



FSP Newslink

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

Issue 6 – February 2006

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

What a Start to 2006 for Pattie and Amber

So much has happened since my story in the August Newslink I thought it would be good to share with you the news about myself and Amber.

I have now passed my NVQ level 3 course on Emotional Intelligence. Whilst I knew it would be hard work I was determined to see it through. Over eight months I have done about 3 hours work a week. The eight individual units contained five to eight assessments for which a report of some 250 or 500 words were needed depending on the particular subject.

What is emotional intelligence you might ask? I suppose it is as simple as how to get the best out of myself and those I meet and work with, in my daily life. To achieve this each module examined a particular topic and illustrated the techniques by which the goal could be achieved.

For me the project was about the way I look at training my dog Amber and about my family. This course has taught me how to use my emotions in a positive way and to not just jump straight in. One unit showed me how to break a problem down and deal with it, one chunk at a time. Working on this in the course has helped to reduce the stress that some problems can cause. I particularly enjoyed the sessions when my work was assessed. I am hoping this will lead me towards becoming a voluntary councillor so I



Pattie with her Golden Retriever Amber

am very much looking to starting a further course.

Inside this issue....

“HSP & Walking” Dr Jon Marsden
German HSP survey results

Page 3
Page 9

Amber is my best friend, a 5-year-old Golden Retriever who I rescued a year ago. She was in a subdued state, not doing anything and not eating. It took the first month of love, coaxing and emotional support for her to start eating properly. I contacted a charity called Dog Aid (Dog Assistance in Disability) who agreed she would be suitable to train to become an assistance dog. Over the next seven months, under the supervision of our trainer we tackled one task at a time, soon noticing a new and more confident Amber. In December 2005 she achieved both the bronze and silver Good Citizen Awards passing with flying colours. With these qualifications she secures the title "a companion dog", is awarded her coat and Dog Aid logo. Her immediate next challenge is for the "An Assistance Dog" diploma. In this the aim is for her to fetch things by name and most importantly to bring help if I need it. In addition she can alert me if someone is coming and with the washing by taking it out of the washer.

But this might be hard as our retriever does not retrieve.

I could not have achieved any of this without the help of my husband Paul. I became blind in my 40s and decided on my Active mind, Disabled Body idea. I have been in a wheelchair for 22 years but as you can see this has not stopped me doing things. Here's to many more challenges in the coming years.

Pattie- Raven Chapman (Region 8)

Editors Column

Hello every one, I hope you all had a fantastic Christmas, also wishing you all a very happy new year! Well where do I start! Its been rather busy with my impending move in March clearing out the old and bringing in the new. All I can say is I am glad I don't do this very often. Providing every thing goes ok with my move I hope to see some of you at the Milford meeting In April.

Thank you to every one who phoned, emailed and sent cards after my operation. Many thanks for your concern which was

very much appreciated. I would like to say I am very pleased with the successful outcome. I had a bit of trouble with the wound but that soon cleared up and now I am like a new woman and am getting my life back which is wonderful. I can now get back to using my tri walker which was impossible before the op so I am benefiting more than I ever expected. If any one has any concerns re the op and would like any information I would be more than happy to chat to you about it. You can either email me or ring me and I will do my best to give you any advice I can.

Take care

Sharon Gradidge

From the Chairman

Well hello everyone. January is now done. Virtually everyone I speak to has found this to be a most troublesome time. I suppose "it can only get better" comes to mind so lets "Look for a silver lining" "somewhere over a rainbow".....that's enough. **Who likes a good pantomime then?**

First of all let me thank everyone for their kindness and good wishes during my recent illness.

Cellulitis has attacked me again for the second time in two years. Leaving open wounds has delayed my return to the swimming pool resulting in extreme stiffness in my legs. I am hoping to be back in the water early February and expect to see the effort transferring to some improvement in mobility.

And now to that hairy wart that annually rears its ugly head.....**outstanding annual subscriptions**. For those of you who received a reminder **this is for the past year, 05-06** not the coming. Could I draw your attention to Mike's comments on page 4 regarding this.

I'm so pleased we now have contact with the German HSP Group. Ian tells me something like 90 of us returned the survey. What a great response, thank you. Doesn't it demonstrate our willingness to participate in areas that may help us, and hopefully, our children. A summary of the survey results are detailed on pages 9 and 10, and I must

say a big thank you to Rudolf Kleinsorge for preparing this for us so quickly.

