



HSP Newslink

The Newsletter of the Familial Spastic Paraplegia Support Group
Registered Charity No. 1109398

Issue 13 – December 2007

HSP & FSP – Hereditary Spastic Paraplegia,
Familial Spastic Paraplegia & Strumpell-Lorain Syndrome

POWER TO THE PEOPLE!



My love affair with powerchairs began ten years ago. It was then that my HSP began to cause walking difficulties and I started using a powerchair to accompany my wife, who bought a Pride Jazzy some years before. She has chronic Osteoarthritis and finds walking painful

and her hands are too painful to use a manual chair. When I found it really difficult to get about for any distance I bought a Jazzy 1120 on Ebay for £600 and it improved my life dramatically. My wife and I are music lovers and enjoy going to Symphony Hall in Birmingham

Inside this issue....

Members' Letters Page 5
Madrid HSP Convention Page 9

and to The Royal Opera House in London. Because of our disabilities we get the tickets half price and we are looked after like royalty. We have always managed to find somewhere to park and then we are free to go sightseeing, (yes there are sights to see in Birmingham) as the chairs have a range of about 20 miles. We take them caravanning with us and, as we always choose sites with electric hook-ups, we are able to recharge them overnight. I use the powerchair to take the toilet cassette to the emptying point and to drag the water container to and from the water supply.

As the chairs are quite big we do need a fairly big car to take them around with us. We currently have a three-year-old Ford Galaxy 2.8 V6 (another Ebay purchase) and use lightweight ramps to drive the chairs into the back of the car. Although the car is moderately thirsty we do not do more than about 6,000 miles a year now so it isn't a major item of expenditure. At the Mobility Roadshow I heard about a new Jazzy, which I am going to trial. It has a twelve-inch elevating seat instead of the current six inches and I am hoping that it will lift me high enough to get me into the hot tub by just sliding across from the seat of the chair.

My powerchair enables me to carry all sorts of things, either on my lap or in my trailer (see picture). Indoors I can carry full cups of tea (one or more depending on what size of basket I hang from the index finger of my left hand). It's like having equipment in gimbals on a boat, and I rarely spill a drop. Outside it allows me to do garden jobs that I could not tackle otherwise, like strimming the grass down 150 metres of driveway that I did a few weeks ago. I've even found that with care I can have a bonfire with no fear of toppling over and landing in the fire. I do chemical hoeing with a rechargeable electric sprayer instead of trying to manage a manual hoe. The chairs are also great at coping with all of the gravel that we have around the place.

Some people who use manual chairs say that they like the cardiovascular exercise that they get and I can understand that but at the moment I get that on my cross-trainer.

I hope from reading this you will see why I love my powerchair and maybe you will be encouraged to try one either by hiring, borrowing from a friend, having a free trial from a local supplier or go to next years Mobility Roadshow at Stoneleigh Park, Coventry where there will be lots to try. My wife and I would be happy to see any members who are in this area and let them try our chairs. We can be contacted at: malcolmg.palmer@virgin.net or by telephone on 01780 450092.

Malcolm Palmer

From the Chair

Hello everyone

Well we never actually had a Summer did we? As I write this it's a really cold November day, but I think generally the seasons seem to level out. Do we really need snow and ice after all?

I thought to start with a few words about my research on aids to getting about with HSP. I recently purchased a piece of kit basically consisting of straps and very robust elastic bands. Primarily the straps tighten and increase the ability to lift the foot and leg. My mistake was to put the kit on and whilst standing, lift my legs transferring my weight left, right etc as I watched television. When I took them off after about an hour I realised I had grossly over cooked it. It took me a couple of days to recover. Having now experimented with a couple of walks up and down my shared driveway I am looking to see if some muscle stretching can be achieved.

Ian has mentioned to me just how poor membership enquiries are. Having completed two mailshots over recent years I would consider a third as a necessity. However, I am keen to source a new database and for the moment this is delaying things. I will of course keep you all updated.

You will notice we have included a copy of our poster with this Newslink. Please present this for display in out patients departments when attending your next clinic appointments.

Lastly my thanks to Mike Cain for getting the North West crowd together. I hear it was a great success, especially the speaker from The Disabled Riding Association.

