

February 2012

Belated Happy New Year to everyone, my time still isn't my own and the hours I can spend helping people via the LDN Research Trust is still limited, hopefully over time things will improve. Until I get more time the newsletters will be as and when. If you have time to help in anyway whatsoever just let me know, your help would be appreciated.

The running costs of the charity have increased quite considerable over the last year, everything has risen in price. We pay no salaries and everyone works for nothing so every penny we receive makes a difference. To carry on with our work we need financial support, we would like to ask if everyone could spare just £1, \$1 or 1 Euro a month or £12, \$12, 12 Euro's a year. This would enable us to cover the running costs, continue to produce and send free LDN Aware DVD's to Doctors around the world, these DVD's are proving a great success and many Doctors will prescribe after listening to what other medical professionals have to say and collect funds for trials.

Donations can be made in many ways regardless where in the world you live:

<http://www.ldnresearchtrust.org/ldn-research/114-make-a-donation.asp>

We have a fundraising CD - Enduring Freedom by Synchro
£6 each with FREE shipping, see page 2

Synchro – “ We hope you enjoy listening to the CD as much as we enjoyed making it. At just £6:00 with free P&P, you can have a quality CD AND know that you are helping a worthwhile cause.

Video of CD on YouTube:
<http://youtu.be/VYO5z-CcNPU>

Buy your copy today by clicking the link below.
https://www.paypal.com/cgi-bin/webscr?cmd=_s-xclick&hosted_button_id=ZT8C6QPGZZQGI

Full details in the newsletter page 2.

I would like to say a BIG thank you as always, to those people that makes regular donations, fund-raise and help in so many different ways, without you there would be no LDN Research Trust.

Wishing you all a very good 2012
Linda and all those working with me.

YouTube Video Interviews - LDN User Testimonials

New LDN Users Testimonials can be found on YouTube.

Conditions are listed separately in play lists and people with multiple conditions have a separate playlist. I will continue adding to them over the next few months.

Medical professional interviews for now will only be available on the DVD as listed on page one. Should any LDN prescriber, pharmacist or advocate wish to be interviewed I'm now making appointments it doesn't matter where in the world you live, I can work round the time difference, please [email me](#) .

If you take LDN and wish to be interviewed, I would like to hear from you [email me](#) and I will send you the questions and we can arrange a suitable time and date.

LDN RT YouTube Channel

http://www.youtube.com/playlist?list=PLB031EA9491DCF0C9&feature=edit_ok

Cancer Play List

http://www.youtube.com/playlist?list=PLB031EA9491DCF0C9&feature=edit_ok

Multiple Sclerosis Play List

http://www.youtube.com/playlist?list=PLB031EA9491DCF0C9&feature=edit_ok

ME/CFS Play List

http://www.youtube.com/playlist?list=PLB031EA9491DCF0C9&feature=edit_ok

Fibromyalgia Play List

http://www.youtube.com/playlist?list=PLB031EA9491DCF0C9&feature=edit_ok

Autism Play List

http://www.youtube.com/playlist?list=PLB031EA9491DCF0C9&feature=edit_ok

Multiple Conditions Play List

http://www.youtube.com/playlist?list=PLB031EA9491DCF0C9&feature=edit_ok

Refractory Depression Play List

http://www.youtube.com/playlist?list=PLB031EA9491DCF0C9&feature=edit_ok

Fundraising CD Enduring Freedom by Synchro

£6 each with FREE shipping Worldwide

Last year, we decided to help the LDN Research Trust raise much needed funds by recording a CD for them. We asked people on facebook to send in their favourite songs so that we could decide which songs were recorded. We were amazed when we received over 300 song suggestions. After much counting, we chose the 10 most popular songs to record. The CD contains a mix of classic Rock, Pop and Country so there should be something for everyone. We have managed to record 9 out of the 10 on time We wanted to get it out as soon as possible and here it is. We hope you will all support the LDN Research Trust in its work by purchasing the CD. All money will go to the Trust.



The CD contains the following songs:

Closest thing to crazy, Don't get me wrong, Echo Beach, Something Stupid, One way or another, Dreams, Blanket on the ground, What part of no? and finally It's too late.

We hope you enjoy listening to

the CD as much as we enjoyed making it. At just £6.00 with free P&P, you can have a quality CD AND know that you are helping a worthwhile cause.

Watch on YouTube:

<http://youtu.be/VYO5z-CcNPU>

Buy your copy today by clicking the link below.

https://www.paypal.com/cgi-bin/webscr?cmd=_s-xclick&hosted_button_id=ZT8C6OPGZZQGI

Or visit our shop <http://ldnurl.info/ldnshop>

We would like to thank Synchro for helping us raise funds. to everyone involved in making it and an advanced thank you to you for purchasing a copy.



By purchasing this CD you are helping to raise funds for the LDN Research Trust - www.ldnresearchtrust.com

Registered Charity Number: 1100631



- 1 Closest Thing To Crazy
- 2 Don't Get Me Wrong
- 3 Something Stupid
- 4 What Part Of No
- 5 It's Too Late
- 6 Echo Beach
- 7 Dreams
- 8 Blanket On The Ground
- 9 One Way Or Another

Bob Coleman Drums & Vocals
 Angela Baker Bass Guitar
 Chris Rickenberg Lead & Acoustic Guitars & Vocals
 Roni Congram Lead & Backing Vocals & Keyboards
 Henry Senior Pedal Steel

Produced by John Merriman
 Recorded at Crown Lane Studios, Morden, Surrey
 Cover by Wayne Beauchamp

Our thanks to the following who made it possible:
 J. Martin, K. Longthorn and C. Bartram



Resveratrol - Pharmacist Stephen Dickson



Recently published data, showing positive effects on autoimmune diseases – and specifically a very positive effect on animal Optic Neuritis - the animal model of MS used to test potential drug therapies against.