Which brings me to the AGM. Let me put on record my thanks for the input Nigel has made over the last two years as Group Secretary. His attention to detail with all our committee paperwork and in particular our Charities Commission submission was substantial. So we are looking for nominations to fill this post. Royal Leamington Spa is set to welcome us on 17th June so with the increasing membership and the challenges of an expanding group lets do it really big style.

I'm so very much looking forward to meeting up with Dr Jon Marsden at the AGM. Way back at a previous AGM I seem to remember highlighting what an exclusive bunch we are. Though not substantiated we were looking at an occurrence of 1:30000. The bottom line is; we are the single collective register of those with HSP/FSP in the U.K. I hope you agree; en masse we have a major responsibility to actively support research teams' endeavours. Clearly there may be a benefit for us, but most certainly for our children and future generations. With this in mind, please read through Dr Jon Marsden's article discussing his current research programme. I do hope that our members who meet the criteria (especially those located in the South / South East) make a special effort to volunteer their services, and supply Dr Marsden with the numbers he needs. I believe he requires around twenty volunteers. Thank you for your help.

As always feel free to contact me at any time

David

From the Treasurer

As a follow up to my notes in the November newsletter, I'd like to confirm that we are currently at the point of making a grant of around £3000 to Dr Evan Reid at Addenbrooke's Hospital in Cambridge to help with his HSP research programme. Dr Reid's team are working to try to understand the cellular functions of proteins involved in causing HSP.

We have not heard much from those members who wish to improve their mobility by purchasing scooters etc, to which we may be able to offer a grant. In the past twelve months we have made just two grants, one for a specialist exercise machine, and one for a wheelchair. We have funds available, so please make yourself known to us if you could use some financial assistance towards the purchase of a mobility aid. This could include wheelchairs, scooters, ramps and hoists or indeed anything that may improve quality of life.

Regarding the outstanding subscriptions, these are still trickling in slowly and currently there are 52 outstanding. This is the last quarter of the subscription year, the next financial year begins on May 1st. Reminders have been distributed to all outstanding, so please will you pay your subs or let us know if you wish to terminate your membership. Remember that subscriptions can be paid by direct debit or standing order, so let me know if this is of interest to you and I can send you the necessary form. Please also let us know if you feel a renewal form was sent to you in error.

All the best

Mike Fawcett

HSP and walking: Ongoing research at the Institute of Neurology.

What are the factors that cause walking difficulties in people with Hereditary Spastic Paraparesis? This is a question that a team of physiotherapists and neurologists at the Institute of neurology in London are looking into.

The stiff legged walking pattern seen in HSP could in theory be caused by a number of different factors. The degree the knee bends when it is swung forward, for example, could be because there is weakness (paraparesis) in the muscles bending the knee, the knee flexors. Alternatively, resistance from the muscles which oppose the knee bend, the knee extensors or quadriceps muscle, may reduce the knee swing. Such a resistance could be due caused by excessive stretch

reflex activity (spasticity) or stiffening of the connective tissue within and surrounding the muscle. Weakness in ankle and hip muscles that help propel the limb forwards at the beginning of swing phase can also result in a stiff legged walking pattern. Knowing which factors cause certain characteristic walking patterns will in turn help us to develop targeted treatments such as a specific strengthening, stretching exercises and functional electrical stimulation to specific muscle groups.

To begin to answer these questions we are taking a series of measures of muscle strength, spasticity, limb stiffness and muscle co-activation. We will then see how these measures differ from people who do not have HSP and how importantly they relate to a person's walking. Walking will be assessed by recording joint movements, muscle activity and the forces going through the legs.

The study is ongoing at the Institute of Neurology which is closely associated with the National Hospital for Neurology and Neurosurgery which is on the same site. We are presently recruiting people with uncomplicated, type I HSP who are able to walk at least 200m with or without the use of a walking aid. People should not have any past history of other neurological or orthopaedic difficulties such as arthritis or stroke. We are also keen to recruit people who do not have HSP and have no history of HSP within the family. These people will form an important comparison group. The study takes about 3 ½ hours to perform, with rests. We have a budget for travel expenses but unfortunately are unable to pay for any time off work.

