Synapse

September, 2000

Established in June of 1997 by Joe Alberstadt for people with Primary Lateral Sclerosis, and their loved ones.

Synapse means a means of connecting, and in so doing, nourishing the subjects (neurons) that are being connected by the mere fact that there is a synapse (a sort of connecting or communicating) taking place. -- William G. Figueroa, M.D. Relate this to our interactive communication support group, and it's no wonder the name for our interactive communicating letter is befittingly called SYNAPSE. By interactive discussions, we can help each other. Neglecting to communicate can contribute to our attitudes, incentives, hope and spirits dying. Let's keep these attributes alive through SYNAPSE. Thank you. Joe Alberstadt

Thank-you, Joe Alberstadt

(Joe Alberstadt started Synapose back in 1997. He handed the job to me last June. Several of you have written and shared your thoughts about Joe. They follow.
-- editor)

Dear Joe,
Sorry to hear that you have stopped publishing Synapse. Mark will do a great job I'm sure, but you will be a tough act to follow.

You and I have been friends since 1995. You got my name from NORD. You wrote to me telling me about your condition, and the possibility of your son having PLS also. I was so impressed with your letter, and the upbeat attitude you expressed, that it pulled me right out of the depressed mood that I was in.

In 1997 you started the Synapse newsletter, but you called yourself, just a "messenger". Joe, we all know you put a lot of hard work into Synapse to make it what it is today. You will always be remembered as the person who was responsible for putting this group together. You have been an inspiration to us all. Thank you.
Sincerely,
Frank Cecere
FrankC828@aol.com

Just a brief note to thank you for the wonderful outlet you provided for all of us with PLS through the publication of Synapse.

When I was diagnosed in 1996, I had little information regarding PLS and NO information regarding the progression of the disease. You were kind enough to share the story of how PLS has affected you and encouraged others to do the same, thereby providing me with some insight as to how this disease progresses and what I

(continued on p. 2, column 1--**Alberstadt**.)

2nd Annual Vienna Meeting

(Several PLSers met at Vienna, VA this past July. Here are a few reports.)

Let's call this one Beauty and The Beast. Beauty being Jeff's and Elaina's beautiful new daughter, Shira, and Beast being the PLS that brought us all together. (Does that mean PLS is not all bad?) It was a real pleasure to see all of you again and some of you for the first time. I sure hope that won't be the last time. Ed and Carol, Jeff and Elaina, Owen and Family, and even myself live fairly close by, but this meeting is hardly a day trip for Joe and Carol, Bettie Jo and Don and Galen. (Must be rough paddlin' that kayak up and down I-95 in all this heat.) I think we all agree, it was worth the effort.

I really enjoyed talking to each of you even if I hardly had a clue as to what you said to me. Talk to me in writing, that I understand. I don't know if I did good or bad because if I didn't hear it I don't know if I missed it. I do know I felt very comfortable and appreciated all the hearing help I got. Thanks.

I think it must be a small miracle that all of us on this site have found each other and at less than 400 cases of PLS in the United States it has to be a much bigger miracle to find seven of us together under one roof. Being a part of these meetings rank right up there among the "ten best things that ever happened to me".

It's been said before and I will say it again. Plan a meeting. Whether it is two PLSers or a room full, set up a meeting. You'll be glad you did. It is the best therapy! A great learning and sharing experience. I learned something from Bettie Jo that I have already put to use. With only one usable hand, cutting (meat, salad, etc.) is no easy task. Bettie Jo suggested a pizza cutter. It works!

(Continued on p. 2, column 2, **Vienna**)

PLS Research Fund Update

In four short months, we have raised 42% of our goal of $35,000 to begin research to determine the cause of PLS. The PLS Research Fund at the National Organization of Rare Diseases (NORD) now contains $14,725 (as of 9-8-2000).

Once $35,000 is raised for the Fund, NORD will issue a grant to a qualified scientist to begin research to find the cause and cure of PLS.

To contribute, send your donation to NORD, P.O. Box 8923, New Fairfield, CT 06812-8923. Include a note stating that it is for the "PLS Research Fund".

If you have a credit card that gives travel points, consider charging your donation. You'll earn travel points, and the PLS Research Fund will grow. Call Ms. Jean Campbell at NORD at (203) 746-6518 to charge your donation.

