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Note from our Chairman, PAUL STANLEY:

Welcome to our first newsletter of 2007. As the old year passed, so did one of the last exemptions under the Disability Discrimination Act; that of public transport. From December 4th 2006, bus companies must make sure that the wheelchair ramps on their buses are working and their drivers trained on how to use them. It is now illegal for a bus driver to refuse to let someone on a bus because of their disability. This also includes the ramp not working and not knowing how to use it.

There is much more to the Act and if you are interested, it's on the Disability Rights Commission website, www.drc-gb.org. In an article in one of the transport journals the DRC expressed their interest in seeing this legislation tested in court. Their chairman, Bert Massie, said "We don't want to take people to court, but we will do if bus operators are being discriminatory."

So if you have a problem travelling by bus, contact the DRC helpline.

So, is the Disability Discrimination Act making a difference? From my own observations I would say "YES". Ramps are appearing all over the place and banks, petrol stations etc. now offer assistance. The only problem remains that of attitude, i.e. the person behind the counter. That's another problem to be solved but even this is covered by the act in what is referred to as "making reasonable adjustment to the way services are provided".

So get out there and make use of the freedom promised under the Act...

Paul Stanley

London Branch OUTING – join us for Sunday roast on 11th March

For those of you who live north of the river, we are planning a Pub Lunch on Sunday 11th March at the Abercorn Arms in Stanmore Hill, Stanmore Mddx.

They do a good Sunday roast (the Chairman has already eaten there several times). There is wheelchair access and reserved parking for disability badge holders in the forecourt plus a car park at the rear.

The bus route 142 passes the door and stops nearby, this serves Watford, Bushey, Stanmore, Stanmore Tube Station, Edgware, Burnt Oak, Colindale, West Hendon and Brent Cross Shopping Centre.

For directions go to www.emberinns.co.uk, where you'll find full details and a map. The Abercorn Arms' postcode is HA7 3BU.

We may be able to provide some transport from nearby stations. Contact Jenny Kerbey on 0208 8767482 or jkerbey@yahoo.co.uk if you are interested and we can give the final details shortly thereafter.

London Branch AGM on 15th April

The Third Annual General Meeting of the London Branch of Ataxia UK will be held on Sunday April 15th at the Fairfield Hall, Croydon at 2:30pm. The exact venue is the Fairfield Room which is located on level one.

The building will be open from approximately 2:00pm. There are good public transport links to Croydon from many parts of London and there is also a car park adjacent to the hall. There is a show on in the concert hall that afternoon so the car park may well be busy.

This is where we held our first AGM in 2005 and we were very pleased with the location and the facilities. Hope so see as many of you as possible there.

If you are interested in attending then please return the enclosed invitation to the address indicated on the form.

Nominations to join the London Branch Committee will be taken from the floor at the AGM. If you cannot attend but wish to join the Committee, please contact Jenny in advance at the Branch postal or email address so that your details can be put forward in your absence.

Day out to EASTBOURNE on 28th May

The East Sussex & Kent Branch is holding a sponsored walk along Eastbourne seafront on the Bank Holiday Monday at the end of May (28th May). We are thinking of having a day at the seaside and meeting up with their branch members. Please contact Jenny (jkerbey@yahoo.co.uk or tel 020 8876 7482) if you are interested in joining us.

Report on the CHRISTMAS PARTY, held on 10th December 2006

We held our annual Christmas Party at the Oval House Theatre (52/54 Kennington Oval, London SE11 5SW) on 10th December 2006. Over 20 people attended – Ataxians and their friends and families. A delicious finger buffet was served including spicy chicken, onion and goat's cheese tart and crisp samosas.

Katie Howie (Katie2) and David Neaum organised a raffle with prizes donated by our corporate sponsors as well as Branch members. Prizes included a Waterman's fountain pen; vintage champagne; and bumper bags of toiletries for men and women from the Shaftesbury Pharmacy in South Harrow. We raised £134.00. A big thank you to all Committee members but especially to Jane Henderson, event organiser, and Katie and David who made the raffle such a success. If you were unable to attend, we look forward to seeing you at a branch event in 2007. Happy 2007 to you all!

Robert Fickling



Sarah and Anne go SHOPPING



In which Sarah and her friend Anne drive to Aylesbury in search of a really good walker

As I became more and more dependent on a walking stick, I used to say to Physical and Occupational Therapists, "I really dread having to use a wheelchair" (I'm over it, and have found a chair that really suits me). They would invariably say, "don't worry, there's lots between a stick and a wheelchair." It turned out, there was nothing on offer except a Zimmer frame that inhibits movement entirely and a three-wheeled rollator which can be unstable and forces the user to shuffle rather than walk.

