

# Local charity goes international

When Linda Elsegood found a drug that helped her fight Multiple Sclerosis she was determined to share her story. She told **Neil Haverson** how she set up the LDN Research Trust

Seeing Linda Elsegood perched on the sofa chatting enthusiastically about her charity it is hard to believe that by 2003 Multiple Sclerosis had reduced her to an invalid.

"There are around 30 symptoms of MS and I had just about all of them! Numbness, constant fatigue, vertigo. I had cognitive problems, I couldn't string words together; everything came out as gobbledygook."

But then Linda discovered Low Dose Naltrexone (LDN) which can delay or halt the progression of autoimmune diseases.

She says: "I staggered to the computer, falling over fresh air, and squinting with one eye to find out what other people were doing."

That was six years ago and she is now almost back to normal.

"I still feel as though I've got my head in a guillotine and I do pick up infections easily but otherwise I lead virtually a normal life."

Linda is quick to point out that LDN is not a wonder drug – and it's not always easy to get.

"The patent has lapsed so it's not licensed," she explains. "I spoke to the manufacturers to try to persuade them to do some research but they weren't interested. It's very cheap so there is no money in it for them."

"Any clinician can prescribe it as it's therapeutic. Some doctors will and some PCTs fund it on the National Health. Doses are only 3mg and there are no side effects. But I don't want to give people false hopes; it doesn't work for everybody with MS."

Linda's story was told in the local paper and she was inundated with calls from all over East Anglia. She decided to spread the word and see if she could get some research started.

She registered the LDN Research Trust as a charity.



**SPREADING THE WORD:** Linda Elsegood, with son Leo, helping others fight Multiple Sclerosis.

PICTURE: SUBMITTED

"I wrote over a thousand letters to all and sundry. But when I set up the website, that's when things really took off."

After five years she has a database of 6000 subscribers from all over the world including Tobago, Australia, New Zealand and in America where LDN was approved by the Food and Drug Administration in 1984. Linda gets around 50 enquiries a day and almost 40% of those who receive her emailed newsletter forwarded it to someone else, so word is getting out."

But Linda is still fighting for funding for research – and to help her run the charity.

"I run everything and it has to be paid for; I have no money coming in."

But she is undeterred. There is hope of some initial trials being carried out in Scotland later this year and the first LDN awareness week takes place this month.

"I wanted to get the word out to people

who don't have a computer so I thought I would have an awareness day. That went to a week and then a national week. Now it's gone international!"

## Details

**LDN Awareness week runs from October 19-25.**

On October 25 at The Holiday Inn, Norwich Airport, the charity Proventus is holding an MS presentation between 2pm and 5pm. Linda Elsegood will be speaking about LDN.

To find out more about LDN and Awareness Week contact Linda Elsegood, PO Box 1083, Buxton Norwich NR10 5WY; 0844 4145295 [contact@ldnresearchtrust.org](mailto:contact@ldnresearchtrust.org) [www.ldnresearchtrust.org](http://www.ldnresearchtrust.org)