Central Ataxia News

Ataxia UK

Issue Eight

May 2007

Introduction

Welcome everyone to the latest edition of our newsletter, I hope that everyone is well and enjoying the good weather. Have you been on holiday yet or are you going later in the year? I’d love to hear your holiday stories and I’m sure other members would, especially details on location, how friendly people are to disability and your ability to get round etc.. Please pass details either directly to me via email or post (Details at bottom of page) or hand them to Chris, Brian or Sarah. Changing the subject rather I’ve brought myself a mobility scooter, range about 6 miles and top speed 4 mph although once I’ve fitted go-faster stripes I’m hoping to go faster. It has 4 wheels, a blue base, a handle bar with controls for going forwards and backwards, a horn and a speed control. There is a removable seat and the steering column folds down with the single battery beneath the seat. I was recommended to the company by a friend of my father’s.
They were very friendly and gave good advise, like not to have a 3 wheeled scooter as stability would be compromised in my case. As I have been looking at scooters for a while I was pleasantly surprised when I asked the price (a lot cheaper than a lot of places).
The company is ‘Capitol Mobility Services Limited’ and they are in Solihull, Contact me for further details if required.
A handy utility for the computer is ‘Regseeker’. It is available from the following address:-www.hoverdesk.net/freeware.htm.
The software is easy to use but email me if unsure, Its main job is to clean the computers registry of junk/obsolete entries and so speed certain tasks up.
A quick reminder for Chris’s sponsored slim, good luck.
For money saving tips visit http://www.moneysavingexpert.com/
If you haven't got a computer then most public libraries have them and it's usually free to book time on them.

<u>QUOTE FOR THE ISSUE</u>

‘NO MATTER HOW HARD YOU HUG YOUR MONEY, IT NEVER

<u>Inside this issue:</u>

Meeting Minutes

ATAXIA CENTRAL BRANCH

Minutes of Meeting held on 1st May 2007
At Oxley & Fordhouses Community Centre

Present: Brian & Edith Doody, Chris Dymond, Liz Crook, Harry Fancott, Chez Cooling, Margaret Arkwright, Brian Hanuier, Sue & Sarah Murkett

Apologies: Jenny & Margaret

Introduction

Brian welcomed everyone to the meeting and advised the group that a new member may be attending shortly. Her name is Diane and she is interested in the group as a means of supporting her brother James who has been diagnosed with Ataxia.

Table top sales and fundraising

The sale held in March at the Scouts Group, Tettenhall raised only £28.00. For the time and effort involved this was not felt to be viable. However, Chris suggested another venue may be more successful, for example Forget-me-not Club in Codsall. He also suggested that the Birmingham Midshires may provide some matched funding if a member of their staff is involved with the next fundraiser. Chris and Brian asked the group to consider any suitable venues in their own areas so that table top sales might be more profitable.

Chris told the group that he is doing a sponsored diet for the next 4 weeks. Everyone had sponsorship forms and he promised to lose 12 lb by 31st May. Forms and monies will be collected at the next meeting. We all wished him luck – as he tucked into his last chocolate biscuit (for the next month anyway!!!)
Sue and Sarah suggested another form of fundraising based around the national lottery bonus ball number each week. This could generate up to £49 per week, split between the Ataxia charity and the individual weekly winner. Information was handed out and the group decided to consider this idea at the next meeting.

Presentation from Karen Whitehouse, Pension Service

We had a very interesting presentation about state benefits. This department deals with the over 60s age group only. Karen outlined the details of Pensions credit, which replaced the Minimum income guarantee. It means that everyone over sixty should have a minimum to live on each week. This is £119.05 for a single person, or £181.70 for a couple currently. She then detailed the various ways the benefits work and some of the complexities of the system. Needless to say it is not straightforward so she gave very useful telephone numbers for anyone wanting to check their own specific entitlements.

These are:-
Freephone : 0800 991234 (8AM – 8PM) for telephone assistance/information
Local Rate : 0845 6060265 for your local office to arrange a home visit
Internet : www.pensionservice.gov.uk

Meeting Minutes

Both these telephone numbers are for over 60s so anyone younger needs to contact their local welfare rights groups or social services etc for similar assistance.
Brian discussed the errors that had been made in his and Edith's benefits and suggested that it was worth every everyone in the group checking their own entitlements as mistakes had drastically effected their income.

