

NEAD TRUST

Non Epileptic Attack Disorder



NEAD TRUST - Newsletter

1st Edition

ABOUT US

Welcome to this the first edition of the NEAD Trust Newsletter. We would like to take this opportunity to introduce ourselves and tell you all a little bit about us and what we are all about.

We are at the moment a non profit organisation, set up by myself Michelle Reed and my partner David Porter. I suffer from the condition; I was diagnosed with it in 2005. At the time I was diagnosed I had never heard of the condition and knew nothing about it I so I tried to find out some information on the internet. I searched for months and found nothing, except a few American websites but nothing from the UK.



Michelle & David

As a sufferer of the condition I felt alone, vulnerable and very frightened about what to expect, I felt like I was the only person in the world with this illness and

I felt very depressed. After discussions with my partner, who is also my fulltime carer, we decided to start up a website, the aim of the site was to allow people with NEAD to talk to fellow sufferers in the hope that it would provide some much needed support and allow people to share there experiences with each other through a forum, this helped me so much to know that I am not alone and what I go through on a daily basis is very similar to other NEAD sufferers.

We started the website in February 2008, and since then we have gone from strength to strength, we are getting more and more members, and this has prompted us to set up the organisation.

NEAD Trust was started in October 2008 it is a non profit organisation at the moment and hopefully within the next year we will be a fully operational charity. The organisation and the charity have been set up by myself and David and we have a board of trustees, these are people who suffer from the condition or know someone who does.

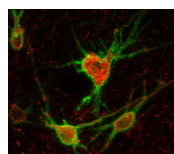
The trust has been set up to provide services and support to NEAD sufferers and there families, at the moment the trust runs the website, provides marketing and promotional materials to all the NHS trusts in the UK so they can advertise us and the condition, we run a coffee morning/ support group in Sheffield and hopefully by the end of the summer there will be others too.

The two main aims of the trust are support to people who have NEAD and raising awareness to those who don't. This we feel is vital as all too often people are quick to turn their backs on what they don't understand, and with this illness not enough is known about it so people make assumptions and they are often wrong. Like the assumption that epilepsy and NEAD are the same, when in fact they are very different.

What is a Non-Epileptic Seizure?

Non-epileptic seizures are events that look like epileptic seizure but do not involve abnormal, rhythmic discharges of cortical neurons. They are caused by either physiological or psychological conditions.

Confounding neurologists and other physicians, non-epileptic seizures are frequently misdiagnosed as epilepsy.



Cortical neurons

Misdiagnosis means that appropriate treatments are not received by the patient. In addition, the misdiagnosis can be dangerous because it can result in administration of unnecessary and potentially harmful medication.

Statistics on the prevalence of these misdiagnoses are not available. Although it is believed that as many as 5% of people diagnosed as having epilepsy have Non-Epileptic Attack Disorder and up to 7% could have both.



Video EEG Equipment

Inpatient hospitalization for video-EEG monitoring is a costly but effective way to distinguish them from epileptic seizures as non-epileptic seizures tend not to respond to anticonvulsant medications. Also, many people with epilepsy experience non-epileptic seizures as well, finding evidence of one does not rule out the presence of the other.

Charitable Status

NEAD Trust is a Non-Profit Organisation but we are currently applying to become a UK Registered Charity but we cannot do this without you! We need all the help we can get to raise funds as to become a registered charity we need to have a minimum amount of £5000 in secured donations!

We do have a **donate now** function on our web site neadtrust.co.uk as well as selling a wide range of products including T-shirts, Caps, Mugs, etc

Please don't delay, donate today!!

Diary of a NEAD Sufferer

Elaine Harwood is a NEAD sufferer and has been for many years yet she does not let this condition rule her life, this is her story about her recent trip to India to help the children there.

It had taken nearly a year of preparation for our trip to India. We had fundraising events throughout the year and with hard saving.

St Richard's Church has supported Operation Isaac which Rev Gordon Small (rtd) started after meeting Pastor Isaac in Singapore in 2000, and we have continued to do his work. The first team went out there in 2001 and again in 2005 (when Jim McConnell, Gordon and Heather Walters were part of the team of six) the reason is to share the needs of the children in the orphanage, the widows and share the word of God with outlying villages around the area of Morrispet in Telani.

Our journey started at Heathrow terminal 5 at 6 am. The flight was to take over nine hours and cover 5,123 miles, plus a 7 hour train journey once we arrived at Chennai. We had a good flight and arrived in India at 0145am, it seemed to take ages for our luggage to come onto the carousel. Isaac and Joseph were there to greet us, as well as the noise and smell that go with India. We then had to wait nearly 5 hours for our train to arrive.

On arrival at Telani, we were once again greeted by the pastors with garlands of flowers each. This is a high honour for anyone to receive.

Our daily routine was cold showers at 7am with breakfast at 9am. This consisted of cold fried eggs, fried bread and this time peanut butter and jam, Ann had her porridge which we took over with us. Following this we had bible study and prayer and discussed what we were going to do in the evening. Lunch was around 1330, this was made up of fried rice with chicken or fish, chapatti and Dahl. Because of the heat, 96 plus, each afternoon we rested for a couple of hours. We never had our evening meal till 9pm following our meetings at the villages. Again this was cold, boiled rice, potato, beans, chapatti and Dahl. We were encouraged to eat oranges and bananas at each meal. You soon got used to eating cold meals.