The Connecticut Connection

From October 27th - 29th, PLSers will be coming from all over the country to Rocky Hill, CT (outside of Hartford) to join together, share their experiences with PLS, and just have fun. Everyone is staying at the Marriott Hotel. They have reserved 12 handicap rooms for our group @ 85.00/night (normally $129/night). Call 1-800-228-9290 for reservations. The rooms are under the name PLS-Friends.

On Saturday the 28th, the group will be meeting at the nearby Wethersfield Country Club from 9:00am to 2:00pm. A continental breakfast and luncheon will be served.

Everyone planning on attending should contact one of the co-hosts for details:
Frank Cecere, 136 Amherst St.,
Wethersfield, CT 06109, (860) 529-8958,

(continued on p. 2, column 2--**CT**)

Alberstadt

could be dealing with in the future. Also, I was bolstered by your positive attitude and the fact that you and Carol continue to enjoy traveling, refusing to let PLS takeover your life. (Sometimes I wondered how you found time to publish Synapse not to mention all the surveys and results!)

Thank you for caring enough to bring our "PLS family" together. Best Wishes to you and Carol.
Marlene DaBaldo
MONPO89@aol.com

Dear Joe,
I just got the latest issue of SYNAPSE and I was pleased to see Mark Weber had taken the helm. I'm sure it is a lot of work to put out a publication like SYNAPSE, and I could see you really had your heart in it. Loving what you are doing makes it harder to stop, and I know as much as you resisted passing the baton to Mark, you knew it had to happen.

I know the Joe Alberstadt 'byline' will continue to enlighten our lives when we read SYNAPSE, and I look forward to seeing it. It took a lot of determination and initiative to get SYNAPSE off the ground, to bring together people facing similar obstacles and communicate to them and with them. I have written you a few times and although I sometimes need some prodding from Lorraine, once I begin it is a pleasure, but sharing is the purpose of a paper like SYNAPSE. If we share our stories we can laugh about some and be warned by others.

My falling seems a little more often now, and luckily I can just brush myself off after most, but I recall an issue of SYNAPSE where you and others wrote to warn us of the dangers of just 'brushing it off' and saying "I'll be OK." I know better now.

I'm going to close with my sincere thanks for doing what you have done in bringing us all closer together. The stories of your trips, and of meeting other PLSers have been a pleasure to read for all. I plan to stay in touch. Be well,
Dwight Harvey

Dear Joe,
Thank you for all the work and time that you put into SYNAPSE. I also appreciate your personal phone calls and your caring for all of us. Glen's symptoms, unfortunately appear to have speeded up. He can tolerate his electric jazzy wheelchair for only 3 hours, which we don't quite understand. We now have a hydraulic hoyer lift so I can transfer him from bed to chair. I totally dress him and he no longer rolls over in bed, nor can he reposition himself in his recliner.

In the summer of 1997 he used a cane occasionally, by Feb. 1998 used a walker constantly and by fall of 1998 used an electric wheechair. His standing ability is down to seconds, holding onto bars very poorly, body beat and leaning over very such to left side. However Glen rarely complains, but I know be hurts on the inside.

Thank you for listening and caring.
Barbara Wilson
Enid, OK

Hi Joe,
You and I were corresponding before Synapse ever began....remember.

I've enjoyed the friendship over these years. I also enjoyed your editing Synapse. You displayed realism with humor.

Let's not stop corresponding. I don't get to go to any of the PLS reunions, but you and your wife are more than welcome to visit us. Either here in the sticks of Upper Michigan or in Puerto Vallarta this winter.

Mark: You've got a hard act to follow. We'll be waiting, anxiously, for you to "show your stuff". Good luck.
Cheers,
Anita Zimmerman
nitazimm@up.net

Vienna

Thanks Bettie Jo. Bet I would have learned more, if I could have heard more. Well, there is other thing I learned. The name Bubba fits, but I'm not saying who.

Thanks everyone for a great time. Let's start planning the next one. And just a harebrained thought…could a national meeting of PLsers work out if we planned it for two or three years in advance?
Ronnie Grove
Frogrove@intrepid.net

To: Joe and Carol, Don and Bettie Jo, Jeff and Elaina, Ronnie and Doris, Owen and Ginny, Penny, Dave and Family, and Galen.