Most importantly it allows us all to care and share. Look out for his article on page 6. Over the nine AGMs and countless local meetings I have enjoyed I am constantly amazed by new coping strategies and brilliant ideas I would never have thought of had I not attended.

Which brings me to our 2008 AGM. Dr Chris McDermott will be updating us on the HSP segment at Warwick on Saturday 21st June. So many of you have sought a longer time to talk amongst yourselves so on this occasion we will have just one other speaker. For me our AGM is the highlight of our year's activities.

Finally, we apologise for the delayed issue of this Newslink. It was a deliberate move, so that we could include a write up on the recent international HSP convention in Madrid. Ian Bennett went over to represent the UK FSP Support group and met people from similar organisations worldwide. Apparently there were 29 presentations from many people associated with HSP including geneticists, neurologists and social workers. Please read the full report on page 9.

Bye for now

David

Secretary's Spot

I've spent all year with a monkey on my back - but at last I think I can get rid of it.

We did our questionnaire about this time last year trying to find out how we could help members to get the best out of the HSP Group meetings. Since then the committee have all been thinking how to use the information to guide what we do. Regional meetings have now been held in Scotland, Merseyside, the West Country and the southern Home Counties as well as our AGM in the Midlands.

We would very much like to have another meeting somewhere around the north of the M25 to allow people from the north London areas, Hertfordshire & Essex to meet each other. So I would like to ask someone to

volunteer to set up an initial meeting to "test the water". We can arrange to publicise the meeting in Newslink, but we'd like the organiser to choose a venue and invite people by phone - we can help with advice and guidance on what has been tried before – even suggesting speakers who might attend. Contact any Committee Member if you are prepared to give it a go.

The other strand from the Questionnaire is that of assisting people who otherwise cannot get to meetings. Several members indicated that getting a lift to meetings might help them. We would like all members who would go to a meeting if they could get transport to let a committee member know in good time so that we can try and make arrangements to help. We can consider a range of possibilities from asking other members if they could give a lift up to hiring a suitable vehicle if there were several members needing transport in an area. So please let us know so we can plan the help!!

Having said all that I think we have now got all the information from the Questionnaire and acted upon it.

So at last I can feel the monkey climbing down....

Best wishes for the Christmas season.

Dave Harris

From the Help Desk

Hi Everyone,

I hope you are all keeping well and are not having too much trouble with the cold weather. An electric blanket on the bed is wonderful if you do suffer, you can get dual controls if you have a partner who cannot deal with the warmth on both sides of the bed. He/she can remain comfortable as well, and you can remain cosy all night, if you need to. It is worth the extra money to get the dual control. Myself and John have one and can give anyone informed advice if they need it. Please feel free to call.

Likewise if anyone has any queries please ring or email me. Hope everyone has a lovely Christmas and New Year.

Best Wishes to you all.

Love Stephanie xxx

From the Treasurer

We now have 72 members paying by Standing Order. We would like all members to pay by this method eventually as it cuts down our administration costs. Forms are available on the website and from John Mason or Ian Bennett. We will also be sending out the form with the renewal letter in May.

Last year 85 people returned the Gift Aid form. This enables us to reclaim from the Inland Revenue tax paid on subscriptions and donations. Thank you to all of you who have returned the form. Please remember we are only allowed to reclaim tax if the person giving the subscription or donation is a taxpayer. There is no cost to you and you only have to submit the form once.

This year we reclaimed £326 which will allow us to make another grant to a member.

We have some members who have expressed a wish to make a regular monthly donation. If you would like to do this we are happy to send you an appropriate standing order form.

John Mason

Research and us!

During my recent visit to Madrid (see report on page 9), one issue that quickly became apparent was how much better our European and American counterparts are than us at raising funds for research. Obviously, we are the largest body of HSP affected individuals in the country, which means we are invaluable for any research that requires live HSP cases for their studies.

With this in mind, please take the time to read the enclosed letter from Andrew Crosby discussing his research into cases of Autosomal Recessive or sporadic HSP, and the possible future treatment of such cases. Please make the effort to get in touch with Andrew if you can help in any way.

