



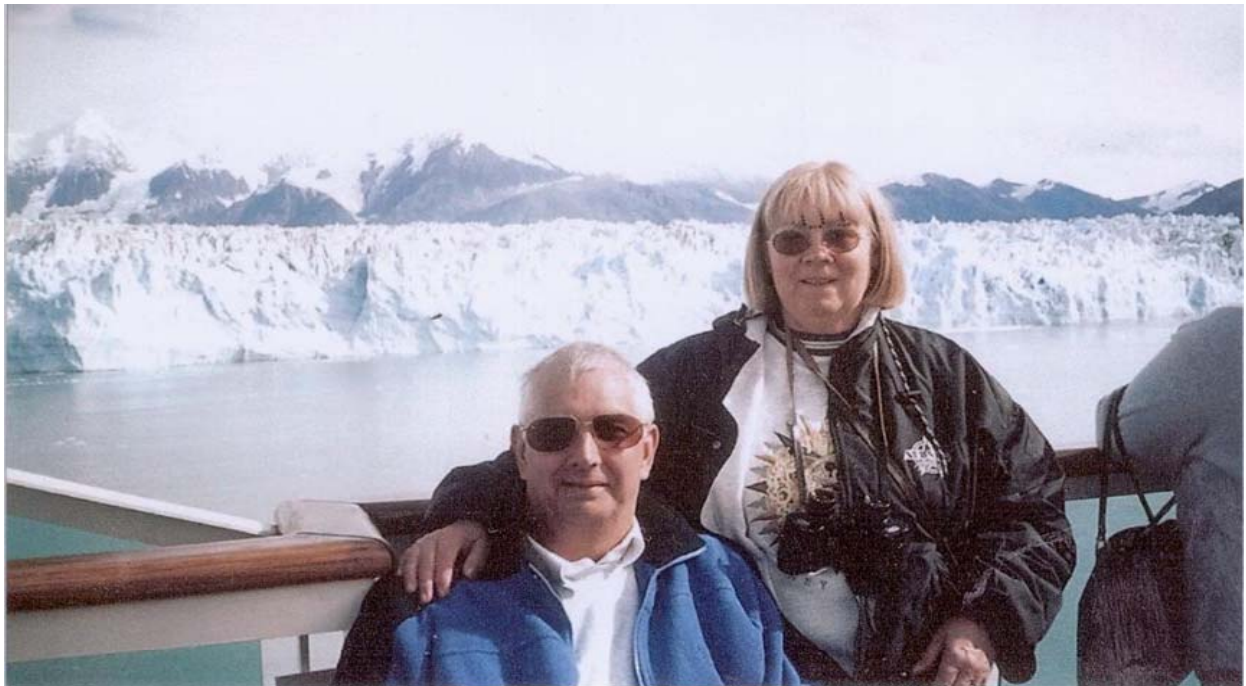
HSP Newslink

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

Issue 24 – Sept 2011

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

I'm Still Standing (Just)



Peter with his wife Anne, at the Hubbard Glacier in Alaska

During a recent conversation with Ian, our chairman, I suddenly realised I was reaching my “3 score and ten” this year and having developed what I now know as HSP type 31 from pre the NHS (1948), I was probably one of the few people who’ve had experience of the condition and the progressive disablement that goes with it for a full lifespan.

Having been born into the back streets of Tyneside during WWII; with my two elder brothers evacuated and my father

dead on active service I was brought up by my widowed mother and can remember being trailed around those white tiled school clinics with my funny walk.

Subsequently, as life moved on, I believe **disablement isn't a handicap but another tool in coping** with the frailties and circumstances of life thrown at everybody as social and personal change take place.

Having the disablement just gives you another set of tools others don't have, to

cope with life. Nature gives you compensatory senses and skills to help with what normal life throws at you, such as patience, heightened reactions and development of the other limbs and most importantly anticipatory survival skills (I always have a 2nd or 3rd backup plan to minimise risk to me).

In my case, as I grew up, I was placed in normal schooling (not pleasant in the 50's when you're "different") by mother who thought it best I learn to cope; went through to grammar school and into a 40 year career in the civil services because she told me I had to get a safe job as she wouldn't always be there.