Thanks for a great meeting and fun time--it was great to see you all again and meet the new folks. A special thanks to Joe and Carol Alberstadt for setting it up and for the "photo" album of so many folks we see on the site each day--it's great to put a face to the name.

Thanks to Ronnie for the Berkeley Spring water and to Don and Bettie Jo for the maahvelous Moravian cookies--you all are very thoughtful!

Jeff and Elaina--Little Shira was the sweetest little thing and my Carol sure enjoyed being a "grandma" for a while.

Fudruckers may not let us back in next year but we had fun! Thanks for a fun afternoon.
Ed and Carol Ames
Mingoeja@erols.com

CT

FrankC828@aol.com, or

Dolores Carron, 139 Forest Dr., Newington, CT 06111, (860) 666-9862, d.carron@worldnet.att.net

Shopping for a Cure

Shop online with "Pages that Pay" merchants. Merchants listed at the top of the PLS Awareness Website (http://www.geocities.com/mdmfoo/PLS.html) will pay 1% to 22% of every purchase made through the PLS Awareness website to the PLS Research Fund at NORD. Shop until you drop!

Fundraising Idea

When I spoke to Jean Campbell at NORD, she mentioned that it is possible to have donations automatically charged to a credit card in an amount and at intervals designated by the donor. For example, you could authorize a charge of $XX to your credit card on the XX day of each month, and NORD would automatically process your donation. *(And you'll get travel points each month, if your card gives travel points.--editor)*
Marlene DaBaldo

Baclofen Pump Update 9-6-2000

I just wanted to let everyone know how I'm doing with my Baclofen pump after almost 6 weeks. I really put it to work on our trip to Greenbrier. It is a lovely resort but is so big that I had to walk quite far to get to

Baclofen Pump

meals and activities. I had a dose increase the day before we left for our trip.

The day of the trip I was still trying to decide if I needed my 4-wheel walker or if my cane would suffice. We drove from Sedona to Phoenix to spend the night as our plane was leaving early in the morning and I get real cranky if I don't get enough beauty sleep. So my husband and I decided to take a short trip to a shopping mall prior to dinner and check out my walking abilities. I've always started off pretty good but rapidly go down hill when walking any distance.

We walked around the mall for about an hour (I haven't walked that far in almost a year) and while I was a little tired I was still walking fairly well, without any aid. So we decided to leave my walker behind and just take the cane.

When we arrived at Greenbrier the next evening I was exhausted and dragging quite a bit. I thought possibly I'd made a mistake in not taking the walker. Most of the kids were there to greet us as we arrived (we had a family gathering to celebrate my mother-in-laws 93rd birthday) and were amazed at how well I was doing. Here I thought I was doing pretty poorly but they had last seen me at Easter and the difference was amazing to them. The next morning after a good night's rest and I was near perfect!

The really amazing thing is my speech. While the doctors didn't promise much change in my speech, they did say it could help with it and boy did it. If you'd never heard me speak before you wouldn't know I have problem. It just gets a little slurred when I'm tired. Some words are still difficult but I just try to avoid them.

Now I can't wait for Sept. 6th when I go back for a refill. They said I could get another increase in my dosage then. They do 10% increases at a time and I had no problem adjusting to the increase this last time. In fact I forget I have the pump at times. It is still a little tender at the pump site but no big deal. The main adjustment has been my clothes not fitting (waistbands bother me now) so poor me, I have to buy some new clothes. Pity, Pity. Anyway, I really feel as if this pump has given me my life back.
Jennifer Thomson
mdmfoo@yahoo.com

Speech problems in PLS?

(Karen Deda asked that question in PLS-FRIENDS. These responses followed. Of course not everyone with PLS experiences speech problems, regardless of how long they have had it. -- editor)

I first noticed mine about 3 years ago, it started with slurring some words and when I had something to say I found myself beginning the sentence but unable to finish it. It appeared that I was still talking but nothing was coming out until I stopped and started up again to finish what I started to say. Now I cannot talk very much at all.