We have links on <http://www.dicksonchemist.co.uk/Home/Default.aspx> - follow the tab on the top to RESVERATROL.

Who should try resveratrol? Anyone with:

1. CogFog or diagnosed with CCSVI could potentially benefit from Resveratrol - as it has been shown to increase brain blood flow significantly.
2. Autoimmune disease, especially MS - due to the positive study in animals with Optic Neuritis.
3. Anyone who has a family history of diabetes - as prevention.
4. Anyone with coronary heart disease.
5. Anyone who wants to take something that has been shown to make animals live a bit longer :-). (It is being investigated by Glaxo as a life-extension drug - with amazing results in animals - see video on our website!) Potentially anyone with metastatic cancer may benefit - but you must contact us first to let us do the relevant research for your specific indication.

Warnings:

Do not use if you have breast, prostate or hormonal responsive cancer - it may stop your cancer medications from working properly. (However, it has been shown to be effective in hormone treatment resistant prostate cancer)

Call 0141 647 8032 or email homedeliverypharmacy@yahoo.co.uk with your requirements, phone number, and we will call you back. Please note, our telephone can be quite busy, but we have added a helpful messaging service - you can press * and leave us a voicemail, which we check regularly and will call you back.

The price is £17.99 - including P&P. We will donate £1 to the LDN Research Trust for every pack sold.

LDN Aware Voices Double DVD

£10 each



Listen to how over 40 advocates - Doctors, Scientists and Patients use Low Dose Naltrexone to successfully treat Multiple Sclerosis, Rheumatoid Arthritis, Fibromyalgia, Lupus, Crohn's Disease plus many other Autoimmune Diseases and Cancer.

DVD 1 - Tracks

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DVD 2 - Tracks

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- 2 - 4 Cancer
- 5 - 6 CFS/ME
- 7 - 8 Crohn's Disease
- 9 - 10 Fibromyalgia
- 11 Hashimoto's Thyroiditis
- 12 HIV/AIDS
- 13 - 16 Multiple Sclerosis
- Multiple Conditions
- 17 Alopecia Universalis, PCOS & IBS
- 18 CFS, Fibromyalgia
- 19 Epstein Barr, Fibro, CFS, Hashimoto's
- 20 Lupus, RA, SS, Nash
- 21 MS, Cancer
- 22 Relapsing Polychondritis, Sjogren's Syndrome
- 23 Parkinsons Disease
- 24 Psoriatic Arthritis
- 25 Rheumatoid Arthritis
- 26 RSD - Complex Regional Pain Syndrome
- 27 Sjogren's Syndrome

Presenter/Producer: Linda Elsegood Recordings Edited by: Simon Congram
 Assistant to the Editor: Rachael Thomas Cover Design: Malcolm West.
 © 2011 Produced by the LDN Research Trust - Registered Charity 1106636
 PO Box 1083, Buxton Norwich NR10 5WY Tel: 0844 41 45 295
www.ldnresearchtrust.org

To order copies of this CD or the LDN Aware DVD
 please email: contact@ldnresearchtrust.com



Listening to Doctors, Scientists, Advocates & Patients
 Low Dose Naltrexone Therapy for
 Autoimmune Disease and Cancer

Introduction by Jackie Young-Bihari
 Patron of the LDN Research Trust
 Widow of the late Dr Bernard Bihari



We will also send out free copies to a medical professional if requested by you. To request a copy for your doctor etc, please send their name and practice address, with your full name and we will be happy to do it. We did this last year and the results were amazing. Many doctors felt comfortable prescribing. However this costs a small fortune in postage alone. Therefore we need to raise funds to cover the costs of the actual DVD plus the postage.

You can also buy a copy from our shop <http://ldnurl.info/ldnshop>

**Thank You for your support in helping us to help others.
 Together we can achieve so much!**

SPECIAL Offer - Buy both LDN Aware & LDN Voices DVD's For ONLY £16 with Free Shipping while Stocks Last

Please click the link below to make your purchase now.

https://www.paypal.com/cgi-bin/webscr?cmd=_s-xclick&hosted_button_id=UAR2Z2E4UEHR6



Tribute to Celia Danks who sadly passed away last year. Written by her husband Stewart

When I first met Celia in 1984 she was working as a nurse in the Geriatrics ward at Eve's Lane Hospital in Chorley. When she moved up to Glasgow she worked for a time as an agency nurse, then for a year as an industrial nurse at the Collins plant in Bishopbriggs. She decided to retrain as a social worker, so she went back to school to get enough qualifications to go to Queens college, graduating in 1989. She then obtained a position with one of Strathclyde Regional Council's area teams at Drumchapel in Glasgow. She started and helped to run a groupwork project, which allowed her to combine her interest in art with social work. By this time I had installed a kiln in our shed to allow Celia to fire her own pottery. This led to her involvement in community theatre productions, with one play having a promising young chap called David Tennant in the lead role. Changing tack, she left SRC with a colleague to start a social work agency, and wrote social background reports to the Children's Panel for the Reporter. On an investigative trip to Cambeltown for the Reporter she came across a unusual breed of dog in a bed and breakfast she was staying in. This led to her interest in Dandie Dinmont terriers and she went on to co-found an international charity to fund research into eye disease in the breed, edited a Terrier Club magazine for a number of years, showed her own dogs and also qualified to judge the breed



Celia was diagnosed with stage 4 non-small cell carcinoma of the lung in 2006 and after receiving chemo and radiotherapy was given a 50% chance of still being around in after 6 months, and a 5% chance of still being around after 2 years. I found this out independently. We never discussed the reality of the statistics face to face.