As I worked through numerous jobs in Social Security, mainly dealing with the welfare aspects of people with problems and encountering different attitudes to disablement in a civil service career I found, like most people, life also came up with the regular problems everybody has; marriage, kids, tragedy, kids developing HSP, finance, etc: all the time realising we are all basically equal with different skills and the grass isn't greener on the other side.

An old GP once said to me "you've got this condition but it's not life threatening – you will have a normal life span with a deteriorating quality of life" and so far he's been correct.

I've had a life which to date has covered:

- Growing up in poverty
- Never having a father around
- Being disabled in a normal world as society changed attitudes
- Dealt with the NHS throughout it's lifetime
- Married, had children, fostered others and adopted one
- Buried a child because of someone else's fault
- Struggled with family finances
- Driven for over 40 years after someone told me I wouldn't drive anything. This included, because we needed the money, delivering hire cars around the country, strippers to their venues and official cars at work, in between working full time

- Travelled in later years to holidays in Spain, Alaska, Disneyworld, Mexico, Canada and USA. Have wheelchair, will travel!
- Abseiling down Holborn Tower in London and Lake Vrynnwy Dam in Wales for charity
- Branch secretary for the Soldiers, Sailors and Airmen's Families Association (SSAFA) for four years
- Receiving an MBE in the Queen's Birthday Honours list in 1993 for my work in Social Security (from benefits clerk to National Press Officer and all points in between)

All I have experienced isn't down to me but what fate supplied, helped by the support and goodwill of a good partner and friends along the way, so if I can help any member from my experiences please do not hesitate to contact me through Ian.

Peter Rutherford MBE

Chairman's Column

Please accept my apologies for the delay in producing this Newslink edition. Life has been hectic at home with a couple of family health problems. You will notice that I've received a number of contributions from members for this issue so thank you for your input, please keep it up. Particular thanks to Peter Rutherford for his interesting piece on a life time with HSP. You'll also notice that we continue to get plenty of new members joining our Support Group and I'm sure you'll all join me in welcoming them aboard.

It was great to see many of you at our AGM back in June. Our three speakers were very interesting, thanks to Paul Taylor from Odstock Medical, Amanda Austin from Plymouth University and Martin Webb from Warwick CBA. The minutes of this year's AGM are included at the end of this Newslink. Next year's AGM will be on June 16th at the usual location in Leamington Spa. Remember that the AGM is your opportunity to get more involved in the Groups activities. We'd welcome new committee members so perhaps you could give this some thought between now and then and this applies to new

members as well. I personally think that committee positions should change fairly regularly to ensure that new thoughts and ideas are continually brought forward.

I mentioned it at the AGM and I'll mention it again now; If anyone is interested in getting involved with the Newsletter, please let me know. This could involve writing a regular column or taking over the entire task. Maybe we have a new member out there with some editing experience.

It is with regret that I inform members that our former chairman, Mike Fawcett passed away on 14th August. For me personally it was a great privilege to have met Mike and I will remember Mike for many very positive reasons. He was a key member of our group for many years working very hard for our cause. In addition to keeping our accounts accurately up to date, together with former chairman David Pearce, he travelled many miles, searching for all of our AGM venues. He loved to travel both internationally and within the UK. In previous years, Mike has visited me twice down South in Wimborne and my family once had a very enjoyable long weekend with him showing us around the Skipton and North West Yorkshire area. He was a very proactive committee member and took the trouble not only to attend every AGM, but also to attend regional meetings in Yorkshire, Surrey and Devon. I was delighted that members attended his funeral and you'll read their account of this later in this Newslink. Their account echoes what any of us who'd met and got to know Mike, thought of him. I personally will never forget Mike and always admire his attitude to life and his refusal to allow HSP to inhibit him.

Recently there have been some interesting and challenging fundraising activities taking place. I'd like to thank everybody who has been involved with such events and as you know all funds generated are put to good use. We continue to assist members purchase mobility aids, particularly those of limited financial resources and any surplus funds are offered to research teams. Particular thanks go to four of our members who jumped out of an aeroplane and to Stephen Orpin who competed in a very demanding Iron Man event, all of which

raised significant funds for our cause. You'll read about the personal experiences of the parachute jumpers later in this issue.

We have now applied to ten different charitable trusts for funding and unfortunately we have had no success with this to date. This is however something we'll continue with.