Now that we are a registered charity and established with over 300 members, we are in strong position to have more involvement with both researchers and funding providers. Indeed, some research doesn't qualify for

funding unless the research team is in direct communication with the community it is aiming to help, i.e. us! As a consequence I believe that we should now consider forming our own team of three or four members who would then liaise with both researchers and grant providers. A group such as this is sometimes called a "steering committee". This team would be our Support Group's contact for certain research projects, and with experience would certainly gain skills in sourcing grants. It could even be that we are in a position to apply for our own funding and then choose where and how we want this money spent.

Any members who are interested in being part of our "steering committee" please let me know.

Ian Bennett

Useful Information

The Oswestry Standing Frame

The Oswestry Standing frame has been available on the market for the past 26 years and is designed for use by paraplegics, hemiplegics and tetraplegics.

The use of the Oswestry standing frame can improve sitting balance and function for individuals with spastic paraplegia. It allows the patient to stand, with the lower half of the body supported, in order that they could exercise the trunk to improve strength and balance.

Oswestry Frame seeks new home

I have an Oswestry Frame that I need to find a new home for. These frames are a very useful way of having support whilst standing with the added advantage of stretching the ankle muscles. If you have a look at the internet you will be able to see how the frame can be used, although consultation with a physio would clearly be useful. The frame is in excellent condition and I do not intend to make a charge for it although I would seek a contribution to the postage.

You can contact Ian Smith on 020 8421 5262 for more information.

Members' Letters

CRUISING (again)

Hope you don't mind another article on this subject, but it's aimed at those of you who haven't yet made your minds up on this delightful means of holiday-making.

I previously gave the recommendation, from an article that I had read, that a particular ship from the Celebrity Cruises fleet, namely Constellation, was considered very suitable to users of wheelchairs and scooters. I followed that up by booking a cruise on Constellation from Dover to the Baltic Sea in 2005.

Well, this year my wife and I used Constellation again on a cruise from USA to Bermuda, St Maarten, Aruba & Curacao (managing a visit to New York City en route), and it was very noticeable how easy it was to use wheelchairs on board, because I think I noticed up to 30 of them during the fortnight.

Needless to say, we thoroughly enjoyed both cruises immensely.

John Moore

A great couple of years

On returning home in September 2005 following a six week intensive flight training course in the Southern hemisphere, armed with a South African Private Pilots Licence (PPL), I confidently believed I was more than adequately prepared for adventuring within UK airspace. How wrong could I have been?

Make no mistake, obtaining my SA pilots licence was in hindsight, invaluable, but it's only now, after 110 hours (60 of these flying in the UK) that I appreciate how fortunate I am to have continued my flying with the British Disabled Flying Association (BDFA) who now own their own planes and allow use of them at a much reduced cost. My first 13 hours flying with the BDFA were in the Bulldog, alongside Alex, one of their instructors, with the intention of achieving type approval for this aircraft.

Unfortunately, I came to discover that the South African CAA does not recognize the

Bulldog for type approval meaning I could not use my SA licence to fly this plane solo in the UK. However, I've recently been informed that due to forthcoming changes in their rules, this may not be the case in the near future. Although my training in the Bulldog was immense fun, what I didn't fully appreciate during these hours was just how much I was learning about the UK airspace and communication procedures, and how different these are to the environment in the southern hemisphere where I was trained. Not only is our airspace busier, but our airfields and their associated restricted zones are much more condensed. Believe me, it's very easy for the inexperienced and unfamiliar pilot to stray somewhere he shouldn't – I've done it myself! In the UK most of our communication is with a local Air Traffic Service Unit (ATSU), requesting the required services from them as they are nearly always close at hand. In SA however, some of the pilots radio work involves communicating with other aircraft to ensure there is no conflicting traffic in the locality. The nearest ATSU could be hundreds of miles away.



I must emphasise here that I am not criticising the South African training at all. On the contrary, the level of training was first class and it was one of the greatest experiences of my life.

Looking back, I believe that it was in South Africa where I learned how to aviate, thanks entirely to the sponsorship of Flying Scholarships For The Disabled (FSD), but it is in the two years since where I have begun mastering how to navigate and communicate. However, I still feel that I'm nearer the bottom of the learning ladder than the top,

but with the help of many a willing BDFA instructor, my aviation, navigation and communication skills are gradually moving in the right direction.