If you are interested in volunteering for this study, would like an information sheet or to discuss the study further please contact Jon Marsden either by Email (j.marsden@ion.ucl.ac.uk), telephone (Sobell Department for Motor Neuroscience and Movement Disorders, Institute of Neurology, 8-11 Queen Square, London, WC1N 3BG) or phone (0845 155 5000 Extension 3965). We are going to describe the study in more detail and to feedback the initial

findings at this years HSP AGM and through future issues of the newsletter.

Dr Jon Marsden

Volunteering for the above

On 16th January I travelled to London and was welcomed by Dr Jon Marsden and Gita Ramdharry at the National Hospital as their first volunteer for the research programme Jon Marsden has discussed above.

The tests lasted for about 4 hours, but Dr Marsden was confident that he would become more efficient now he'd been through the routine. The experience was very interesting and totally painless. It was a pleasure to assist researchers who are clearly very interested in understanding more about our condition. This increased knowledge may enable them to find further treatments/therapies that may be of great help to us.

If any of our members are in two minds as to whether or not to volunteer, please go for it! I really hope that as a group, we can supply Dr Marsden with the number of volunteers he requires. I guarantee that you will rarely have a more pleasant hospital appointment, and at the end of the day it can only be of benefit to all of us.

Ian Bennett

FSP Support Group AGM Saturday 17th June

This will be held at the Trident Technology and Business Centre near Royal Leamington Spa and Warwick. We are occupying a large conference room at the top of the building reached by a lift. There is also a separate dining room for our buffet lunch. The building is only 2 years old and has ample car parking.

As an experiment this time, instead of being seated in long lines theatre style, we have been offered circular tables with 4 to 5 seats at each. This will enable us to socialize better, and the tables will be useful for the lunches and refreshments.

David has been organising the speakers. First of all Karen Varker from the Calvert Trust

will talk about holidays available for the disabled and about physical activities.

Following Karen, Dr Jon Marsden from the National Hospital will discuss the study / research he has been conducting titled “Impairments affecting stiff-legged gait in Hereditary Spastic Paraplegia”. Dr Marsden will be accompanied by Gita Ramdharry who is a neuro physio from the same hospital. They are very keen to gain knowledge and information from us so they will be conducting an open forum session.

To confirm attendance, please complete and return the enclosed slip, and send payment to Mike Fawcett by 19th May.

Directions of how to get there will be included in the May newsletter. Leamington Spa is in the West Midlands, just to the South East of Birmingham, three miles N.E of the M40. We have chosen this central site to attract members countrywide. We are hoping for a top class attendance for such an excellent site.

Useful Information

If any of you are looking to further your education, the following organisation is a must as they may be able to provide some funding for equipment & they may be able to advise you on the best sources of potential funding for the course you want to follow :- SKILL – the National Bureau for Disabled Students – www.skill.org.uk

Disability Link. is a ‘Product Guide’ for our independent living. It is an interesting read as it gives advice and information as well as product details.

It is available on a free subscription – to subscribe call 0117 954 7374

FSP Computer Help

Aspects of the Internet:

The first item in this series (see Nov 05 Newslink) briefly introduced some ways of making more effective use of search engines (+, -, “”).

In this item I talk a bit more about the Internet to help members get a general

understanding of things they might not yet have had the chance to try.

E-mail

Sending written messages which get to the recipient in a few seconds or minutes *no matter where they are in the world (or in a plane or the International Space Station)* was the stuff of science fiction only a few years ago. Now anyone with access to a computer connected to the Internet can do it - **and it costs nothing to send and receive messages.**

Nearly all companies now have an e-mail address, and most local government and central government departments can now be contacted this way, so it is becoming an accepted way of doing business for many.

The advantages are: convenience (obviously most significant for those who have computers in the home or office), speed, and another way to keep in touch - many people have regular conversation over e-mail.

The downside is that you cannot rely on the message always getting through in good time. Every message has to go through lots of computers, which do jobs similar to Post Office sorting offices. If anything goes wrong between any two machines, your message may not get through. The earlier e-mail systems were very fragile, and messages could get lost completely. Nowadays systems are much better, but even so I sent a message recently which did not get through, and it was five DAYS before I got notified that it had failed.