Over the last six months some of our members have taken the trouble to help Professor Jon Marsden and Amanda Austin with their current research project down in Plymouth. I know that Jon and Amanda are very grateful for your efforts and Jon will be updating us with some of the results and conclusions at our next meeting in Ashburton on October 22nd. It is of course very important that we do all we can to help researchers with their work relating to HSP.

I'm looking forward to the forthcoming Region 4 meeting on October 22nd where once again we can socialise with familiar faces and new members. Anyone is welcome to join us but please let me know in advance if you'll be attending. I have to admit I'm a little concerned as I have a feeling that Eileen has another fundraising idea up her sleeve. I believe dancing in Wellington boots will take some beating, but who knows? *Ian Bennett*

Secretary's Spot

I first want to focus on our fantastic fund-raising through the Just Giving web site. It seems that many people are finding this route to be the best one to use to gather contributions for their activities - and an increasing amount is being generated year on year by a widening variety of efforts - so our grateful thanks to all involved.

Next a bit of fun - the story of our recent return from holiday! We'd spent a lovely couple of weeks away in Cyprus - having been lucky enough to find another villa which had enough "levelness" to make it OK for Carolyn. She was also able to get in and out of the pool unaided (just). Anyway, back to the story - our return flight left on time and was five hours of uneventful flying with a smooth landing at Exeter airport.

There were eight people with disabilities on board and their carers. When the lift vehicle

arrived - some ten minutes after all the able bodied passengers had got off - we found out that it only had capacity for four wheelchairs and their carers. The vehicle now had to descend to ground level and transfer those people to the airport building. This took about 15 minutes, with a further ten minutes to unload them and return to the aircraft.

So eventually it took us about 50 minutes after landing to get into the airport building. We got through that very quickly however and into the car park where we were met by our car which had been to an off-airport car park. As we tried to open the car we had a problem. I used the key in the door and got access, but the battery was dead and the car wouldn't do anything.

So now we had to call out the breakdown service for a jump start. This was quick - only 25 mins to get to us and we were running again after a jump-lead start. Now it was about 2 hours after landing and we were ready to leave the airport! Due to the state of the battery we had lights which dimmed every time there was a change of power levels all the way home, so I was very careful not to switch off the engine as we stopped to drop off members of the party. We did get the car fixed the next day and joy-of-joy the battery was still under warranty so it didn't cost.

So even if your holiday has gone well there can still be "a sting in the tail".

Dave Harris

Michael Fawcett

22/05/1937 – 14/08/2011

Mike sadly passed away and three of us, Christine Snow, Mark Tomlinson and Debbie Best from Mike's Region, Region 10, attended and would like to share our condolences with you.

We arrived at his funeral and wow what a guy our Mike was. The testimonies in remembrance of him were very touching and beyond description. He had done so much as regards travelling, education and never could get enough!

We all got the same feeling of Mike being a fighter, never would he accept he had HSP.

He has travelled so much beyond what you might have thought possible, but as his son said, he just got on with life, booking this holiday, that holiday, travelling, nothing was going to stop Mike from doing what he wanted to do. He never mentioned his disability when arranging these holidays; he just took it in his stride. He even took himself to Blackpool last Christmas 2010.



Mike enjoying a recent HSP AGM

It was Mike amongst others who got the HSP Group up and running. His son, in his testimony said so much about how Mike had loved the HSP Group! It pulled at our heart strings! The three of us were so pleased to have been there and Mike's family were so pleased to have us with them, the three of us were touched beyond description.

We certainly felt that we need to be a lot more positive in remembrance of Mike, so let's put into this HSP Group as much as we can, give our own stories of life and let us thrive in remembrance of Mike.

M	Mindful
I	Intelligent
K	Kind
E	Efficient
F	Friend
A	Asset
W	Wise
C	Courageous
E	Esteem
T	Talented
T	Thoughtful

Just a few words that in our eyes that described Mike.

He'll always be remembered. *"Rest In Peace"*
Christine, Mark and Debbie (Region 10)

HSP Sky Divers

On July 30th four of our members bravely did a parachute jump to raise money for us. The four of them have all written a few words about their amazing experience.

