



Contaxia

ATAXIA EAST NEWSLETTER

Spring 2007
Issue #19



A WORD FROM THE AE EDITOR

Welcome to the 19th edition of the AE newsletter, I keep hearing **when and not if** as a treatment/cure for Ataxia, lets hope 2007 is the when!, I have recently subscribed to the FARA (friedreich's ataxia research alliance) website (www.curefa.org) so I can receive their updates on the latest treatment as they describe "the promising road ahead" – I am a bit of sceptical though..

We added a baby daughter (Honoka) to the Thornton family, in November 2006, so that was the best Christmas present that I ever got.



As there has not been a meeting yet in 2007 this is a shorter (in articles) version of Contaxia.

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### CHAIRMAN'S CHAT

With not to much to report I thought I would try and summarise what has gone on through the winter months, at least it has been relatively warm, helping the old joints move a little easier - know what I mean?

I have received a lot of information about the Disability Discrimination Act from several sources and you might think I should be an expert on it, but it can be 'mind-blowing'. One document, received by email, ran into some 36 pages, far too big to print off and reproduce in our newsletter. Suffice to say, I have stored it on my computer, so if anyone wants a little advice on a particular subject, I will do my best and probably with the help of AUK we may get somewhere?

From the many updates I also receive from the various Volunteer Services, both Peterborough and Lincolnshire, you would have thought we would be able to 'run' a well organised and efficient group but to 'get there' I would have had to attend that many courses I would never be at home? Be assured I always 'pick up' on anything that would benefit us at AE, so that you do not miss out. Nothing really exciting so far?

You will see the notification for the next meeting in this newsletter, it's our AGM, so you again have the chance to have your say in how the group progresses. Each committee member's position is up for election, can you help us improve on what happens in AE. We will not go through the 'official' sending out notifications, just please, come along and support us.

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NEWS

MS CANNABIS SUPPLIER IN COURT ORDEAL

A woman with multiple sclerosis who narrowly avoided jail for helping to supply cannabis chocolate bars to disabled people has told how she was driven to the point of suicide by her court ordeal.

WINTER FUEL PAYMENTS

The DWP [Department of Works & Pensions] have notified us that if you think you may not automatically receive the Winter Fuel Payment you should call the helpline and request a claim form. [08459 15 15 15] The forms must be returned by **30th March 2007**. This applies to people aged 60 or over.

SUMMER HOLIDAYS

We are all thinking about that lovely summer holiday, but with our problems, where do you go? If you have had good or bad experiences of anywhere, home or abroad, please let us know so that other AE members may benefit or avoid?.

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#### AE CHRISTMAS MEAL 2006

It seems ages ago now, in fact, the beginning of December last year. There was a good turnout of members, I can't remember exactly how many, but we had a good meal. It was disappointing



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that we were wedged in a long part of the pub.

During the summer the pub had a refit and a lot of the place was partitioned off, this made it not the best of places for the disabled customer. It is their loss as we will not be returning another year, a new venue will be sort for this year.

It can be seen from these poor pictures things were a bit tight



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ATAXIA UK BRANCH RULES

As Æ is a branch of Ataxia UK, under the new 'Branch Guide' we need to establish a few simple rules and standards! Though only basic guidelines, to start quoting them in our newsletter will take up to much space, plus it needs members input before being finalised. So again please come to the AGM on the 14th April to see what is decided?



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## FUNDRAISING

Not too much has been organized so far, but if anyone thinks they have a few good ideas then please come forward and let us know, even a quick phone call to me may set things in motion to raise our much needed funds.

One definite fundraising date is the 23<sup>rd</sup> June, when we have a 'tin' collection in Boston Town Centre, any help would be appreciated, if only for an hour or so.

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SOME LIGHT-HEARTED STUFF

YOU KNOW YOU ARE LIVING in 2007 when...

You pull up in your own driveway and use your mobile phone to see if anyone is home to help you carry in the shopping.

You haven't played solitaire with real cards in years.

You have a list of 15 phone numbers to reach your family of three.

You e-mail the person who works at the desk next to you.

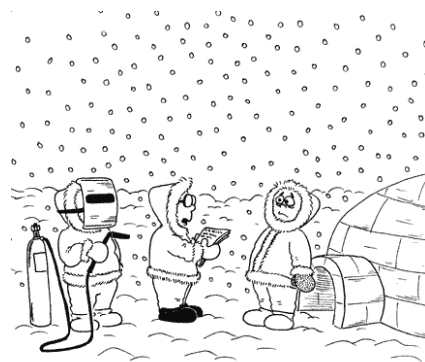
Your reason for not staying in touch with friends and family is that they don't have e-mail addresses.

Every commercial on television has a web site at the bottom of the screen.

Leaving the house without your mobile phone, which you didn't have the first 20 or 30 (or 60) years of your life, is now a cause for panic and you turn around to go and get it.

You get up in the morning and go on line before putting the kettle on.

You're reading this and nodding and laughing.



You are 3 months behind with your mortgage payments. I'm afraid we'll have to melt your igloo.

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## DATES FOR YOUR DIARY

**Æ AGM**

**This is to be on Saturday 14th April, starting at 2pm in the usual venue, the Stanground Community Centre, Stanground, Peterborough. There will be the usual raffle and light refreshments. Hope to see you there.**

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CONTACTS

Æ Chairman:
Dave Stubley
33, Grosvenor Road,
Frampton,
BOSTON,
Lincolnshire, PE20 1DB.
Tel: 01205 722771
e-mail: djstubley@aol.com

Æ Vice Chairman:
Terry McKenna,
terry.mckenna1@ntlworld.com

Æ Editorial:
Sthorn71