To try and use the phone is a disaster. I have even had people hang up on me or ask me if I am drunk. Now I don't bother to answer the phone and only talk to my immediate family. I do have a TTY machine that I use for any phone calls that I make.

I hope I have been some help to you.
Ronald Southgate
southgate@home.com

My first symptoms were slow and slurred speech. It was if I'd had one too many glasses of wine. I never felt any difference in my throat.
Linda Gentner
Lkgentner@aol.com

My problem is exclusively in my throat. I have laryngeal spasms called spasmodic dysphonia. My speech is clear but I sound very hoarse and will have words choked off by a spasm. It also leads me to cough a lot.

The first thing I noticed was the cough, next the hoarseness (sounded like allergies at first).
Lavon Lockwood
lockwood@texas.net

It affected my tongue muscle first. My tongue felt very thick and sluggish, kind of numb (like it had been given a shot of Novocain). I had to talk "around my tongue" by using very exaggerated mouth movements. Whatever I tried to say came out sounding like I was completely soused.

After that condition improved I noticed my throat would feel like it was "closing off" or tightening up which caused my voice to lack volume and sound very "breathy". Then I started noticing I had excess saliva in my throat, which caused me to choke once in a while. And then my upper palate affected, causing my speech to sound nasally. All during this time (within a 4 month period) I couldn't enunciate clearly -- I had trouble pronouncing certain consonant sounds without slurring.

My speech has slowly gotten worse since then--the slurred words more indistinguishable. All of the other symptoms remained except for the "thick tongue" feeling. My tongue still doesn't move like it should, which is the main reason for the slurred speech. And it's not much help while trying to manipulate food around in my mouth either.
Lyndal Brown
LyndalGBrown@aol.com

PLS affects my throat. Just recently I noticed some slurring, a lisp etc. pronouncing some words. A throat study done last year showed that fluids leak into my lungs due to throat muscle involvement.

As I write this, I am on my second antibiotic to try and clear up a lung infection caused by aspirating so much fluid. So yes, PLS can start at the throat first.
Jerry Simmons
simmonsgd@cbpu.com

With me it started (and still does), when I get extremely tired. I have to coax the words out of me, by a certain way I have learned to breathe. I have taught myself how to control it, and try not to get myself to that point, but sometimes it's difficult.
Rita DiClemente
ritadfromhollis@webtv.net

I am actually in the initial phases of speech problems. I can only tell you that it is scaring the heck out of me. It feels as though I have a vice around my neck muscles and I have to squeeze the words out. The volume is affected as well as the clarity of words.

I also have the feeling that I need to swallow a lot. It somehow feels like I have something in my throat that is not functioning properly. I also have a slight increase in saliva and choke easily because of that. So I guess you could say I am having spasms in my neck and problems with muscles in my throat as well. Anyone else with these symptoms?
Sue Niquette
niquetterealestate@worldnet.att.net

My voice problems started with hoarseness and frequent clearing of my throat. I would

Speech Problems

lose my voice if I talked too long or was stressed.

When I had the flu and took an anti-viral medication (don't know if that contributed or not), my voice became very halting like. It seemed as if I could only speak on an exhale, and then it was only one syllable at a time. That cleared up but returned when I took the interferon/ribavirin medication.

Now my words are slurred. I have a different tonal quality, and when tired enunciation is extremely difficult. It goes back to the exhale type speech when really tired. When I am well rested, my voice can seem almost normal, but with use deteriorates rapidly.
Jennifer Thomson
mdmfoo@yahoo.com

In my case, PLS affected my speech first. After a year, I wasn't able to talk if I was angry or happy. I couldn't narrate something funny. Then came a stage, 3rd year/4th year, when I used a pen & a piece of paper, and I kept writing key words in bold letters as I kept talking. This helped to free the flow of my words.

