"Care today … cure tomorrow"

The Lowe Syndrome Trust

2016 Newsletter

This newsletter is a brief overview of the achievements of this small charity during the past year.

The Lowe Syndrome Trust was founded as a small voluntary charity in June 2000 with an aim to raise funds to support research into Lowe Syndrome and support families and medical professionals.

All research projects, events, a full story about the charity including TV and Radio can be found on www.lowetrust.com.

Lorraine Thomas

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Founder, Chair & Trustee
The Lowe Syndrome Trust

LOWE SYNDROME TRUST

Lowe Syndrome Trust at Number 10

Lorraine Thomas, founder of the Lowe Syndrome Trust, and her husband were invited to No. 10 Downing Street to meet with Secretary of State, Karen Bradley.

The small gathering was a lunch reception in honour of small voluntary charities such as the Lowe Syndrome Trust. The government directive this year is to support small charities, which will help enormously as it is a battle competing against the more established well known causes. Lorraine has met with government on many occasions to highlight the cause of the Lowe Syndrome Trust and its work and achievements.

Fundraising

I am proud to be Trustee of the Lowe Syndrome Trust, a very small UK charity, supporting Lowe families and raising funds to support vital research to find better treatment and cure of this devastating disease. Lowe Syndrome affects the brain, eyes, kidneys, bones and muscles. Sadly leading to a short life expectancy. With your help we can be one step nearer a cure.

We hope you will support us by booking your next meal at this restaurant via Charitable Bookings and choosing The Lowe Syndrome Trust.

Jonathan Ross

https://itunes.apple.com/gb/app/charitable-bookings-giving/id1058902592?mt=8

Registered charity 1081241

Donate to the Lowe Syndrome Trust when you book a table at this restaurant.

The charity is registered with CHARITABLE BOOKINGS !!
(just select Lowe syndrome Trust as favourite)

https://itunes.apple.com/gb/app/charitable-bookings-giving/id1058902592?mt=8

- Download the app from iTunes
- Choose LOWE SYNDROME TRUST charity as favourite
- Choose restaurant
- Make reservation from the app / phone via the app
- Pop up confirmation appears
- Charity bookings send confirmation email
- Restaurant donate £1 per diner

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"I am proud to be a Trustee of the Lowe Syndrome Trust"

This year has been an exciting year for fundraising at the Lowe Syndrome Trust. There are many ways people can help families stay strong and hopeful by helping fund our ground-breaking research.

With the help of LST trustee Jonathan Ross, we launched a charitable bookings promotion where people can make a donation when booking restaurant tables.

This year we also launched the Lowe Syndrome Legacy Gift scheme. Any gift left in a will, no matter how large or small, will make a lasting difference in the fight against Lowe syndrome. Gifts in wills help us to support families and fund new research.

Quotations from families

"I love my son more than anything in the world, but I can honestly say I absolutely hate this syndrome with everything in me. It is ruthless and seems so cruel. "

"Everything in our boys' lives is so special. I now know that before Russell was born I took a lot of things for granted. Now every little accomplishment that Russell does is a very big thing"

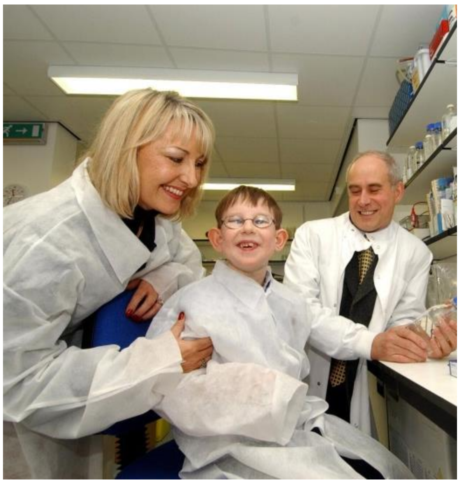
"These boys have so much fight in them, more than they are given credit for"

… and researchers

"Funds from the Lowe Syndrome Trust have made all the difference to our knowledge of this rare but devastating disease. We have discovered that the disease affects the way cells grow in contact with their neighbours. We can test how to reverse the effects of Lowe Syndrome, which will underpin the future development of drugs"

Dr Tim Levine
Institute of Ophthalmology, London

Research update



The Lowe Syndrome Trust supports cutting-edge scientific research in the USA and UK, in order to investigate the symptoms of Lowe syndrome and develop new treatments. We are committed to discovering therapies and treatments that will improve the lives of boys suffering with Lowe syndrome, with the ultimate aim of curing this devastating disease.

Breakthrough research

Here are brief summaries of what our current research projects are working on.

- **Prof Martin Lowe – University of Manchester & Prof Claudio Aguilar – Purdue University**

  We have developed a type of zebrafish that have symptoms like those seen in boys with Lowe syndrome. We are using these fish to screen different drugs to see if they can reduce or prevent those symptoms, with a view to testing whether those drugs can be used to treat Lowe syndrome in boys.

- **Dr Rudiger Woscholski – Imperial College London**

  Lowe syndrome is caused by a faulty enzyme in the body, which leads to a build-up of a particular chemical. We have designed a series of drugs that could stop this build up from causing the symptoms of Lowe syndrome. Next we need to start testing these drugs in model systems, like the zebrafish.

- **Prof Chris Oliver – University of Birmingham**

  We are looking at the development of behaviour disorder in Lowe syndrome including things that indicate risk factors for challenging behavior. We are also looking in detail at how behaviour is established and maintained.

“The Lowe Syndrome Trust has made an enormous contribution; it has not only raised awareness of Lowe syndrome, and provided support and information for patients and their families, but it has also been a very strong impetus to research into Lowe syndrome, and other rare related inherited disorders, both in its funding of research and in encouraging wider international research collaborations. The many doctors and scientists involved with Lowe syndrome are very grateful to the Lowe Syndrome Trust and its supporters for their continuing support.”

Professor Robert Unwin, University College Hospital & Royal Free Hospital
Chair, Lowe Scientific Advisory Board,

In memoriam

Here are some of the boys who have passed this year, and are now free from Lowe Syndrome. Their loss is what

Lowe Syndrome Trust Needs YOU!

The Lowe Syndrome Trust is a very small charity and there are many things we would love to do if we had more time and person-power!

Are you interested in volunteering time, energy or expertise to help us support families, raise awareness and raise funding for research to find a cure?

Do you have skills in areas like IT, social media or design?

If you want to get involved then please get in touch with Lorraine: lowetrust@gmail.com