After the therapy her oncologist just told her to go home, there was nothing more he could do. She did some research, and after negotiation with her GP got herself an 'off-label' prescription medication called Low Dose Naltrexone. She took this therapy, confounding her

oncologist two years later when he could find no trace of progression of her disease. She collected signatures for a petition and joined the pressure group LDN Now. She presented evidence to the Scottish Parliament's Petitions Committee, to try and get clinical trials and LDN accepted as an approved therapy. She was disappointed with the level of non-clinical support offered by the Health Board, having co-opted the assistance of her local MP Gordon Banks

Celia's disease had been stable from 2007, and she found time for drawing, poetry, painting and sculpting and also set up and moderated some cancer and LDN support groups on the net. She was always full of confidence for the future, although she did get anxious when her routine tests were due. She continued to breed her dogs as late as last year when her youngest brood bitch Jasmine was mated and had one pup. Celia was there to help with the whelping, and I was glad she was able to see the latest of her line born last September, just five weeks before her sudden passing, which wasn't cancer related.

Celia is greatly missed by former colleagues, friends and neighbours both at home and abroad, and by all her sisters and brothers, sons, grandchildren, nephews and nieces, and not least by me. She leaves a huge gap in all our lives.

We at the LDN Research Trust miss Celia personally and for all the help and support she gave to people with Cancer either taking LDN or considering starting.

No one can fill Celia's shoes and we send Stewart our sincere condolences.

When is Naltrexone Not Low Dose? - Dr Tom Gilhooly

The use of Low Dose Naltrexone for a wide range of immune-related disorders is becoming more established in medical practice. The standard doses of 3mg and 4.5 mg have developed more from clinical habit than from large scale trials. Clinical trials have been limited due to the lack of pharmaceutical company backing, and so far no dose findings studies have been conducted. This begs the question; what is the optimal dose, and when is low dose naltrexone not low dose?

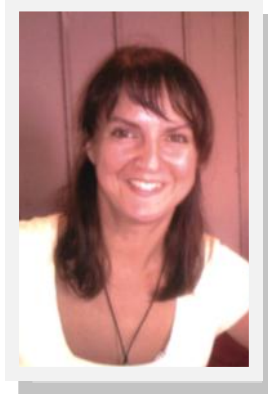
I have had the opportunity to work with both low dose naltrexone and standard dose naltrexone at 50mg. The main difference is that the high dose almost always causes total opiate blockade and as such is very, very unpopular with patients. An Australian study found that 96% of opiate-dependent patients stopped the drug voluntarily within six months. The addiction patients who are most likely to stay on treatment are doctors and airline pilots, who have very strong motivation to remain off illicit opiates. Basically they are usually in the "last chance saloon," when they have admitted an opiate addiction and, let's face it, you not want your airplane to be operated by someone high on drugs! These patients complain bitterly of feeling unwell on naltrexone, and especially of low mood. The experience of total opiate blockade is not a pleasant one as the body's own opiates, the endorphins (endogenous morphine), cannot access the opiate receptors due to the presence of naltrexone. This dramatically reduces the release of the "feel good" chemical dopamine (which is key to our mental well being), in the brain. I had a consultation with a naltrexone patient recently in one of the addiction units that our practice provides medical cover for. I had been warned by the nursing staff that this patient was aggressive and intimidating having assaulted one of the doctors in the previous rehab he was in. When asked about the 50mg Naltrexone he was on he said it was great, and completely blocked the heroin he had

tried while on it. So far so good. He then told me he had not felt right since starting it, stating that he had felt depressed since the first dose. His aggressiveness was probably just a manifestation of the opiate blockade and lack of dopamine in his brain.

In contrast to full dose naltrexone, low doses increase endorphin levels, which actually increase dopamine levels and tend to improve mood. This occurs as long as there are available opiate receptors to stimulate! When the dose of naltrexone is titrated up to the level of opiate blockade, the patient immediately notices that they feel tired, physically and mentally. There are opiate receptors all over the body, not just in the brain, so it is not just a physical effect. In most patients the opiate blockade lasts about 8 hours so it is bearable and worth finding out what the maximum tolerated dose of LDN is. In my experience there can often be a "threshold" dose where the positive effect increases markedly. This dose is often above the so called maximum of 4.5mg of LDN. Naltrexone is often classed as a pure antagonist with no actual opiate activity, but the commonest side-effect of sleep disturbance is clearly an opiate effect, as it is not normally an issue when the drug is taken in the morning. In a small number of "slow-metabolisers", opiate blockade and therefore sleep disturbance does occur with the morning dose. Individual variations in the metabolism of naltrexone is the reason why we titrate to find the maximum dose. Any dose below opiate blockade is considered to be "low dose naltrexone" with the dose range in our clinic being from 0.5 mg to 25mg. Standard doses of naltrexone range from 50 to 200mg and are almost always above the threshold that causes opiate blockade which would be undesirable in patients suited to LDN.