So with e-mail don’t assume everything is ok, if the message is important it might be wise to check by phone to be sure it got there.

Chat Rooms and Discussion Forums

Once you have become used to using e-mail, you might think about some other means of communicating on the web. Both of these are methods by which groups of people can “share” thoughts and conversations. A “Chat Room” allows several different people to type their thoughts as short messages which are presented on the screen one after another (much like the old football results teletype) and can be thought of as a “conversation” between several people. Normally there is no “permanent” record of

the conversation - most users think of it like a phone call. A Discussion Forum is a little bit more formal, ideas are discussed much more like a series of e-mails collected together, and the forum proceedings can be viewed again at a later time, because a record of the messages is preserved.

Electronic Documents

What we have seen so far is that the Internet is allowing people to interact in some new ways. I would just like you to think about the fact that there are probably more types of computer now than there are types of car. They all can talk to each other via the internet, and if you use the appropriate software e.g. a web browser such as Firefox or Explorer then you can see **on-screen** information offered by any of these machines.

The thought I'll leave you with this time is that things get a little more complicated if you need to send the equivalent of a printed document to these many computers and want it to look the same wherever it is printed. I'll talk a little about this next time.

Well that has probably got your head spinning, so I'll stop now. Please let me have your questions and suggestions for the next items... you can send them to me at dave@vadcar.org.uk

Dave Harris

New communication facility

I'm Phil Stringer, I live in Manchester and have worked for many years at Manchester University looking after the software on the many computers we have there. I seem to spend a lot of my time on Family History and for a number of years have provided an e-mail list for our family history society. This has been very successful and provides a very useful tool, especially for those who don't live locally, to interact with and obtain help from fellow members. So I thought it would be a useful addition to the facilities provided by our group. An 'e-mail list' system contains a list of e-mail addresses and sends each e-mail it receives out to all the addresses. It allows a group to share mails easily.

I have found that it is only through talking to other group members, especially at meetings, that I have realised that many of the problems I've experienced in dealing with FSP are also encountered by other group members, and learning the ways they have dealt with them has helped me as well. We can't all get to meetings and if we have a problem it would be nice to have a convenient way to talk about it immediately, and that is what the e-mail list can provide.

How it works

The basic mechanism is to send an e-mail to hspgroup@sentinel.mcc.ac.uk (which is my desktop computer at the university!) and a copy is automatically sent to all the members who are registered on the e-mail list. All the list members will read your e-mail and some will no doubt reply with their experiences and suggestions. The normal way of replying to list messages is to use 'Reply All' which besides replying to the originator, will also send a copy to the other list members.

Frequently with such lists other list members who do not post the original query, or reply also find the answer useful and wonder why they didn't think of the question themselves.

Now there are a few technical details that I need to explain, but I'll try and keep them as brief as possible.

- Firstly how do you join the list? The list is all managed via web pages and the one for our list is <http://sentinel.mcc.ac.uk/mailman/listinfo/hspgroup>. If you go to that page you will find boxes in which to enter your name and e-mail address. Then click the 'Subscribe button'. This results in an e-mail being sent to you to confirm that you want to subscribe to the list and acts as a check against anybody else trying to sign you up to a list you know nothing about. All you have to do is click the 'Reply' button when you receive the e-mail and it then joins a list awaiting approval. I will do that as quickly as I spot such requests and this is the mechanism that we will use to only allow FSPgroup members to join the list.
- That may sound a little complicated, so we are going to automatically add

everybody for whom we have an e-mail address to the e-mail list two weeks after this newsletter is sent out. You will know that you have been subscribed when you receive the introductory e-mail from the list containing your password. We do appreciate that some members may not want to be a member of the e-mail list. You can opt out by e-mailing Phil.Stringer@manchester.ac.uk or by using the built-in mechanism to unsubscribe by going to <http://sentinel.mcc.ac.uk/mailman/listinfo/hspgroup> and entering your e-mail address in the unsubscribe box near the bottom of the page, and confirming it with your password.