Coffee Morning 25th September 2007

Brian has arranged this fundraiser to coincide with Ataxia Awareness Week. He asked for as many of the group as possible to attend the coffee morning to show support. It is to be at Starbucks in Wolverhampton. Starbucks have kindly agreed to promote the group with information displayed and 2 donation tins on the counters for one week. This should be a good opportunity for both fundraising and awareness. Brian added that getting publicity is important for this event. The group discussed ways that this could be done ie photographs and an article sent to the local free sheet newspapers. Previous experience with the Express & Star means they will not be particularly helpful.

New Venue

Sue & Sarah told the group about a recent visit to the Oasis Centre , Pendeford Square, Emsworth Crescent, Pendeford. This venue was completely accessible. It provided a light buffet at a very reasonable price and charged no room rent. Both suggested it might make a good alternative venue as it is very close by and suitable for everyone to attend. Chris said he would visit the centre and look into the availability of this venue for future meetings.

Date of next meeting

Next meeting will be Tuesday 7th August 2007 from 11am. It will be held at the existing venue (unless otherwise advised nearer the date).

Meet a Member

Garage Sale, 2006

Hello, I'm Melanie, 40 years young, I was diagnosed with Spina Cerebella Ataxia about ten years ago. I accepted a long time ago that my condition would slowly get worse and there was not a lot I could do about it but to be aware and know my limitations. How I understand it is that, the majority of CA's are inherited and caused by faulty or defective genes. I have two teenage children, who are very good to me and don't mind pushing Mom around in the wheelchair and never get embarrassed of me if I slur my words or fall over awkwardly in front of their friends or in the street. Neither of them shows any of the symptoms of SCA and it is unlikely that they will develop the condition, (Thank God!). However, it is more than likely that they are a 'carrier' of SCA. How it was explained to me was; each human cell has 46 chromosomes made up of 23 pairs of genes and each pair of genes is made up of one from the mother and one from the father. In my case, both my parents, who are not afflicted by SCA (although they are 'affected' by it because of me), have one correct copy and one faulty copy of the gene, unfortunately they both passed their faulty gene on to me, a 1 in 4 (25%) chance of occurrence. This means that I have two faulty genes, therefore any offspring I produce cannot help but have at least one faulty gene as I only have faulty genes to pass on! My children's father hasn't had a genetic test but chances are that he will have passed on a correct copy, making the children carriers rather than being affected by the condition. This is where I turn my attention to future generations. Both of my children have at least one faulty gene, so there is a small chance that they could pass this on to their offspring (my grandchildren). I will strongly encourage my children to seek genetic counselling when they are ready to start a family, and by knowing my SCA number, at least they will know which gene is faulty and where to look for it.I think it is important to be aware of this condition. I would hate my children to go through the same anguish as my parents. They were devastated to watch their once active and independent daughter become unsteady and more dependent. This is why research is so important and this means raising funds for Ataxia UK to continue the medical advances.

Meet a Member

The damage is already done for me, the next generations need to carry the interest into the future and eventually, in the very distant future, it could become possible, with increased medical research and advances, to eradicate the debilitating condition of ataxia. I recently held a Garage Sale for Ataxia UK raising £105, my Ebay sales are an extension of this, most items are second hand but good quality, some are new but unwanted and therefore donated to raise funds. Proceeds from the items I sell I will donate to Ataxia UK at 6 monthly intervals.
Ataxia UK is the UK's leading charity for people with Ataxia, their families and carers, supporting people affected by ataxia and funding research into causes and potential treatments. I want to say a GREAT BIG THANK YOU to everyone who has purchased anything from me since November 2006. Together we have raised £105.87 and I am proud to send a cheque for that amount to Ataxia UK. Since November, I have parcelled up and posted over 50 items to various parts of the world. Total sales (minus the small charge per item that Pay Pal take) amounts to: - £184.67 From that amount I take only the actual cost of posting, packaging costs and my time I donate. Therefore, any profit made from p&p goes straight to Ataxia UK. (e.g. if I charge £1.50 p&p and it only costs £1.00 at the Post Office, 50p donation goes to Ataxia UK) Postage amounts to: - £ 78.80 Fees are charged by EBay for listing the items and a small percentage is taken from the final sale amount. EBay fees amount to: - £ 30.37 This amount I have decided to make my donation, as I enjoy EBay and since I have been selling, I have had communications through e-mail, with people all over the world, which is very exciting. And, as I always include a leaflet 'Ataxia… what's that?' in every parcel, I am helping to increase awareness of Ataxia. I am still selling and, with your help, I hope to have another cheque for them later in the year.

My cat, Roy 'helping' me list items on Ebay!