Seven years have passed by. Now I talk only to my family members. I avoid talking on the phone. My voice is weak, and I get out of breath especially when I am not seated.
Jagan Hekhuis
cjagan123@hotmail.com

Botox Treatment may Improve Speech Problems

My wife has been receiving botox injections for her speech for over five years, with amazing results. It doesn't work for everyone, but I strongly suggest anyone with speech problems to investigate the possibilities. The procedure takes about 20 minutes in the doctor's.
Check it out...Good luck to all.
Doug Brand
St. Petersburg, FL

So far, the recovery of my voice has been nothing short of amazing. I also have gastroesophogeal reflux and was put on acid blockers so my vocal cords wouldn't get burned any more. I have noticed that since that I start coughing rather quickly and wonder if it is caused by the Botox. (I have much more coughing than before and primarily when I talk). After the Botox treatment, my voice did not get soft or breathy at all and I had no problems swallowing. Overall I found the Botox treatment very good and worth it.
Lavon Lockwood
lockwood@texas.net

There has been much discussion lately of botox and the baclofen pump. I have both.

Of botox injections to improve speech, I am very enthusiastic. I have had four shots, starting in November of last year. The first one showed significant improvement. As you probably know, the voice gets very weak and breathy for a period of 1-2 weeks. During this period you have to very careful with liquids which tend to go down the wrong way. Then the voice slowly strengthens and much of the PLS-caused strain disappears. I was able to speak more normally but still slow. It worked so well, that with the audio-laryngologist, we decided to try it also in the tongue in the hope that would loosen the tongue and make speech even more normal. That was a disaster. It might work for somebody else but for me, it made the speech very unclear. With the next two shots, it was more like the first one.

The effects are supposed to last 3-4 months but I suspect that the more you do it, the longer it lasts because there is still botox in the system.

It really doesn't hurt. I use the most basic anesthesia, and I don't look which seems to help. The whole thing takes about five minutes.

I recommend this. And if it doesn't work, no harm done. The effects wear off and you're no worse off than before.

As for the pump, my experience is less happy.

It depends what you want from it. If you want relief from painful or excessive spasticity without the side effects of oral baclofen or Zanaflex, then the pump is for you.

If, however, if you want improved function (as I did), I would be very careful.

In 1997, my doctor recommended the pump. I was extremely spastic yet I was walking normally but increasingly stiffly. Downhills were becoming a problem; falls were not. I figured with the pump, I would buy a few years like that and maybe more. Maybe I could run again.

In October 1997, I fulfilled a long time goal by walking the length of Manhattan, from the Bronx to the Battery, about 15 miles in 7 1/2 hours. In December, I had the operation to put in the pump. I had good results for about six weeks. I felt looser and was walking better.

Then, suddenly in early Feb '98, I started losing my balance. I couldn't figure it out. I was far less spastic but suddenly I was walking worse than before the pump. Nothing in PLS happens overnight. So I was convinced it wasn't the disease. But my doctor couldn't figure it out either. We adjusted the dosage. I went to physical therapy. Nothing brought me back to where I was before the pump. By June '98, I was using a cane because of falls and that's basically where I am today. Why haven't I shut it off or taken it out? I don't know. I may yet.

So, that's my story for what it's worth.
Jeffrey Glassman
jeffrey210g@worldnet.att.net

This is in reply about Botox injection in the legs. I had my first one at Mayo in 1991. It worked very well and lasted about 5 months. I had five more treatments. Each one lasted a shorter time. Then my doctors said that it was too risky to continue, since my legs got a little weaker each time. However it was wonderful while it lasted.
Evelyn Bannwart
ebann@adsnet.com

I have had botox injections for 5 years now. In the beginning I had two injections a year but now I have only one. That because they either hit the vocal cord correctly or pretty close to it. I never get used to the injection--it really does hurt. I can't relax during the procedure so I tighten up the muscle in that area so they have now given me a valium one hour before injection. It takes about a week for the botox to take effect. During that week, I lose my voice. I can only whisper. (My husband loves it.)

Gradually my voice comes back and the effect is wonderful. I can speak without straining to get words out. The only drawback is difficulty with liquids. I choke a lot with the muscle so relaxed. It's difficult to swallow liquids, but I have no problem with solids. But I understand that it affects everyone differently.

Botox Treatment

I go to an ENT doctor along with my neurologist and a tech that he brings with him. The whole thing takes only a few minutes. When they hit the right mark (when everyone agrees that they are pretty close) they release the shot. They need me to say "eeeeeeeee" during the time the needle is in. The big thing is RELAX. Sure! How can you relax with a needle in your throat!!!!