Katerina`s Adventures in Rhodes - Katy Pitsi



Katy Pitsi has self-published a book called 'Katerina`s Adventures in Rhodes' It`s about her travels around the beautiful Greek Island of Rhodes. Katy, 43, who was diagnosed with MS in 1994, does voluntary work, is single and lives in Bristol UK.

Says Katy: "It took me three years to write the book. After paying for my book to be edited, I found the self-publishing company Authorhouse online. I paid for their basic publishing package and after it was completed, my book dropped through my letterbox! I`m proud that I finally achieved it!

I wasn`t going to let the fact that I have Multiple Sclerosis stop me from flying off to the Greek Islands for some fun in the sun. My book is a diary about holidaying in three different resorts on the Island of Rhodes; Tholos, Stegna and Pefkos.

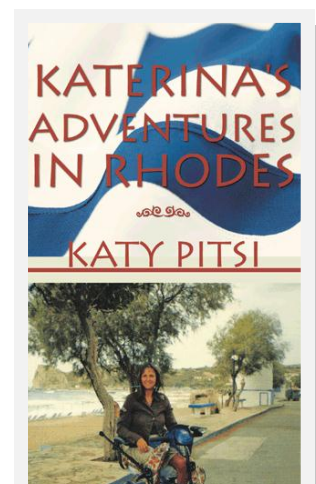
I bought my first mobility scooter in 2004. It is my friend and companion when I travel. This, along with my love of writing, is what inspired me to write this book. It`s all about the time I had there, the wonderful people I met, the obstacles I faced and the challenges I overcame whilst travelling with my mobility scooter.

'A life without a risk is a life unlived!'

'Katerina`s Adventures in Rhodes' is available from Authorhouse.co.uk. Price £10

Katy`s comments about taking LDN; 'I started taking LDN in February 2007. I have secondary progressive MS and have stayed moderately stable since taking it. I believe, as told by my LDN supplier Dr Bob Lawrence, that LDN `halts' the condition. If all it does FOR ME, is 'halt' the progression of my MS, then I will continue to take it.

I also notice that if I take a couple of days break from LDN that I have a sense of euphoria!'



Thanks to John Donnelly for his help and support, John has a world database where you can add your LDN story and read what others have to say.

<http://www.ldndatabase.com/>



ARMY COAST TO COAST OFF ROAD MOUNTAIN BIKE CHALLENGE

Sulle Alhaji

On Sunday 3rd June 2011 a team of 9 Army personnel set off to attempt to ride one of Britain's toughest off-road coast to coast mountain bike routes. This was an Army Expedition that would see us crossing 220 miles of Britain's most challenging countryside tracks and trails

At 10 o'clock on Monday 4 June we set off on the first leg from St Bees, on the west coast of Cumbria. This was a 39 mile leg, but due to the Lake District National Park being in the way, it took a staggering 12 hours to complete, and when we finished riding we just had enough time to eat and then sleep. The next day was just as demanding, as this was going to be the longest leg, covering 46 miles. Fortunately for us we set off early and made good progress, in fact we completed this leg in a record time of 11 hours.

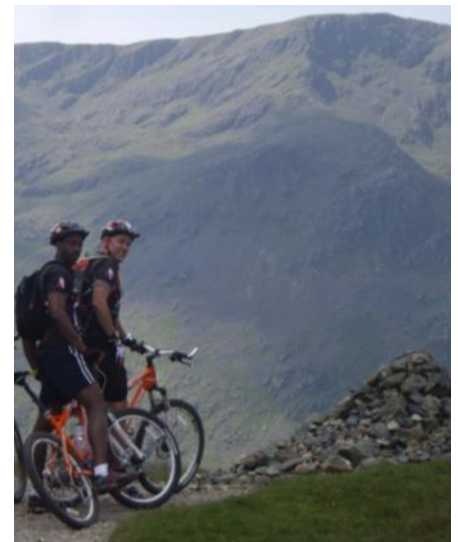


The team at the start point in St Bees



Ascending Blacksail Point

Day three consisted of a 41 mile leg. After a few miles into the ride our luck with the weather ran out and we got absolutely soaked as the Yorkshire moors showed us just how unpleasant it could be. We did stop at Britain's highest inn, at 1732 feet above sea level. The Tan Hill Inn is situated right in the middle of where our coast to coast route crossed the Pennine Way, and was a most welcome break from the rain, although short lived, as when we got back on the bikes it was as if someone had thrown a bucket of water over us.



Blacksail Point

Day 4 was a steady 44 miles but the attrition rate from riding such demanding terrain was taking its toll and we had to pull together and draw on our military *esprit de corps* and infamous sense of humour to keep us going through the rain and lightning storm which was following



The finish, Robin Hoods Bay, after 220 miles,

The final day was the shortest, at only 38 miles. The rain kept coming and the wind kept blowing but when Robin Hoods Bay came into focus, there was a feeling of relief but a sadness that we had come to the end of the road.

Continued ARMY COAST TO COAST OFF ROAD MOUNTAIN BIKE CHALLENGE



The organiser Sulle Alhaji

During this expedition there was an opportunity to raise funds, and more importantly to promote awareness of the LDN Research Trust. This was achieved by setting up an advertising stall at the Aldershot Army Open Day, where 20,000 visitors were expected. During the open day, several people suffering from autoimmune disease visited my stall and I was surprised when each of them said that they had never heard of LDN or the LDN Research Trust. I felt really privileged to be able to inform them about the LDN Research Trust and to suggest that they view the website and read the testimonials, as there might be similarities with their condition and symptoms. I also had quite a few people from the health industry, be it managers of health centres and people who work in residential homes. Whatever their status, I gave them handfuls of LDN leaflets to take back to their place of work. All in all the Army Show was a great success. The LDN Research Trust got some publicity, and I also raised some money for the trust. Together with the money raised by the rest of the team members I think we raised in excess of £2,500 for the LDN Research Trust.