- What do I do if I'm going away on holiday and want to temporarily stop HSP group e-mail's from being sent to me? Again go the web page above and enter your e-mail address and the password which is sent to you when you signed up, and you will then be given a number of options to customise your subscription, including one to switch off the delivery of e-mails.
- But I want to see any messages that I may have missed! Well again go to the web page and you will find an archive of all the messages that have been sent to the list, that only list members can view. Over time we should build up a very useful repository of information about coping with FSP.
- Is an e-mail list a source of computer viruses? No, this list is managed by one of the most popular list managers, mailman, and it only allows plain text messages to be sent via the list. It does mean that you can't send pictures etc. to everybody on the list, but as it removes all e-mail attachments, that prevents any viruses arriving via e-mails to the list.
- Could spam (unsolicited e-mails) arrive via the list? No only list members can post directly to it, everything else has to be approved by me as the moderator. I will discard any rubbish that other people may try to send to the list. But for example if researchers are wanting to

send queries to the list, then these I will approve.

- What content is suitable for list messages? Some people may already be on a number of other e-mail lists and not want to receive too much e-mail. So please only post items with an FSP connection. It won't be a place to discuss the weather!
- What do I do if I don't understand all this and require more help? Well e-mail Phil.Stringer@manchester.ac.uk and I'll do my best to help.

I hope you find this is a useful addition to what the FSP group provides, so if you have e-mail then please go to the web page and join the list now. I'm planning to post details about how I've traced FSP in my family back for the last 200 years two weeks after I received this newsletter, so do join it and find out how I did it.

Members Letters

Unfortunately, there are no suitable letters for this issue. Please remember, if we receive no letters, we cannot publish any. The content of this section is entirely dependent on input made by our members. Please share any experiences that you may have had which you feel may be interesting or relevant to our members.

Regional News

April Afternoon Tea Regions 1 & 2

Usually a number of our members arrive well before the start time and help with re-arranging the room in readiness for the afternoon's activities. For our November Afternoon Tea this was not the case. Having prepared the room and nobody had arrived we were getting worried in case we had the wrong day!! In fact there were forty of us on that afternoon.

We had the usual format of Carers having the first hour separately to chat and share allowing everyone else to time to socialise. The Carers, so I am told, had a good chat and hardly any moaning.....

After these separate chat groups, Dr Jon Marsden joined the whole group and asked lots of questions to help him with his research into gait analysis. This led to much discussion, highlighting the differences and the similarities between us. Although gait was the topic all areas affecting our lives with HSP were discussed. To give an idea, topics such as body temperature, ability to sleep were included as well as any ability to walk backwards. Some of our members have actually since spent time with him at the National Hospital in Queens Square. Dr Marsden has offered to return at a later date to tell us of his latest findings.

We followed this with a lovely tea and general chat amongst the whole group. We'd like to thank Phil for organising a raffle and all those who contributed prizes, to help towards the cost of the venue and the refreshments.

For those that were in attendance remember when trying to stand- 'Nose over Toes'

The date of the next afternoon tea is going to be: Saturday April 22nd NOT the 16th. Thanks to all those who spotted my obvious mistake. We look forward to seeing anyone who can make it.

Take care during this cold period of the year!

Best wishes,

Michael and Jane Bennett

Forthcoming events

Region 10 Meeting

Saturday 18th March
The Dormouse Public House, York
Anyone needing directions or further information please ring Ray Exley on 01904 626799

Afternoon tea Regions 1 and 2

Saturday 22nd April 3 – 6 pm
Milford Day centre
Contact Jane Bennett on 020 8853 4089 for further details.

Region 4 get together

May 6th 11-30 am (times to be confirmed)
The Dartmoor Lodge Hotel – Ashburton
Two speakers, buffet lunch, and hopefully a raffle. Exact agenda to be finalised. Region 4 members to be sent full details shortly.
All members welcome.
Contact Ian Bennett on 01202 849391 for further details.

Mobility Roadshows:

5th & 6th April Royal Highland Centre near Edinburgh Airport.

For details, please call 0870 770 3222 or visit www.justmobility.co.uk/roadshow

8th, 9th & 10th June Kemble Airfield near Swindon. visit www.mobilityroadshow.co.uk

FSP Support Group AGM

Saturday 17th June 10-15 am – 4 pm
Trident Technology and Business Centre at Royal Leamington Spa.

