



A WORD FROM THE AE EDITOR

Welcome to the 18th edition of the Contaxia newsletter, it's the AUK AGM time of the year, I won't be attending this year, due to personal reasons.

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AE NEWS

Keen All Round at Deacon's School

When Les Keen, a groundsman at the Deacon's School, Peterborough, decided to run for Ataxia UK in the Flora London Marathon, students were keen to get involved, too.

The school had chosen to support Ataxia UK by raising funds to help research into ataxia.

While Les followed a rigorous training programme, pupils with staff support, were busy throughout the year with their own projects.

A sponsored haircut by Mostafa Pirpashteh gathered more than £200 and Mohsin Shabir collected about £50 for his sponsored "silence." A group of musician students, calling themselves "The Band", donated their prize money of £300 for winning a "Battle of the Bands" contest.

Les himself raised close to £1,000 from his marathon run and with cash raised by other school activities, he presented a cheque for £1,871 to Dave Stublely,



chairman of Ataxia East, the regional branch of Ataxia UK.

Accepting the cheque on behalf of Ataxia UK, Mr Stublely (a sufferer of ataxia) told the assembled students and staff: "We are very grateful to the school for supporting Ataxia UK. Funds are desperately needed to finance research into ataxia. The money

donated through the school's fund-raising efforts will help medical teams discover the causes of the various forms of ataxia. With the encouraging advances in medical science, the day that a cure is discovered is not far off. When that happens, you know you will have helped with this cheque for £1,871."

Money is still being donated and the final figure is expected to be in excess of £2,000.

Ataxia Awareness

To try and promote ataxia awareness in our area Dave Stublely put himself forward to take part in a radio item on LincsFM. The reporter came down to Dave's house and interviewed him all about ataxia and the effects it has on you and your lifestyle.

The report went out as part of a news item on Tue 29th August, it started on the 10'clock news and went on in various edited articles, every hour, until the 9 o'clock news at night, so giving ataxia good coverage throughout the day.

To follow on from this, he then did a newspaper interview for the Boston Standard, which came out on Wednesday 20th September, in time for awareness day, 5 days later. The reporter Jack Blanchard did a good job in putting over the ataxia information.

Boston Charity Showcase Event

As a lead up to the Ataxia Awareness Day,



Sue behind the stall with our new Ataxia Banner hanging in the front.

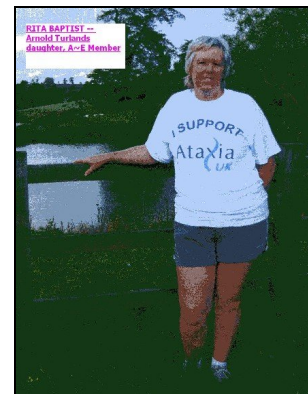
AE took part in the Boston event to raise ataxia awareness. Held on Sunday 21st September in Central Park, Boston, the event was well attended by many local charities and 'help' organisations. Last years event

was held at the Princess Royal Spots arena especially built for disabled events, which AE attended, but as this is a little out of the centre of Boston and so the event was moved to Central park. This proved to be a good move as the attendance was better on a lovely sunny day.

Sue had set up a small Tombola to raise a few funds for the group and we managed to raise about £60, not a bad days work with a lot of the usual questions being asked "What is Ataxia"?

Rita Baptist – Great North Run

Daughter of Arnold Turland, an AE member from Northampton, Rita Baptist decided she wanted to support AUK as well as her father in the fight to find a cure for Ataxia.



She therefore applied to be able to take part in the Great North Run, the northern equivalent to the London Marathon, which is run around Newcastle. Rita was successful and on the 1st October, she lined up with several thousand others at the start. Anticipating to be able to run the first 9 mile and then complete the rest at a walking pace, she was surprised that with the support of the magnificent crowd it lifted her spirits and strength and she was able to run the full 13.1 miles. Rita said it was a fabulous experience and was proud to complete the run in 2hr 49min and 14sec. The amount raised has not yet been totalised, so if you feel like supporting her, please send in your donation to the H/O, Well Done Rita.

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MEETING NOTES, 28-10-06

The Chairman Dave Stubley opened the meeting with an apology, his notes for the meeting where 'stuck' in his computer and so he would have to work from memory. He introduced a new member, Jean Pearson from Dogsthorpe, Peterborough and the speaker for the meeting, Sarah Fletcher of Peterborough Council for Voluntary Services.

Present - Alison Crosby, Lesley Gordon & partner Alan & Doreen Granger, Sue & Gerry Howard, Sheila Jones, Terry Mckenna, Jean Pearson, Bob Robson, Dave & Sue Stubley, Mona & Keith Taylor.