Sherrill Casburn's experience:

When a sky dive was suggested as a charity fundraiser for HSP, I thought hmm, always fancied trying that, and if some 'C' list celebrity can throw themselves out of a plane into the jungle, then why can't I? Not suggesting Lowestoft's a jungle of course!

B & B booked for me, my hubby Michael, and two sons Jake and Zach, plus a friend who had come to gloat, sorry watch, we were all set.

The day started rather cloudy, not so good, but after a poached egg on toast (which I was hoping wouldn't show itself a few hours later) I was feeling positive and excited.

Caroline Begg and I set off for the airfield and met up with Ian, Mark and some relatives and fab friends who had come along to watch the show. I wasn't feeling nervous at all which I wasn't sure was a good thing! The staff were fantastic and within a couple of hours we were all looking like the real macoy, dressed in boiler suits with goggles and a hat that looked like a third nipple and crutches at the ready.

As we stood by the plane waiting for our instructors, I was anticipating some ex marine type with a six pack and a smile to go with it (I'd done my research, I knew most were ex forces, only my instructor turned out to be a cross between Catweasle and Biggles in the older years! Never mind I thought, it just wasn't meant to be, you'll just have to do it again some other time, he he!

The plane journey seemed to take forever and we had risen above grey cloudy skies into beautiful sunshine, and then it was time to take up my position literally sitting on the edge of the plane, feet crossed arms crossed and head to one side and then we just fell and at speed, Wow! The cold air hit my face and the noise a rushing sound with me shouting WHOOOO, it was an amazing feeling. A tap on the shoulder from the instructor and my arms were free to hold out to the side, unbelievable, another tap

and arms crossed again as the parachute was deployed and a pulling sensation, then silence and the most amazing view...Jeff, my instructor asked how was I? "This is bloody fantastic" I said, "I'm definitely doing this again!" We eventually saw the hangar we had left earlier and my two sons waving. I was still alive! It was the most amazing thing I have ever done (apart from giving birth of course) and I'm glad I had the opportunity to do it. The staff were fantastic with us, and as we all headed off for a well earned lunch I felt like I was walking on air. If only, but without the crutch you understand.....

Carrie's experience:

When Ian Kitchen asked me to do a skydive for HSP, I couldn't think of any reason why not.

Since this would be my third dive I was more excited than nervous.

As time got close it was dawning on me that I would be doing another dive, the only part that made me nervous was the landing but..... I had no worry.

The morning arrived and we made our way to Beccles airfield and we met up with everyone.

The weather was not fantastic, but there was no reason for not going up. We met our diver as we were heading to the plane. I asked when we would be diving and he said near the end, which I was happy with as I had always gone first.

As we headed off and got higher and higher, we got through the clouds and then there was lovely blue sky. We reached 13000ft and the door opened, one by one everyone else shuffled forward and disappeared out the door; I got nervous now being the last. I will admit that I closed my eyes as we left the plane, but then once opened I knew why I loved doing this..... AMAZING!

Once through the clouds we made our way slowly to the ground and had the best ever landing.

I made my way to Sherrill, Mark and Ian to find out how their first dive was and they all said "when can we go again?"

It was a great day spent with friends and family and I would like to thank all those who donated.

Mark Tomlinson's thoughts:

Hi folks and with being scared of heights I decided to take part in the sponsored skydive thanks to Ian Kitchen. So below are some do's and don'ts.

1. Don't expect to be asleep and miss the jump if having to set off in the early hours of the morning.
2. At destination try and say more words than 'nervous'.
3. Make sure someone is taking part who has skydived before for confidence.
4. Never go outside the hangar and watch people landing.
5. Always enter the plane first and not near to last to escape jumping first.
6. If your brother in law gets persuaded to join the jump and your niece cries, it's not your fault.
7. When free falling, flapping your arms like a bird will not slow you down.
8. Spiralling down to the ground is not good for your stomach.
9. When landing try and use your arms to lift the legs up.

A brilliant day and experience was had and a big thanks to everyone concerned from myself and family.

Ian Kitchen's Experience:

Many of you know that I have done a bungee jump for HSP in 2009 and raised some money for the charity and one day I was wondering how I could top it? I thought the only way that I could would be to do a skydive. I spoke with Caroline Begg at Jane Bennett's meeting in the south east, she mentioned she had done a couple and how much fun they were. This started the ball rolling and we started asking if any others would like to join us in doing a group sky dive. After a fair amount of interest we finally got two other members to join us - Sherrill Casburn and Mark Tomlinson.