New Members

We welcome the following new members:

Mr Malcolm Palmer
Northants
Region 8

Mr Dan Higgins
Uttoxeter
Region 7

Mr Hugh Cribb
Southwell
Region 8

Mr Daniel Gibson
Leicester
Region 8

Mr Gordon Rattray
Petersfield Hants
Region 1

Miss Anne Peters
Bromley Kent
Region 1

Mr Peter Rutherford MBE
Gateshead
Region 10

Mrs Christine Williams
Manchester
Region 9

Mrs Marion Nichols
Burgh St Peter
Region 5

Mr Robert Haacke
Cheltenham
Region 3

If any members are interested in contacting one or more of the above new members, please contact the relevant area coordinator, or the membership secretary, who can then supply their full contact details.

First report concerning the survey about the symptoms of HSP

In autumn 2005 we have developed a questionnaire concerning the symptoms of HSP. We have asked HSP'ers to answer questions on whether the described 43 symptoms are affecting them and when they occurred. People from all over the world took part in this kind of survey. Up today we have received 176 responses from countries such as Germany, UK, USA, Austria, Denmark, Norway, Spain, Venezuela and also from Argentina. Thanks to all of you.

The evaluation of the questionnaire shall provide us with information regarding to how often the symptoms occur and after what time after the breakout of the illness one can expect these symptoms. It also should be made visible whether there are differences in interdependencies of gender, age or age of breakout of HSP. Additionally we are trying to determine whether there are differences between the dominant hereditary way and other forms.

In the following we present the first results by 3 examples. We use three questions for this.

Question 9: Increased walking problems at cold temperatures (winter)

Question 26: When walking, it is tried to achieve stability and security through finding hold on the sides.

Question 28: Repeated falls and increasing uncertainty when walking

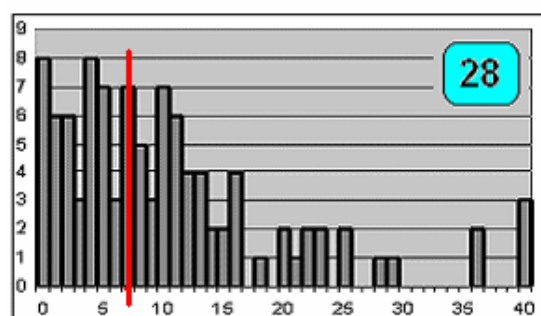
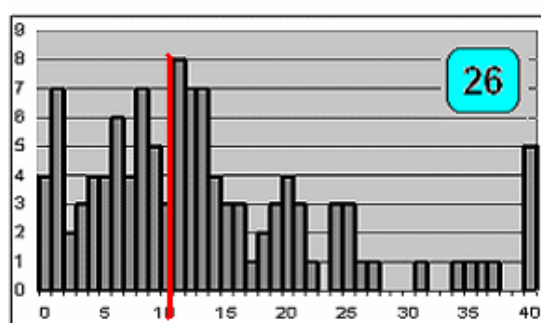
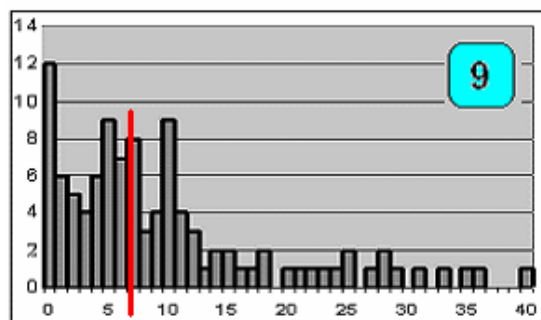
	Question: 9	Question: 26	Question: 28
Participants	176	176	176
Answer „YES“	135	151	142
Answer „NO“	36	20	26
No answer	5	5	8
Yes answers %	76,7%	85,8%	80,68%
Answers incl. date	107	113	105
Focal point	6.3 years	10.9 years	7.3 years

The three graphs present exemplarily the evaluation of the answers with their dates. The lower axle shows the years since beginning of the HSP. The left axle shows the quantity of "yes-answers". Through the evaluation of the question 9 (winters) it became apparent that 76.7% answered with "yes". About 25% from us do not (or not yet) know this handicap at all. The diagram shows that this symptom occurs more often in the first years of the HSP. All, who haven't had this symptom after 6.3 years, have better prospects every year that it does not occur at all (see the red line at the year 6.3). The Graphs 26 and 28 can be read in the same way.