To accomplish such a ride in just 5 days is astonishing, well done to you all.

I would like to thank Sulle, his wife and fellow team mates for all their tireless support and financial help, which has enabled us to produce the LDN Aware Voices DVD's that has helped raise further awareness of LDN.

The amount of money you raised is amazing, thank you all so much.

Linda



The LDN Stall at the Aldershot Army Open Day



COAST TO COAST ROUTE

Disabled Motorists Federation

Peter Lyne

The Disabled Motorists Federation (DMF) continues to diversify, not only by increasing its relationship with many central and local government organisations, but also through its associations within the charity sector. It is important to realise that the needs for disabled people, their carers and families are many-fold, and this is the reason why the DMF have been fortunate to establish associations with commercial companies who can provide a wide range of bespoke services. These can include specialist insurance provision.

(refer to www.disabilitytalk.co.uk) and you will notice that Orbis Insurance can offer a wide range of services, including travel insurance for people with diagnosed medical conditions. Through another division of the company it can consider insurance services for people who are unable to secure insurance through any other provider; for whatever reason, there are about 4 million members of the UK population who fall into this category.

Orbis can also address matters relating to household insurance, and would be very keen to enter into discussions with members of residents' associations, in order to identify their specific needs.

On visiting www.disabilitytalk.co.uk readers will note that as well as Orbis developing an extensive list of nationally located accessible hotels and guesthouses (eg recent associations with Shopmobility and Open Britain), details of many charities and government departmental directories are displayed.

Disabilitytalk is keen for its viewers to make full use of the on-line forum on issues which they would like to raise (please



note, generalised information, and not that of a personal nature) or any other topic which they believe would be of interest to visitors of the forum. For example tourism, recreation and leisure and social inclusion issues may prove to be of relevance.

Within the last few days the Disabled Motorists Federation has secured the services of a provider of a wide range of legal services. Perhaps a particularly important issue to consider is that community care legal services for children, adults, elderly and the 'at risk'

sector of the population can now be dealt with. To gain access to these facilities in the first instance please contact Peter Lyne (National Vice-President, Disabled Motorists Federation) peter@dmfed.org.uk or use the Contact Us facility on the home page of www.dmfed.org.uk and your specific requirements will be forwarded for immediate attention. We appreciate that confidentiality may be required, and if so simply send contact details and an appropriate solicitor will be in touch.

As far as www.Disabilitytalk.co.uk is concerned, once again, please make contact with Peter Lyne first.

If representing a regional or national charity, we are always keen to consider arranging reciprocal website links.

There is no charge for this facility.

George & www.anticancer.org.uk - Dr Pan Pantziarka

My first wife died of cancer a week before her 30th birthday. This was only three weeks after a diagnosis of ovarian cancer. We had two children, a daughter aged eight and a son, George, who was only fourteen months old at the time. Ten months later George developed a small lump on the side of his face, which we initially assumed was just a normal bump. But this bump, which was very hard to the touch, grew bigger rather than going down. We knew that something was wrong but initially the doctors seemed to think that I was just being a bit paranoid after what had happened to my wife. I can remember clearly when our worst fears were confirmed – it was on the day of George's second birthday when the biopsy result confirmed that he had cancer (a type of muscle tumour called rhabdomyosarcoma).

This was devastating news, and we were certain that it had to be connected to George's mother somehow. But we were assured that it was just a case of bad luck striking twice – there was no link between his muscle tumour and his mother's ovarian cancer. The odds were astronomical, but it was purely chance.

George spent nearly two years in and out of treatment. For a few months in that period he went into remission, but we saw signs of the tumour coming back after only a few weeks. Again told we were being paranoid. The disease did come back and George was treated with more chemotherapy, radiotherapy and surgery. At the end of the treatment there were signs of residual disease and were told to go home and prepare for the worst. We refused to give up and tried all kinds of vitamins, herbs and other treatments and despite some scares the tumour never came back.

From the ages of four to fifteen George was clear of cancer. He was a happy kid, very positive, very funny and a pleasure to be with. We took care with diet and worried about his health, but once we were past the ten year mark we really started to relax about cancer. However when he was fifteen a routine visit to our GP uncovered something suspicious on his scalp. This turned out to be a skin cancer (basal cell carcinoma), and was most likely a long term side-effect of radiotherapy. This cancer was surgically removed almost immediately, but a few months later his chin started to go numb.

We went backwards and forwards between different hospitals, fearing the worst, but again we were told not to be paranoid about cancer. Unfortunately the final diagnosis was osteosarcoma (bone cancer) of the jaw.



After his third cancer diagnosis George was genetically tested. The test showed that he suffered from a rare genetic condition called Li Fraumeni Syndrome (LFS). This presumably came from his mother, because my test was normal. People suffering from LFS have a defective TP53 gene, which is a tumour-suppressor gene, and are likely to suffer from multiple cancers, like George did.

George died on 25th April 2011. He was 17 years old, and had suffered a long, hard battle with the cancer that finally killed him.