I set up a just giving page for the group and was pleasantly surprised that we passed the

total a few days before the jump – I knew from the bungee jump that knowing how much money you have raised gives you a little bit more guts to go and do it.

Anyhow, we all turned up at Beccles Heliport on the 30th July at 9am, most of us had an early start to get there. We booked in and got our jump suits fitted and learnt the basic positions we had to get ourselves in.

Throughout the waiting we all kept getting an attack of the jitters, with the exception of Caroline as all she wanted to do was do it, as this would be her 3rd jump.

Finally, we all boarded the plane, it was an extremely tight squeeze but we managed. We flew up to 13000 ft and then they opened the shutters on the door. From my own experience as soon as I looked downwards I felt really peaceful as everywhere I looked was bright blue and the clouds looked like fluffy pillows, this seemed to calm me down considerably!

I watched the others jump one by one and then suddenly it was my turn, by the time I had remembered everything I had to do I was suddenly upside down falling through the air at 120 mph for around 40 seconds. Then all of a sudden there was a big tug on my shoulders as the parachute opened. After a few minutes I landed safely on the ground with a big bump and a smile on my face. I can honestly say it was one of the best experiences of my life and I am so glad I did it.

After the skydive all the jumpers, their families and also Della and Roger Brookman who came along for moral support had a celebratory lunch at the local pub and a chat about what had happened. I believe we are all planning to do another one, but this time for fun.

Finally, I just want to say a big thank you to the committee for approving the grant to help with some of the costs for the jumpers, we have easily covered this in donations. I estimate that we will have raised over £2500 for HSP once all of the cheques and sponsor money has been collected in. Also, could I thank every single person who donated, we really appreciate it.

Useful Information

Research Grant Update - 17/06/2011 – Prof. Andrew Crosby, St. George's University of London

Following up from the visit I made to see Dr Evan Reid at Cambridge, I recently spoke to Professor Andrew Crosby, another recipient of an HSP Group research grant, on the phone to discuss the research his group is doing into HSP.

Prof. Crosby's research group is also looking into the possibility of there being a single mechanism responsible for the development of problems in nerves that cause HSP. However, the mechanism that Prof. Crosby's group is investigating, or "biochemical cascade" as he puts it, has the potential to explain the development of symptoms across a number of different gene mutations. Their work is still at the hypothesis stage, but future work will continue to develop and assess the validity of the hypothesis that this particular biochemical cascade is responsible for a wide range of HSP.

Professor Crosby expressed his gratitude to the group for the grant, as the money was used to help in work to discover two new genes that are responsible for HSP, one of which was strongly related to the biochemical cascade they are focussing on.

Again, I would like to thank Prof. Crosby for taking the time to talk about his work and HSP research in general. I also think it very positive to have both Prof. Crosby's and Dr. Reid's group making such good progress in understanding exactly what is going on behind the scenes with a range of different HSP genes. It is clear that any possibility of treatment is some way off, but the fact that there are such efforts being made to understand what is happening at a fundamental level can only be a very good thing for the prospects of future treatments.

Simon Hubbard

Sylvia Ayling from Region 1 recently purchased a trolley that she has found invaluable and would like to share the following related information with you.

Folding Walsall Trolley (AA5975) (with standard wheels) £97.38 excluding VAT

Greetings All,

I have just acquired the above from UKS Mobility, as carrying such things as up till now, filled teapots and anything heavy has obliged me to ask someone else to do such things for me. But I must say, my new trolley is proving to be an invaluable piece of kit, and in case you have been thinking of getting one yourselves I would highly recommend that you have a look at it on their site.

Both can be viewed on their WEB site <http://www.uksmobility.co.uk/household/trolleys/walsall-trolleys> Either contact Malcolm Simister, Development Manager, at orders@uksmobility.co.uk or call him at 0161 973 8168 Monday - Friday, 9am - 5pm

Kind Regards,

Sylvia

Members' Letters

Life on the Ocean Wave

Dave and I plus members of the local Multiple Sclerosis group enjoyed a glorious day of sailing from Weymouth in the Jubilee Sailing Trust (JST) Tall Ship "Lord Nelson". The ship is fully accessible with lifts (9), disabled toilets, wide decks and lounge and dining facilities. All are designed to allow people in wheelchairs to access them independently. On arrival at 8.30 am we were welcomed with bacon baps and hot drinks and were fully briefed for the day at sea. Throughout the day we were well catered for with mid morning and mid afternoon cakes, biscuits (all freshly made on-board) and hot drinks and a very good choice of lunch, with all the catering provided by the crew.