Flying with the BDFA, whether solo or with instruction, is always great fun. This is a point I can't emphasise enough! Almost everyone associated with the BDFA has already had a successful career in aviation, and now seem intent on "giving something back" and ensuring others get similar enjoyment from their aviation pursuits. When I first returned from SA, I gained a couple of hours experience at a local flying club. Unfortunately, I didn't enjoy this at all as I found myself sat next to someone with no communicational or personal skills whatsoever, and I paid around £300 for this privilege. Imagine being trained to fly by Simon Cowell and you'd be in the right ball park. If I'd remained in this environment, I don't believe I'd be flying today. How lucky I am to have found somewhere that's not only an immensely enjoyable environment, but less than half the cost of anywhere else.

Reflecting on the last two years, I don't think there could have been a better introduction to flying. I am currently converting to a UK licence and hopefully by the time you read this I'll have completed this process. Bournemouth Commercial Flight Training have recently been very helpful with my licence conversion and I am very grateful to them for all their enthusiastic assistance.

I can't begin to explain the enjoyment that I now get out of my flying and I certainly forget all about Hereditary Spastic Paraplegia whenever I'm taking to the skies.

Thanks to FSD for providing me with the opportunity in the first place.

Thanks to the BDFA for providing the perfect, affordable flying environment, enabling me to continue enjoying the best pastime imaginable.

I hope many more people are able to follow in my footsteps.

Ian Bennett

P.S. Good luck Carrie with FSD application

Regional News

Regional Meeting in Preston in October

The meeting was organised with the intention of giving 'northern' members an opportunity to meet and possibly set up some regional meeting for the future.

In the event, 30 people said they would come, and 18 turned up.

As you can imagine, I was full of trepidation at organising what for me, was a first event and I had no idea what might happen, how many might come, or what they would want.

I'd planned the day to give lots of opportunity for people to share views. We had a video, a speaker (two as it happened!), a DVD (which we didn't show), and some handouts.

We watched the video supplied from a German group. This showed how massage is used in the treatment of HSP there, and was met by the general response from those in the room – 'so simple, yet should be available here'. A discussion about the benefits and availability of massage – both muscular and neural – followed. It seems that the service is available in patches for a limited time, but not generally available to us all.

We touched upon the use and availability of FES – (Foot Electrical Stimulation). One member (who is fitted with the device) generously gave a demonstration and explanation of what the device does and answered questions from those present, who generally had no concept of what was available in the North West.

The main speaker was from the national society 'Riding for the Disabled'. He gave a most encouraging talk about what is available in all localities and which 'holiday' centres take 'casual' visitors. He covered both Horse riding and Carriage driving. This latter is located in the North West near Lancaster, and I know of another in Darley Dale, Derbyshire where you can learn driving

(Prince Phillip does it – you ride a carriage with 4 or 6 horses pulling it!!)

The unexpected speaker was from Preston Community Service Volunteers. She had come thinking we were a Preston group (none of us was from Preston) – though Preston is a regional centre for HSP. However, she did light the flame that other local CSV groups exist within a national framework, and would be able to take ‘advertising’ of regional meets etc in their localities.

People were happy to talk and share views and experiences. The most common issue was lack of local knowledge, and a patchy availability of services. There was some useful help in applying for and maintaining benefits (DLA etc)

One member offered to establish an online resource available to Region 9 Members covering health experiences, and also social experiences including a ‘list’ of places that are easily accessible and those that are not.

In the event the day went very well and lasted for the planned time, (though we could probably have shaved 30 minutes). The food was questionable – indeed we got a total refund, but the coffee and biscuits provided a good opportunity to chat.

The people attending want to have regular meetings – probably every 6 or 12 months. The question is where? We want easy car parking, short distances, easy access, no heavy doors, decent food – and cheap!!

Mike Cain

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0161 456 7531

Region 4 Get Together

On Saturday 27th October a couple of very welcome gatecrashers from the South together with 20 members from the West Country met at the Dartmoor Lodge Hotel in Ashburton, Devon.

The first 45 minutes was spent watching the DVD from Germany showing different

physiotherapy techniques for various stages of our condition.

During the remainder of the afternoon, members simply chatted amongst themselves over a cup of coffee.

Christmas cards were sold and a raffle was conducted which raised useful funds for the group.