Apologies – Alan Beckley, Chris, Ann & John Chapman, John & Mags Hackett, June & Ray Houlgrave, Kirstie Jones, Simon & Mihoko Thornton.

Treasurers Report – Lesley informed the meeting that we had £858 in the N&P account. £1000 had been sent to AUK and a letter of receipt had been received by the chairman.

Fundraising — Lesley Gordon completed the Three Peaks Challenge in the required 24hrs, raising money for Ataxia and Arthritis. The total has not been finalised but about £100 could be coming to Ataxia.

It was hoped to arrange a street collection in Peterborough, when the weather improves next year and also a collection in Hampton Court, [Tesco's]. An application had gone in to Boston Borough Council for a collection next year. I was suggested by Sarah Fletcher that we try a collection at a 'Posh' home game, this will be looked into.

The ASDA bag pack and fundraising event was cancelled this year because of alterations to the store.

Ataxia Awareness Day – There had been many events to support the day, many not on the actual day, but still raising awareness. 29th August and LincsFM did an interview about ataxia with the chairman, this went out on the news programme from 1pm to 9pm. Saturday 9th September saw members of Æ travelling to Skegness to give support to Lee Hennell an FA sufferer from near Newark, who had cycled from Newark to Skegness in support of Ataxia and raising funds. On Sept 10 was the Boston Showcase Event where Æ had an awareness stall and a small Tombola raising £60. Wed 20th September, Boston's local newspaper, the Standard, ran a small article about ataxia. On the 25th AUK, in particular, Julie Greenfield, made several radio interviews across the country, all to raise awareness.

The chairman had been notified by Pit Rink, AUK's chairperson, that the Chief Executive, **Alastair McDougall** had resigned from his position on 6th September. He will continue with one or two commitments he had entered into but a replacement is being sort as soon as possible.

A discussion then followed about help in paying utility bills, it was mentioned that **Charis**, a charity set up by Anglian Water, and based in central Peterborough, was set up to help people finding hardship in paying their bills.

The chairman had been invited to attend a **Disability Equality Commission** meeting as part of a Lincolnshire wide consultation process to improve facilities for disabled people throughout the district council's area. It was soon apparent that a lot had to be done and so anyone with a particular problem with amenities or services could put their problem forward. From the Æ meeting it soon proved that disabled toilets need a lot of improvement.

Athletic for those with Disabilities, Æ had been approached by Boston and District Athletic Club to offer any member of Æ a chance to join them on a Thursday night for athletic activities. It is held at the Princess Royal Sports Arena in Boston, especially built with disabled people in mind. More details can be found by ringing Peter Arnott or Nanette Johnson on 01754 820455.

The next Æ meeting will be the **Christmas meal** on 9th December at the Paul Pry pub, Lincoln Road, Peterborough, starting at approx 2pm. A copy of the menu will be circulated asap and a reply date of the 2nd December if you would like to go. There will be a nominal fee to pay towards the cost once it is established how many want to go.

The Æ **AGM** will be held on either the 7th or 14th April, subject to confirmation, so please note it in your diary as it involves the election of committee members for the year. Your chance to have some say in which way you want the group to go.

After a short Tea Break, **Sarah Fletcher of Peterborough CVS** gave the meeting an interesting talk about the work of the PCVS. PCVS is a charity set up to support other charities and small groups doing charitable work. They will help any group with their fundraising activities as well as provide information about employment law and how it affects groups.

They can advise people on how to set up a group and then support them with help in photocopying, binding, laminating and even writing newsletters. They will do the end of year reports if required. There are 530 groups associated with them including Æ.

Advice can be found on several issues including the new 'Direct Payment' recently issued by the government. Carers Project support and the advice on benefits are available. A 'Sitting Service' is organised so that carers can take a short break and complete something they wanted to do, away from their usual 'chores'. Should anyone want to do voluntary work, PCVS will find something that will suit them.

At the moment PCVS are running a Trustee Recruitment Project where people wishing to help an organisation/charity and get more involved in the running of the group can learn the 'legal' side of the work. PCVS can also provide grants for groups and individuals in the Cambridgeshire area who have worthwhile projects they want to complete. The Fund Finding project has proved popular with both groups and individuals alike.

Sarah provided many leaflets to support, illustrate and explain PCVS's work, these will be available at Æ meetings and some distributed with Contaxia, when next produced.

Dave Stubley thanked Sarah for her time in coming to the meeting and expressed that he had used some of PCVS's courses, etc. and had found them very beneficial, he could only recommend that others utilise their services.

Finally the **raffle** was drawn with various donated prizes and giving Æ £23 to cover expenses.

The meeting closed at 4.45pm

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