Once out of the harbour we were shown how to use the ropes to change the sails. This was hard work with everybody helping do this even wheelchair users, it certainly gave you an

appetite for all the food they were providing! It was interesting to realise how many times sails needed to be adjusted – being involved as part of a working party certainly brought that home!

If this had been a weeks cruise they would have taken people up to the top of the mast, they can hoist people in wheelchairs up there as well if they want to, not me thank you! They have a “buddy” system so you have someone looking after you all the time you are on board.

The weather was fine and sunny with the wind creating a gentle swell and it was lovely sailing along with just the sound of the wind in the sails. An unexpected bonus was being entertained by three dolphins just outside the entrance to Weymouth harbour as we returned. We disembarked in the same exciting way we had gone on-board, those in wheelchairs were lowered down the gang-plank by means of a rope held by two crewmen whilst a carer guided it to the shore.

It was a brilliant day and an exciting experience. I would recommend it to anyone who fancies a taste of life on a sailing ship.

Details about the JST can be found on their web site: www.jst.org.uk/

There is a year round programme of voyages of differing lengths from various ports around the UK and you can find out about these and make bookings on-line.

Carolyn Harris

Dear all

I joined the HSP group on behalf of my 12 year old son, Arthur, who has the diagnosis. This came as a surprise, although in retrospect his Dad’s ‘bad leg’ has turned out to also be HSP – not the result of a botched childhood operation for knock knees.....

I have (like many others) been on a steep learning curve since my son was two, having to learn to be the archetypal ‘pushy mum’ with the medical profession. Their original suggestion was that he was merely copying his father’s gait, then he was prescribed drugs for Dopa-responsive Dystonia which made him feel permanently nauseous and finally when he

did get a diagnosis of HSP the help available was lamentable. Happily I got him referred to Bristol Children’s Hospital having heard a wonderful paediatrician on Radio 4 and, if nothing else, I feel that Arthur is not the first case they’ve ever seen. (Again, I’m sure many of you are familiar with having to tell the specialists what HSP involves as opposed to vice versa!)

Arthur generally had a wonderful time at primary school including doing a ‘show and tell’ of his camouflage pattern DAFO’s and climbing Pen y Fan with his walking poles in year 6 and being awarded the trophy for ‘courage’ at the leavers ceremony-not a dry eye in the house.

He has now joined his older sister at secondary school and (after some persuasion) all his lessons are on the ground floor as he finds coming down stairs in a crush a bit precarious.



Tamsin and Arthur Rowlinson

As part of a sporty, active family he has always joined in. He came last in the school marathon but with a huge smile on his face and the whole school chanting his name. He has a killer serve in tennis and consequently doesn’t usually have to play any further points (a great tactic!) He fields for the school cricket team as he is extremely good at throwing himself over. He has taught himself to fall like a stuntman (look out for a small boy rolling a la James Bond along the pavements of Hampshire!) He came skiing for the first time this year and although he wasn’t able to keep up with his sisters in ski school we found a wonderful instructor who tore up the metaphorical ‘bend zee knees’ rule book and taught Arthur to ski in a way that suits his body. I felt very privileged to do a blue run as

a family, with Arthur yelling “Come on Mum” as he careered down the slope. (He never did learn to stop!)

I don’t know what the future holds for his mobility but I do know that he is (mostly) happy with himself and has a great ‘can do’ attitude. So I have no big point to make just, I hope, a cheerful tale.

To all of you who constantly have to put in maximum effort just to do the physical things I take for granted –I salute you.

I will be running, along with my partner, sister and brother-in-law, in the Great South Run in October 2011 to raise funds for HSP.

My fund raising page is

<http://www.justgiving.com/Tamsin-Rowlinson>

Tamsin Rowlinson Region 1

To Reach for the Sky

In 2009, a friend of mine mentioned FSD (Flying Scholarships for the disabled) because I was having problems with confidence issues, after various low points in my life. I straight away said “No way, could I learn to fly a plane”. So I put it to the back of my mind and left it at that.