As usual, a number of members stayed the night in the hotel, so the meeting didn’t really end until leaving the bar in the evening. Earlier in the evening a meal in the hotel restaurant was enjoyed.

Thank you for the enthusiastic input to all who regularly attend the region 4 meetings. I look forward to seeing you all again probably next April.

Ian Bennett

REGIONS 1 & 2 Afternoon Tea Saturday 17th November

Our regular gathering at Milford in Surrey, is a convenient central location for Regions 1 and 2, but is also a reasonable distance for members from other regions. As on previous occasions we welcomed John, Stella and Janet from Essex and Maggie and Andre from Bracknell not to mention Ian (Bennett) who is good enough to drive from Dorset for the afternoon. There were thirty of us on this occasion.

Following the Carers time there was the opportunity for an ‘Open Forum’ session. This enabled members to discuss the difficulties of using public transport other than their own car, especially the ease of using taxi’s and buses for the wheelchair bound. As we so often find, there are major differences between the facilities provided by local authorities. For those living in London there can be greater benefits due to Transport for London’s awareness of the disabled.

Not everyone was aware of ‘Access to Work’; a government body which helps the disabled continue to work. Contact details

can be found in the Information Booklet issued by our Committee.

Our afternoon finished with tea and refreshments and the raffle. The next meeting has been booked for 19th April 2008.

Best wishes for Christmas and the New Year.

Michael and Jane

Forthcoming Events:

Mobility Roadshow

Stoneleigh Park, Coventry
12th, 13th and 14th June 2008.

Region 4 get together

March or April 2008 (to be confirmed next Newslink)
The Dartmoor Lodge Hotel – Ashburton

All members welcome. For further details contact Ian Bennett on 01202 849391

Afternoon tea Regions 1 and 2

Saturday 19th April 3 – 6 pm
Milford Day centre
Contact Jane Bennett on 020 8853 4089 for further details

FSP Support Group AGM

Saturday 21st June 2008
Trident Technology and Business Centre at Royal Leamington Spa

New Members

We welcome the following new member:

Mr David McKen Hythe Kent Region 1	Mr Philip Love Wanstead London Region 2
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Useful Contacts

	Email	Telephone No:
David Pearce - Chairman 8 Brinkworth Road, Clayhall, Ilford, Essex, IG5 0JS	pearcey david@yahoo.co.uk	020 85512905
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Stephanie Flower - Help-Line 37 Alexandra Road, Great Wakering, Southend, SS3 0HN	FSPgroup@aol.com	01702 218184
Ian Bennett – Memb Sec/Reg 4 co-ordinator 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	ian.bennett@tesco.net	01202 849391
Sally Langton - Group Awareness		0116 2700450
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 88534089
John Moore – New Member Co-ordinator	johnmoore@drift66.fsnet.co.uk	02392 592784
Michael Cain - Region 9 co-ordinator	Mikeregion9@fsmail.net	0161 456 7531
Liz Ferguson - Region 11 co-ordinator	lizferguson1@ntlworld.com	01415 779695
Colm Treacy Neurogenetics Clinical Nurse Specialist	colm.treacy@uclh.org	020 76762115

HSP Convention – Madrid

This year we were kindly invited to attend a meeting organised by the Spanish HSP society, Asociación Española de Paraparesia Espástica Familiar (AEPEF). The meeting was held in Madrid over two days from 30th November – 1st December. In total well over 100 delegates attended from Europe, America, South America as well as a representative from the Australian HSP society (HSP Research Foundation). Attendees included people with HSP and carers as well as clinicians, scientists, social workers and local government representatives working within the field of HSP. The meeting covered a wide range of topics including clinical management, current research, psychosocial issues and health policy together with presentations from support groups from around the world.

The first day started with an overview of the clinical presentation and history of HSP/FSP. This was followed by presentations on advances in genetic research and the mechanisms underlying HSP. The day was concluded with talks on the clinical management including rehabilitation, potential orthopaedic management, spasticity management and incontinence. The second day included presentations on the factors that affect walking in HSP, the psychological and social impact of HSP and health policy within the Spanish community. The session ended with presentations from the USA, Australian, German, Spanish, French and UK support groups.

