2000 after her son was diagnosed with the incurable syndrome in 1999. No Government support or UK research of the syndrome was available at that time, and for the last 7 years Lorraine has devoted her life to raising money for the charity.

Lorraine Thomas explained: "The Lowe Syndrome Trust is delighted to award a grant to the University of Manchester to further research into the rare disease called Lowe Syndrome. Sadly, due to lack of awareness and funding, many children only live until their teenage years due to the complications of the disease which causes partial sight, blindness, arthritis, rickets, mental impairment, speech and development delay, tooth and bone decay and kidney failure."

"The objective of the Trust is to fund medical research which will eventually lead to the development of drugs to better regulate the metabolic imbalance of the disease and eventually a cure of the syndrome."

Since founding the charity, Lorraine has persuaded many celebrities to back her cause including Jonathan Ross. He says "As a trustee of the Lowe Trust, I am delighted that we are able to fund the Manchester project which may result in better treatment and eventually a cure of Lowe Syndrome. We also hope that this research will entice more interest into the disease from research scientists worldwide".

The LOWE SYNDROME TRUST HAS 10 PLACES FOR THE BUPA 10K RACE

Contact Lorraine on lowetrust: [@homechoice.co.uk](mailto:lowetrust@homechoice.co.uk) or 07958 444020 for application.

The BUPA London 10,000 (10k) will take place on Bank Holiday Monday, May 26th 2008 at 10.00am and will have 12,500 entrants in its first year. The 10,000m race will start and finish in St. James's Park and use Green Park as its assembly area.

Race information

The BUPA London 10,000 will start and finish in St. James's Park and use Green Park as its assembly area.

The race will start on Birdcage Walk and follow an anti-clockwise route around the City of Westminster and the City of London via Parliament Square, Embankment, Blackfriars Bridge, Queen Victoria Street, Cannon Street, Great Tower Street, Crutched Friars, Fenchurch Street, Leadenhall Market, Cornhill, Queen Victoria Street, Puddle Dock, Embankment, Horseguards Avenue, Whitehall and via Trafalgar Square to the Finish in The Mall.

Runners will pass many of London's famous sights, including Westminster Abbey, Houses of Parliament, Big Ben, The London Eye, Cleopatra's Needle, Tate Gallery, Millennium Bridge, The Monument, Lloyds of London, Leadenhall Market, Bank of England, Mansion House, St. Paul's Cathedral, Horseguards, Nelson's Column and Admiralty Arch. Buckingham Palace acts as the backdrop to the start and finish.

Dave Bedford from London Marathon Ltd said: "We are pleased to be working with Nova to produce this exciting new road race, which will be a great addition to both the London Marathon and Great Run stable of events held in and outside London. The mass field will boast an array of elite, club and charity runners, and we fully intend for this race to become a landmark on the annual running events calendar in the UK."

Brendan Foster from Nova International Ltd added: "We are excited to be working with London Marathon Ltd to stage this new event in the heart of London. Much of the course takes in the proposed route for the 2012 Olympic Marathons so you could hardly get a more inspirational location for the BUPA London 10,000. We are certain that the strengths of both organisations will combine to deliver what we are both best at doing; staging world class road running events."

Thanks once again to all our supporters in helping us find a cure for the Lowe Syndrome disease.

Lorraine Thomas

Chair

The Lowe Syndrome Trust

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lowetrust@homechoice.co.uk

www.lowetrust.com