The thought kept coming back into my mind. “What if”. Hmmmmm. So Early 2010 I decided to put my details on the FSD website. Within a day, I was phoned by Sue Whitby. We had a short chat, then Sue sent me the forms to fill in. I put them away for a few months, but knew I would have to get them sorted at some point. So, by October 2010 I had everything together, including an A4 statement about myself. I posted them and waited until the selection panel had decided which applicants had got through to the next stage. A three day stay at RAF Cranwell.

There were over 300 applicants and 24 got through to that stage. We went to Cranwell and had various tests, a thorough medical and interviews. We were all looked after very well. At the end of the second day, all my tests/interviews were finished. So, I went home to await the decision. I was very proud to have got that far and be at Cranwell.

After about three days, I got the phone call that I was one of the lucky one’s. :O) I was to do my scholarship with two other people in Aero’s Mountford, Wellesbourne.

Wooooooooooooooooooooooooooooo. Hehehehe amazing feeling.

The whole month there was the most exhilarating, amazing and emotional period in my life. It was very hard work. Flew every day. :O) and when not flying, we were studying. Of course, we had a few leisure times too. Got to be done. We stayed at a lovely farmhouse. The idea was to show that we could look after ourselves and cope with everyday things, along with flying a small aircraft.

I won’t go into it all, as I would be going on about it for days and I don’t think the Newslink would be able to fit it in. But, I would like to say (with pride) that on my last lesson, on my last day of flight training, I went SOLO!!!! woooooohoooooooooooo! Hehehehe. Also, I passed three exams. Air law, human factors and meteorology.

I feel very privileged that I was given the chance to do this and very grateful. Needless to say, my confidence levels have soared and believe, if I want something enough and have the right help and support, I can achieve almost anything. Well, within reason. Lol

I nearly didn’t go for the scholarship, but am so glad I did. I was happy to be flying and had no grand ideas of going solo. See what happens if you try. So, I say: “if you can, go for it”. You never know what the outcome will be, but at least you tried. :O)

Della Brookman Region 3

Forthcoming Events:

Region 4 get together

Saturday October 22nd 2pm onwards
The Dartmoor Lodge Hotel, Ashburton
Call Ian Bennett on 01202 849391

Professor Jon Marsden from Plymouth University will be joining us to update us on his latest research regarding the effects of hot and cold temperatures on HSP.

Region 3 Meeting

Date to be arranged
The Orange Tree, Hitchin
Call Della Brookman on 01462622946 or
07513004040
or Ian Kitchen on 07540476735

Afternoon tea Regions 1 & 2

Regions 1 and 2 will be having their Autumn
Afternoon Tea on: - Sunday November 20th
from 3:00 to 6:00 p.m.

At: - The Clockhouse,
Chapel Lane,
Milford,
Surrey. GU8 5EZ

Yes, we will be meeting on a Sunday. This will
not be the first one on a Sunday and may not
be the last!!

We will be welcoming Professor Andrew
Crosby and Karen Stephens from St Georges
in London. Karen joined us in April 2010,
when blood samples were needed from HSP
and non HSP sufferers. They will give a short
presentation regarding the genetics of HSP and
the work that is being carried out at St
George's.

We hope you are well and will be able to join
us.

Take care. Michael and Jane.

Region 6 (Wales) Meeting

Date to be arranged - All welcome
The Atlantic Hotel, Porthcawl
Call Peter Bateman on 01656 788502

HSP Support Group AGM

Saturday June 16th 2012
Trident Technology and Business Centre
Leamington Spa

New Members

We welcome the following new members:

Christine Soleas
Bristol
Region 4

Matt Harmer
Brentford
Region 2

Tracey Edwards
Fareham
Region 1

David Rose
Warwick
Region 7

Doreen Robinson
West Sussex
Region 1

Gwyn Jones
Llanelli
Region 6

Michael Horsman
Herts
Region 3

Robert Bourne
Stoke on Trent
Region 7

Samantha Thompson
Leominster
Region 7

Colin Haines
Hove
Region 1

Desmond Williams
Walsall
Region 7

John Marks
Cornwall
Region 4

Melanie Bradley
Loughborough
Region 8

Paul Whiteman
Herts
Region 3

Samantha Medley
Perthshire
Region 11

Steven Quinn
Greenwich
Region 2

Fiona Matthews
Gloucester
Region 3

If you are interested in contacting any of the new members listed, please contact the relevant area coordinator, or the membership secretary, who can then supply the necessary contact details.