Obviously as a family we are devastated. It has been painful to watch his suffering, and it is painful now without him. But we are also angry and want to do something constructive to remember him by. One of the things we are doing is publishing the web site www.anticancer.org.uk. George and I had discussed setting up a site to share the information we had gathered about treatments, hospitals, supplements and research. We bought the domain name and he worked on the logo, but as the disease took hold we never got round to setting up the site. However, now the site is up and running and new information is being added to it everyday.

Part of the aim of the site is to mobilise cancer patients, and their friends and families, to become more active in demanding access to better or different treatments. Things like anti-inflammatories, metronomic dosing of existing chemotherapy drugs, off-label drugs (like metformin or celecoxib), and drugs like low-dose naltrexone. There is so much information out there, but a lot of it is out of reach of most patients. What we want to do with the site is help patients become much better informed, and give them the tools to argue with their doctors if necessary.

There is a lot to argue about, based on our experiences and the experiences of other patients and friends that we know. The medical profession is as close-minded and dogmatic as can be. For example there are interesting treatments like photodynamic therapy and cryoablation which use physical means to attack tumours, but many oncologists are either ignorant of these or frankly dismissive, because they have been developed by surgeons and not oncologists. In addition, work done in other countries is often dismissed because it is assumed that we in the UK are as good as anywhere else (some of the statistics, for example with osteosarcoma, clearly suggest otherwise).

Continued George & www.anticancer.org.uk Dr Pan Pantziarka

There is a lot to argue about, based on our experiences and the experiences of other patients and friends that we know. The medical profession is as close-minded and dogmatic as can be. For example there are interesting treatments like photodynamic therapy and cryoablation which use physical means to attack tumours, but many oncologists are either ignorant of these or frankly dismissive, because they have been developed by surgeons and not oncologists. In addition, work done in other countries is often dismissed because it is assumed that we in the UK are as good as anywhere else (some of the statistics, for example with osteosarcoma, clearly suggest otherwise).

The other aspect of this education and empowerment is to point out that there are many unscrupulous operators. The internet is awash with people promoting untested therapies, drugs and devices. The level of misinformation is immense, and when people are feeling desperate and vulnerable the temptation to reach for anything that's there may be especially high. It is important to differentiate between treatments like LDN, which has lots of supporting evidence to substantiate its use, and treatments based on 'magic' combinations of vitamins or herbs.

Some of the people advocating these treatments are well-meaning and truly believe what they say, although in my experience many of them are not cancer patients, and are just reporting what a friend of a friend of a friend has allegedly done. However, there are also cases involving people who are exploiting cancer patients for financial gain. It's a despicable thing to do, and one of the aims of the site is to give people the information and tools to identify what is a serious option to explore, and what is a scam.

Finally, there are doctors and researchers doing really interesting work on new treatments. Some are like Dr Burt Berkson, who is working with patients to try out treatments like LDN and alpha-lipoic acid. Others are working in the lab with rats and mice but are looking at things like diet, altering levels of acidity/alkalinity, immunology and other non-toxic treatments. For many researchers the primary audience they address themselves to is other researchers via conferences and academic papers. A key aim is to open up a channel direct to cancer patients, and to that effect the site will feature interviews, questions and answers, and generally act as a forum for new research to become known to patients and their supporters.

However, the web site is only one part of the activity that we are engaged in. As mentioned previously,



George suffered from a rare genetic condition called Li Fraumeni Syndrome. Currently there is no organisation or charity in this country to support sufferers. A diagnosis of LFS is devastating, yet there is nowhere specifically devoted to the interests of sufferers. At the

moment we don't even know how many people in the country have it. Again, we are lagging behind in the UK and the situation is better for LFS sufferers in other countries. We would like to change that, and are in discussions with the Institute of Cancer Research to see about setting up a support group/charity in George's name.

I have also been asked to become a trustee of the Starthrowers charity, which supports cancer patients. It is based in East Anglia, but the charity supported us (we are based in London) at a difficult time, and I am more than happy to become a trustee. I hope that this association with Starthrowers will be fruitful in bringing things like LDN to the attention of more patients and doctors.

Finally, I want to make clear that this is really a family affair, and that it's more than just one grieving father at work here. Other members of the family are also doing their bit, so that for example in December there will be a series of fund-raising events in aid of Childhood Cancer week in Woodford Green, Essex, organised by George's cousin Penny (more details here: <http://www.anticancer.org.uk/2011/09/volunteers-required-fund-raising-in.html>).

I deeply regret that George never had the chance to try LDN. By the time we had learned about it and managed to get a prescription, it was too late. George was in lots of pain and on such high doses of opiate pain-killers that taking LDN was not an option. We will never know whether it might have helped him or not. We'll never know if any of the other treatments we highlight would have helped. But the very least we can do is not forget what he went through, and to do our best to make sure no-one else goes through it.

I've just published the first part of an interview with Burt Berkson on my website <http://www.anticancer.org.uk/2011/10/q-with-dr-burt-berkson-low-dose.html> I'm sure it'll be of interest to you and other people interested in LDN.

We have started the first support group for Li Fraumeni Syndrome in the UK. It's called the George Pantziarka TP53 Trust - the web site and forum are here: <http://www.tp53.co.uk>

Join the LDN chat in the forum chat room

Do you want answers to your questions about LDN? Would you like to share your experiences using LDN? Now you can have an opportunity to do both in “real time.” It’s a great opportunity.

We will be holding weekly online chats about LDN in the LDN Research Trust chat room.