I chose the latter but was underwhelmed. Then I was cruising the Hochschule Darmstadt University of Applied Sciences web site, which led me to the Gerald Simonds web site (www.gerald-simonds.co.uk, royal mail: 9 March Place, Gatehouse Way, Aylesbury, Bucks, HP19 8UA, phone: 01296-380-200). I typed "rollator" into the search window, not expecting much, and up popped a rather smart-looking, totally functional four-wheeled, folding walker called the ETAC Tango (designed and made in Sweden). I was so smitten that I got my friend Anne to take me to Aylesbury the next day, so that I could have one to

take on holiday. So many people have asked about mine that I now send out spec sheets, and a friend even got one on the NHS.

What I like about the ETAC Tango is that it's stable, light enough to lift (9.1 kg), and has a seat with an optional back rest. Since you walk into a roomy square instead of a tight triangle, you can maintain something like a healthy stride rather than a restricted shuffle. Its handles adjust to accommodate a range of heights, and since it folds to about 20 cm, it's very flexible. I often use it half folded to get through tight spaces like between restaurant tables.

Truth is, though, what really got my attention is the look of the thing. Someone I know called it the "Prada of walkers". You may or may not agree, but it does have a certain visual grace about it, and responses to the walker and me using it have been quite positive.

Have you found a gizmo, large or small, that makes your life easier or more fun through good design? If so, let me know at sjs33@homechoice.co.uk.

Sarah Jenner

SEND US YOUR EMAIL ADDRESS – and stay up-to-date

Please help us to establish our Branch email distribution list by emailing Katie at katie@ohbother.co.uk with your email address so that we can stay in touch.



We also plan to start sending future editions of the newsletter to members via email. This will save us printing, stationery and postage costs, and in turn we will be able to provide better services and events to you. So if you have an email address and are agreeable to help us and receive the newsletter by email from now on, please return the enclosed membership update form to the address indicated on the form, or go to www.ataxiauklondonbranch.co.uk and filling in the online form, or let Katie know by emailing katie@ohbother.co.uk.

Fundraising

The Branch would like to give special thanks to members Robert and Brenda Mole who raised a fantastic £160 at a Christmas raffle at LTE Network Communications Ltd.

Welfare grants 2006/07

As you are probably aware Ataxia UK gives out a small amount of Welfare grants each year. These grants are given in order to assist people with Ataxia obtain various items that they may not be able to afford, for example a respite break, a much needed item of equipment or aid to make life just a little easier.

This year the Trustees have increased the fund so that they are able to assist more people with a welfare grant. There are guidelines but if you fit the main criteria detailed below and there is something you need assistance with, please contact Sheila Benneyworth at the Office.

Criteria:

- You (the applicant) or the person (applying on behalf of a family member) has Ataxia

- You are in receipt of benefits (if you have a partner they should not earn more than £18,000 per annum)
- You have not received a grant from Ataxia UK in the past two years, one year if it was a respite break
- You do not have savings of more than £18,000

Apart from fitting the criteria and completing the forms that Sheila will send you, with the supporting information, the process is simple. Sheila writes a report from the details you put on your form which is then sent to the Trustees who form the Welfare Grants Committee. The applicant's name is withheld. Their decision is usually within 2 weeks which is then relayed back to you with the request to supply an invoice for the item. A cheque is then processed and sent to the supplier direct.

If more applications are received over and above the remainder of the budget for this financial year, Sheila will defer the later successful applications to come out of the 2007/08 budget that commences in April 2007.

If you have any questions regarding a welfare grant please do not hesitate to give Sheila a call on either 020 7582 1444 /0845 644 0606, email enquiries@ataxia.org.uk.

Applications need to be made **immediately** to use remaining money in the budget that finishes at the end of March.

SNIPPETS

- Please note that the Branch's email address has changed to jkerbey@yahoo.co.uk.
- 'If Only I'd Known That a Year Ago' is a RADAR publication that provides an invaluable introduction to benefits, services, rights and facilities for newly disabled people and their families. It costs £8.00 + p&p. Purchase via RADAR's online bookshop www.radar.org.uk or by calling 020 7250 3222.
- Chris Smith has a standing frame which she would donate to anyone who would use it. Chris lives in Hornchurch, Essex and anyone wanting the frame would need to have it picked up from her home. If you would like to contact Chris for further information you can email her at Chris.Smith@qmh-hotels.com
- Oxford. If you fancy a visit to this wonderful university city, one of the two coach services from London is now fully accessible. The Oxford Tube run a high frequency service - a coach every 15-20 minutes throughout the day, 7 days a week. There's even a service through the night for stop-outs!

There are several pick up points in central London and in the western suburbs. Go to www.oxfordtube.com or phone 01865 772250 for information. The service was awarded the Claudia Flanders memorial award for accessibility.

If you have any comments about this newsletter, please email Katie at katie@ohbother.co.uk.