HSP Support Group 2011 AGM Minutes

Saturday 18th June

The Trident Technology and Business Park, Poseidon Way, Warwick, CV34 6SW

The Meeting opened at 10.30am

Present: Committee Members; John Mason, David Harris, Ian Bennett, Stephanie Flower being part of a total of 63 members.

Apologies were received from over 50 members.

Minutes of 2010 AGM were duly accepted as a true record. Proposed for adoption by John Flower and seconded by Eric Spalding. There were no Matters Arising.

Committee Reports:

Help Line - Stephanie Flower. This year the help line has been busy, new members are phoning in greater numbers.

Chairman and Membership Secretary (Ian Bennett)

1. Fundraising had become a big thing this year. More funds were being raised from a range of events and initiatives - a few examples would be given later. Thanks were due to all who were involved with fund raising.
 2. Regional meetings – This year was the tenth anniversary of our first regional meeting! Many thanks were due to Jane Bennett who had run these meetings over the whole period. Jane could not attend today's AGM due to other commitments.
 3. £5000 Grants have now been given to two UK research organisations in support of research into HSP.
 4. Research into the effects of heat and cold on HSP undertaken by Plymouth University was being supported by members and carers as subject in the research.
 5. The committee had co-opted member Simon Hubbard - Simon had done much work in keeping in touch with both research teams and the developing European groups during the year. Simon has agreed to stand for election this coming year.
 6. A new initiative this year had been applying to Charitable Trusts for funding for our organisation. This had come about as a result of a volunteer, Deborah Glanville, whom Ian had met some years ago. Deborah is a professional fund-raiser, and had come forward this year and offered to write some applications on our behalf at no cost to us. Ian has continued to make further application based on the information and suggestions made by Deborah. We'd so far received some rejections, but only about one in twenty applications are successful.
 7. Fundraising - Three very different activities were mentioned: Member Eileen McCarrick and her idea for a "Welly Dance". Ian had been very sceptical, but the event was held, was fun, lots of members participated and it raised £1500 for HSP! Many many thanks to Eileen for a great idea; next mentioned was Ian Kitchen, Carrie Begg, Sherrill Casburn and others who will be doing a skydive on July 30th; finally, a friend of member Mark Lennon - Stephen Orpin - was doing the Ironman challenge on behalf of HSP Group.
 8. We now have 326 members and 48 Honorary Members.
 9. Members were asked to help keep our administration simple by getting Newslink electronically if possible and by renewing membership by Standing Order.
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Treasurers Report (John Mason)

Accounts were distributed to members present, these showing an end-of-year balance of £16,577. Thanks were given to Sonya Mason for her work on the accounts and to Theo White for his work as Auditor. No questions from the floor. Unanimous approval of the accounts followed their proposal for acceptance.

Election of Officers for the year ahead:

All those in post had indicated that they were prepared to continue in their present roles if re-elected

Position	Nominee	Proposed by	Seconded by
Chairman	Ian Bennett	Lorraine Saupé	Terry Reed
Treasurer	John Mason	David Britton	Eric Spalding
Secretary	David Harris	Richard Williams	Pat Reed
Membership Sec.	Ian Bennett	Eric Spalding	Lorraine Saupé
Helpline	Stephanie Flower	Caroline Begg	Terry Reed
Committee Member	Simon Hubbard	John Flower	Lorraine Saupé
Committee Member	David Pearce	David Britton	Richard Williams
Committee Member	John Moore	John Flower	Stephanie Flower

All the above having been duly nominated, proposed and seconded, the meeting formally approved the appointments by a show of hands.

Any Other Business

No issues were raised.

The AGM ended at 11.05am and was followed by three presentations and some demonstrations of various items of equipment shown by members.

Once again, our thanks go to the excellent presentation of lunch and other refreshments by the Trident Technology team.

The Meeting closed at 4.30pm.