I will be hosting the chat on the 1st Friday of every week 9 - 10 pm UK Time starting 2nd February. To check what time that is in your country use <http://www.timeanddate.com/worldclock/converter.html>

Set the date: 3rd February

Set the time: 9pm

Enter Location London

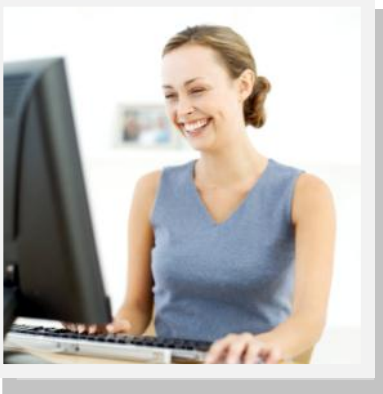
Then your Country

Click – convert time and then you will be able to see the time in your time zone for 3rd February

At first, these chats will last one hour. But we are hoping that, with time once momentum builds and we have more people offering to host these chats they will take place more often, are for longer periods of time.

We need more moderators, so if you have the time and the enthusiasm, please contact Linda Elsegood at contact@ldnresearchtrust.org. We look forward to hearing from you soon. We hope you will join us online!

In order to sign up for our chat room, please go to <http://forum.ldnresearchtrust.org/> and register. It is quick and easy to register, the LDN Research Trust we set up in England when you are asked on registration.



LDN Research Trust Links

LDN RT Main website: <http://ldnurl.info/ldnrt>
LDN RT Forum: <http://ldnurl.info/forum>
LDN RT Chat Room: <http://ldnurl.info/chat>
LDN RT Facebook: <http://ldnurl.info/facebook>
LDN RT on Twitter: <http://ldnurl.info/twitter>
LDN RT YouTube Channel: <http://ldnurl.info/youtube>
LDN RT Birmingham Conference: <http://ldnurl.info/birmingham2010>

LDN RT Shop: <http://ldnurl.info/ldnshop>

To Donate: <http://ldnurl.info/donate>

LDN Aware Website: <http://www.ldnaware.org/>

All ideas and suggestions are welcome to raise awareness and funds for LDN.

LDN Research Trust YouTube Channel

<http://www.youtube.com/user/TheLDNresearchtrust?feature=mhsn>

LDN Advocate YouTube Videos

Part 5 now available - <http://www.youtube.com/watch?v=YywaPg6Yosc&feature=youtu.be>

A BIG thank you to all those that took part.

Would you like to be featured in our series of LDN Aware Videos?

We would need:

Full Name/ First Name/ Initials or none – you choose what you want

A large good quality photo of you, doing something would be good but doesn't matter.

Country

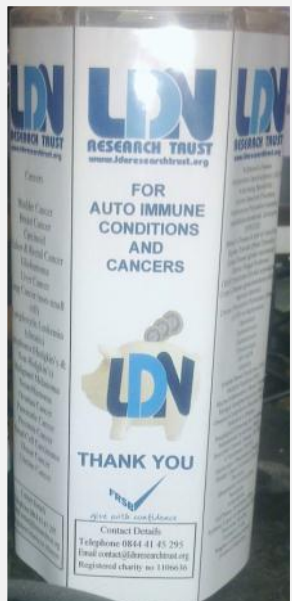
Condition

Diagnosis Date

LDN Start Date

Two sentences explaining what you think of LDN

Please let me know if you would like to take part.



LDN COLLECTION BOXES PLEASE CAN YOU HELP?

We are proud to announce our new collection boxes.

We would like help placing the boxes in Post Offices, shops, pubs, Doctors waiting room in fact anywhere that gives permission for a box to be displayed.

We are looking for people who are willing to take control of displaying boxes, collecting them and banking the money into the LDN Research Trust's Barclay's Bank Account.

Small change adds up and we have managed to purchase 500 of these boxes at a very special rate and if we could find homes for all of them that would be great.

Are you able to help?

Please email contact@ldnresearchtrust.org with your name, address and how many boxes you require.

Thank you in advance. Simon

Are you or have you taken LDN for any condition?

We would love to hear your story, please email contact@ldnresearchtrust.org
We would not use your name without your permission.

Thanks to Cris Kerr from Case Health - Health Success Stories, for all her help, support, sharing stories with us and for compiling the eBooks below.

Those That Suffer Much, Know Much 2010 eBook

<http://ldnurl.info/ebook2010>

201 Reasons Why You Should Know About LDN eBook

<http://ldnurl.info/thosewhosuffermuchknowmuch2010>



Linda Elsegood



Cris Kerr

Shop online and we get a commission

Do you shop online?

Check out the High Street Shops and Major Retailers, for every sale we get a commission.
<http://www.buy.at/LDNResearchTrust?CTY=26&LID=24-07-2008>



Remember each time to use our link every time you shop online.

There are always Special Offers and often Free Delivery from some of the shops, not forgetting the Sales!!

If you think that other supporters of LDN Research Trust would be interested in shopping online to raise funds for the cause, please forward this email on by clicking this link: <http://awin.sendloop.com/f/cnQvdDQvdHlv>

Help fundraise with Everyclick, search engine.

When searching the internet you can help earn us money at no charge to you, regardless where you live in the world.



Membership is free & easy and every search helps raise funds. <http://ldnurl.info/search>
 Save the link as a favourite, use it each time you search the internet and funds will soon add up.