Here, the evaluation of all participants is represented. First conclusions show that there are surprisingly small differences to the occurrence of the symptoms with dominant factors and other forms; also the differences in independencies of age, the breakout age of HSP or of the gender are very small with many symptoms.

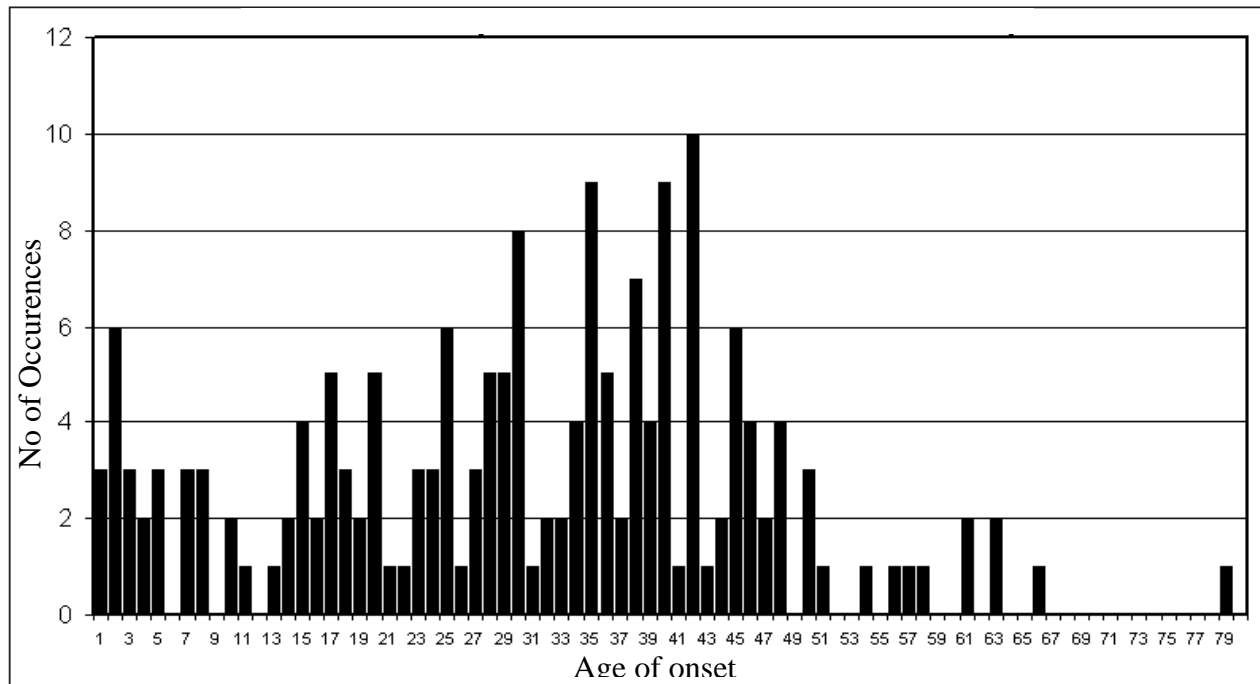
We will probably publish the complete evaluation in spring 2006 on the homepage www.hsp-selbsthilfegruppe.de. The evaluation will be sent to our friends from the support groups of other countries.

HSP-Support-Group Germany
p.p. Rudolf Kleinsorge



Additional:

Regarding the breakout age of the HSP we received quite clear statements. The following chart shows the results.



The lower axle shows the onset age of the HSP. The left axle shows the quantity of responses. (e.g: 10 people had the beginning of their illness at the age of 42 years.) Again, all 176 answers are evaluated here. (HSP-Support-Group Germany)

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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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
Audrey Town - Family Records		01484 861668
Jane Bennett - Regions 1 & 2 co-ordinator	luckyjane82@hotmail.com	020 88534089
Isabell Quinlan - Region 6 co-ordinator		01570 471062
Kathy Chambers - Region 7 co-ordinator		01142 960619
Carol McGowan - Region 9 co-ordinator		0151 2892597
Ray Exley - Region 10 co-ordinator	rayexley@aol.com	01904 626799
Liz Ferguson - Region 11 co-ordinator		01415 779695
David Harris – Committee Member	david18lod@hotmail.com	01305 772286