We each gave 7 talks at, 2 Sunday services, Pastors meeting, Telani, Benugudurapadu, Sreerangapuram and Vellaluru. All the villages were accessed by, in most parts, unclassified roads. The meetings ranged from 40 to 90 strong and I must admit I was nervous at times. We were confronted with motorised rickshaws, bikes, and lorries, and was always under the cover of darkness.

One scary evening, we were confronted with a lorry, whose driver was not going to move, nor was our driver. Imagine, being in a car, lorry was on the offside, and the canal with a bank on the nearside. All I could see in my head was a scene from the Flintstones when their car was tilting over. It was very scary but our driver managed to get us off the bank and back onto the road.

At our first village there were thousands of mozzies dancing around the light, they still make me itch now. The joy on the villagers when they saw us, the children sang their hearts out, it was a shame we did not understand what they were singing as it was in their native tongue of Telugu. It did not stop us clapping, trying to keep in time with them. Ann, Nick and I would then give a 15min talk to them all, which for me was very daunting, what would I say, but God's spirit was with me and with Ann and Nick's support I got through.

The orphanage which is what I went out to see was really good. The children had to be moved because the landlord found out that white people were helping with the rent, so he increased it big time. So they had to find a piece of land and rebuild.

They have done a fantastic job and the children have got a lot more space than before, four toilet areas instead of one, a store room, kitchen, and girl/boys room. The children are being encouraged to grow vegetables (maize, curry plant etc) so that they can be self sufficient to a point. Their meals are very basic, consisting of rice (three times a day) with a lentil mix. I tasted it one day, and it nearly blew my head off..... They now have a play area, and were very pleased when Nick joined in most afternoons



with cricket, orphanage rules apply! the girls played skipping and were throwing a ring to each other.

We saw them everyday, which was brilliant and a real boost for us. They would all greet us every time in Telugu, all 23 of them at the same time. Then silence as they all sat down on the mat, girls one side and the boys the other, youngest to the eldest. We asked them if they remembered the song we taught them in 2005, 'Jesus love is very wonderful' and the actions, to our total surprise they did, so we taught them some others. They tried to teach us one of theirs, which was very funny. One thing we did teach them was 'see you later alligator' much to the dismay of Isaac. So every time we left them to go back to the house, all you could hear was 'see you later alligator'.

Sadly the church has had to be demolished. The land which was leased by a good friend of Isaac's parents had died and the family reclaimed it, that's how it is in India. All the roofing which was paid for by our parish in 2005 has now been used for the orphanage. Church services are now held in the main house, until a new one can be rebuilt. Sadly because of this, due to access, we were unable to see the widows.

The area itself had changed since my last visit, there seemed to be less cattle and more tractors and motorbikes. Now talking about motorbikes. Imagine, dad driving, baby in front of him, mum side saddle holding a baby in her arms. Seriously, that's how it is. Motorised rickshaws which should only carry 4 max, some mornings had over 8 in them. It was a sight to be believed.

On our last day we said our good byes to the children, and yes, I blubbed big time, which in turn started the children off. We had really bonded well with them over the week. That evening they performed for us the Nativity Play, which was brilliant and it was a great closure for us. The Christmas story never changes, even if it is in Telugu.



It was a fantastic and worthwhile journey, I learnt a lot about myself through others less fortunate. They have basic living, poor hygiene and live from day to day. I feel we have much materialistic values today and we forget what matters most, family. I got bitten to death by mozzies, but Ann, Nick and I generally kept in good health.



(front left to right Ann & Nick. Behind Elaine & Pastor Isaac in the grounds of the orphanage)

So it is back to the drawing board now, ready for a team, hopefully to go out in 2011. In the meantime, thanks to the sponsors and donations we receive Jim McConnell and I will be able to continue to send money to support the orphanage and the needs of the children and the work of Pastor Isaac.

Elaine Harwood

NEAD Puzzler

Welcome to the puzzle section of the newsletter answers and winners will be printed in the next newsletter.

Good Luck!!

Six of the Best

Q1). In what profession would you use the acronym "SOCO" and what does it stand for?

A).....

Q2). What is the official national anthem of the USA?

A).....

Q3). The Blue Corn-Flower is the French equivalent to what in England?

A).....

Q4). Which weather phenomenon translates from the Spanish for 'little boy'.

A).....

Q5). Ambassador to the Court of Saint James is the official title for Ambassadors of which country?

A).....

Q6). Which castle is on the island of Anglesey?

A).....

Sudoku

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Latest News

Thank you to everybody for your contributions and continued support.

- Sheffield coffee morning is the first Friday of every month at 10:00am - 12:00pm at the Victoria Hall Methodist Church
Norfolk Street
Sheffield
South Yorkshire
S1 2JB
- London coffee morning on the 26th April address is to be confirmed please see the website for more details.