LDN Research Hypnosis CD's

Ted Heaths Relaxation and Stress Relief CD suitable for all

- ◆ Discover a wonderful feeling of pure relaxation.
- ◆ Within that relaxation:
Produce positive thoughts
- ◆ Remove fears and Anxieties
- ◆ Gain a heightened awareness of your own mind and its power
- ◆ Use the power of your mind to alleviate stress
- ◆ Recognise the power of your mind to overcome Adversity
- ◆ Awake refreshed and alert.

Hypnosis for MS CD from Sharon McKay

will help people to stay relaxed, calm and focussed, and can also help with the following:

- ◆ Promoting your body's own natural healing force.
- ◆ Help you to feel loved, wanted and respected.
- ◆ Strengthen your sense of purpose and meaning on this earth.
- ◆ Inspire you to remain positive in the face of adversity.
- ◆ Help you to reassess your life and goals in a positive way.
- ◆ Help you to deal with other peoples' reactions in a positive way.
- ◆ Reinforce your sense of pride and dignity.
- ◆ Improve your self esteem, and elevate your mood.
- ◆ Boost your confidence and self belief.
- ◆ Help to get rid of fear, and manage each day as it comes.
- ◆ Improve your sense of well-being
- ◆ It can also improve sleep, and sometimes help with pain.



Price: £10

For full Details
<http://ldnurl.info/ldnshop>



Price: £10

Fundraising Items



White Polo Shirts in 5 sizes ideal
£10



Ribbons
.75p each



Key Rings
£2 each



LDN Mascot Lambs
£2 each



LDN Car Stickers
£1 each



Wristbands in 2 sizes
£1.75



LDN Round Button Badges with a pin on the back.
2 sizes. 95p and £1.25p



Silver coloured metal pin badges.
£2 each



LDN DVD's £10 each



Leather Disabled Badge Wallet
£13.50



Canvas Beach/Shopping Bag
£4.00

Check out our range of greeting cards in the shop.

100% goes to the LDN Research Trust on most cards

We would greatly appreciate your support promoting these items.

All these Items can be found in our website shop:

<http://ldnurl.info/ldnshop>

PLEASE can you help?

Times are tough for all of us and raising funds is very difficult. Everyone one at the LDN Research Trust works as a volunteer, no one gets paid and we receive no funding from anyone. We do however have running costs which have to be paid for and we really could use YOUR help!

**Can you spare £1, \$1 or 1 Euro a month
or an annual donation.**

To help support the LDN Research Trust?

Many people said they are embarrassed to make such a small donation, please don't. Every little really does help!

If you would like to make a donation please visit: <http://ldnurl.info/donate>

Most people could afford £1, \$1 or 1 Euro a month, please consider helping us today.

**Your help will make a difference.
Thank you for your support**

Selling Goods on eBay



You can donate a percentage to the LDN Research Trust when listing your items. Every little helps!

Now is a good time to have a good clean and get rid of all your unwanted items and you can donate a percentage of what you raise to the LDN Research Trust.

We are very grateful to all of you that have made donations already via eBay, your help and support is truly appreciated



If you have free time and would like to help please get in touch with us regardless where in the world you live, even if you can only spare an hour a week it would help.

We are looking for people who can: search the internet, help host the chat room (if talking to other people is your thing, this would be fun!) help with marketing, press releases and contacting the media.

If you have any free time and would like to get involved in someway please email contact@ldnresearchtrust.org





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Email: contact@ldnresearchtrust.org
Web Site: www.ldnresearchtrust.org

For information how to obtain
LDN in the UK or for
general LDN information call:

0844 41 45 295

Local rate number

Outside of the UK please email,
we have managed to help
people worldwide obtain LDN

Trustees: Linda Elsegood, Alex Parker, Neil Lucas
Lee Reynolds

Medical Advisers:

Dr Bob Lawrence MRCS; LRCP
Dr Tom Gilhooly MBChB; MRCP
Stephen Dickson BSC(hons) MRPharmS

Newsletter Editor Linda Elsegood - Sub Editor Sophie Marrion

Newsletter Compositor - Simon Congram

Web Master - Lee Reynolds

Forum Manager - Alan Browne Senior Moderator - Derek

Graphic Designer - Graham Parker

Survey Form - Mark Lane

Facebook Administrator - Laura Elsegood

Events Co-ordinator—Roni Cangram

The LDN Research Trust is a non-profit-making Registered Charity, and all helpers are volunteers.

However, we are no different from other charities, in that there are unfunded elements which do ultimately cost us money to maintain and operate.

To help us continue our work we would appreciate help with fund-raising, either in cash or in kind.
You can be sure that all contributions are greatly appreciated, however small.

How to make a Donation

To Make a Donation from anywhere in the world using MyCharitypage.com. This is our preferred method as there are no fees plus if you are a UK tax payer they claim the gift aid back for us!!

<http://ldnurl.info/mycharity>

Gift Aid

If you pay UK Income Tax - like tax on your pension if you are retired, or Capital Gains Tax, or tax on the interest from your savings - then every donation you make, or have made since 6th April 2000, could be worth almost a third more, without any cost to you.

If you want to help the LDN Research Trust to maximise the impact you make through your donations, all you have to do is complete a gift aid form.

<http://ldnurl.info/gift-aid-form>

**To Make a Donation Direct into our Bank Account
Or
To setup a regular monthly payment**

Barclay's Bank PLC
Sort Code: 20-03-26
Bank Account No: 60515213

PayPal

PayPal Donation from anywhere in the world, although they charge us a fee to accept payments.....

<http://ldnurl.info/donate> and then the PayPal Button