Particular points of interest included a presentation by Professor John Fink from USA who highlighted that as our understanding of HSP increases we are beginning to realise that it is not as straightforward as previously thought. Whilst the classification into pure and complicated forms is still clinically relevant it is becoming clear that the distinction is not so rigid. For example, the spastin deficiency, commonly believed to be pure in presentation, can nevertheless rarely present with complications such as peripheral neuropathy or dementia. It is further becoming clear that a family history is not always present and spontaneous genetic mutations can occur. A late onset of HSP is not always seen, SPG3a (an atlastin deficiency) usually has an onset during infancy and can be relatively non-progressive.

There continues to be rapid progress in our understanding of the genetics of the condition. **There are now 39 types of HSP and 17 known genes**, three of which have been identified this year. Professor Fink also discussed current research projects such as the development of animal models of the disease, for example mice in whom the spastin or atlastin gene has been “knocked out”. These and other models will help to increase our understanding of the mechanisms of HSP and hopefully lead to treatments in the not too distant future.

There were also updates on genetic research by groups from Spain and Germany. Within Spain there are estimated to be 9.6 cases of HSP per 100,000 people. Dr Martinez highlighted her work characterising the incidence of different genetic populations in Spain and the process required to identify novel genetic mutations.

Dr Rebecca Schüle from Germany described the development and use of the “spastic paraplegia rating scale”. This includes three subsections addressing function; spasticity and weakness and associated symptoms such as pain and bladder and bowel function. This scale is currently being used to assess the change in disease presentation over time and will be useful to monitor the effects of any future clinical therapeutic trials. She is also a leading part of a team developing an “HSP re-sequencing microarray”. **This “HSP gene chip” will allow the identification of up to 11 HSP gene disorders in one test.** This exciting development will be more far more cost effective than current screening methods that assess one gene at a time. The “chip” could be available as early as late 2008. A representation from the Australian HSP also reported on the development of a similar facility that has just been made available and allows the identification of SPG4, 3a and 6 in one test. Such developments could greatly aid diagnosis when it becomes more readily available in the future.

We were proud to be able to provide an update on activities in the UK with regards to both research and support group activities. Prof Jon Marsden, from the University of Plymouth UK, described his research on the impact of different impairments on walking. This suggested that some aspects of walking were more affected by changes in passive muscle stiffness and paresis than by spasticity. This novel insight raises important issues for the clinical management of HSP including the use of anti-spasticity medication, stretches and exercise regimes that will be the focus of future research studies. Ian Bennett provided an overview of the UK support group's structure, activities and future aims. In particular he reflected on the fact that support for our members was an ongoing priority pointing out some of the facilities such as the telephone help line, regional meetings, newsletter and other literature, the young members networking scheme and the grants made available to individual members. Whilst acknowledging the success of the group in recent years he highlighted that there remains room for improvement in our fundraising, group awareness activities and sponsorship of research. He welcomed any advice on these matters from other support groups from around the world.



left to right: Ian Bennett UK, Rebecca Schule Germany, Henry Wahlig Germany, Philippe Hanriat France, Russel & Karen Johnson USA, Mrs Wahlig Germany, Rudi Kleinsorge Germany, President AEPEF D. Francisco Rodriguez Galvan, Tom Wahlig Germany

This meeting was very beneficial, it allowed us to strengthen our relationships with other HSP communities, clinicians and researchers throughout the world. This has expanded our support network, knowledge of ongoing research and has allowed us to develop collaborations that will generate new research studies in the future. One exciting consequence of the meeting has been the development of collaborations with HSP members and clinical researchers from Germany, Spain and the UK that will generate large scale multi centre research projects in the next year. Such developments will allow research projects to target much larger numbers of people with HSP and ultimately generate more robust conclusions.

We would like to take this opportunity to thank the Asociation Espanola de Paraparesia Espastica Familiar who organised this meeting. In particular the groups' president, D. Francisco (Paco) Rodriguez Galvan and Fernando Gonzalez for their hard work in organising a unique and landmark event whose benefits will be felt for many years. It is hoped that the HSP community with the appropriate support will be able to hold similar multi-national events in the future.

If any of this report generates any questions or comments please feel free to contact us either via E mail or phone.

Professor Jon Marsden and Ian Bennett