But all in all it's worth it. Hopes this helps
Flora Brand
St Pete, Florida

I have started treatment on one leg with botox so obviously there is disagreement out there on the possible bad effects. It's still early but I can report positive if undramatic results.

Given the rarity and the mystery of PLS, nobody knows the long-term effects of anything on PLS whether it's aspirin, jello or doing the macarena. So why not try what's available?

In answer to another posting regarding botox in the larynx, I also have that and it helps. But while it is correct that botox has no effect on the palate, having weak tongue and other parts does not mean that the larynx isn't spastic and could be helped with botox. You ought to see an otolaryngologist (maybe two) who has experience with botox before deciding that it can't help.

Jeffrey Glassman
jeffrey210g@worldnet.att.net

Note: Another approach for very serious speech problems is computer software that allows the user to type in words that the computer then "says". --editor

Speech software for Apple type computers is available at NO COST! Go to
http://www.stazsoftware.com/YSpeak.htm
Frank Reyerse
freyerse@telus.net

There are other programs available. If anyone knows of any good ones, please let us know.

Excess Saliva Medication

I have excess salivation with a tendency to aspirate. I mentioned it to Dr. David Riley, University Hospital, Cleveland, Ohio. He prescribed Sal-trophine, 4 mg, six times a day, which seems to have helped.
Jim Bayless
chagrin2@aol.com

While I do not have the problem of excess saliva, I am taking medication that insures that excess saliva will not be a problem. I have to work hard to get enough to make a good spit. The medication is amitriptyline, and I take it to help a sleep disorder. I have a little apnea (stop breathing on average five times per hour), grind my teeth and have short duration spasms in my leg. After sleep test (how can you be expected to sleep wired with a bunch of electrodes over various parts of the body?) I was put on amitriptyline (one 50 mg tablet at bedtime) and clonazepam (one 0.5 mg tablet also at bedtime). One of the side effects of the former medication is "dry mouth" I like to have something to drink (water or decaf iced tea) all the time. During an annual exam in July, the physician commented at the dryness of the mucus membranes.

According to my neurologist, the low dosages of both medications may be taken indefinitely, with only the minimum side effects. I have been taking both since 1995. The dryness could be of help to those who have problems with excess saliva.
Don Wilson
dcwilso@attglobal.net

Dr. Carlayne Jackson in the ALS clinic here in San Antonio prescribes Robinul for excess saliva. This drug dries secretions and in the past (I am out of the loop now and don't know current practice) was the drug given preop to decrease secretions during surgery (made you feel like you were spitting cotton). It is contraindicated in asthmatics.
Lavon Lockwood
lockwood@texas.net

I found a drug called Amitriptyline that helps me with saliva. My problem with excess saliva occurs when I lay down. I take 10 mg at bedtime (I'm told this is a very low dosage) and it dries everything up. I don't even have to go to the bathroom during the night. I also take one if I am going for a test that requires me lay down for more than a couple of minutes.

I've talked to others, and for some it works well and others it does no good. It's about 2 to 1 in favor. Hope this is of some help. Take care and keep smiling.
Dave Nunn
dnunn@home.com

AFO's (Ankle-foot orthotics)

In the last issue, the discussion focussed on plastic AFO's. I was unaware of another kind…

Incidentally, the goal of AFO's is to steady one's gait, while preventing hyperflexion of the knee.

My husband, George has been wearing metal braces for about 4 years now. He used them on his work boots and we just bought some hiking boots for him to wear on other occasions. He just got another new pair of braces that insurance and MD have helped us buy. He says they feel great and have kept his knees from snapping back even better than the old ones.

The plastic AFO's were out of the question for George because he had to wear boots at work and they couldn't go into a boot. The left brace comes up around the upper left thigh with a velcro strap, another strap just above the knee and another around the calf. There are metal bars with hinges at the knee joint, that run down both sides of the leg, then down to the shoe or boot he wears. It has springs at the ankle to allow for a little movement, but they really help keeping his toes from dragging so much. They put a metal plate in the heel area of the shoe that the braces slide into on both sides of the shoe. He has another brace on his right leg that only comes up to just below the knee. That leg doesn't snap back as much as the left one.

If you have any questions, we would be glad to describe further.
Karen Deda
Deda@Prattusa.com

Yes, there is another type of AFO. It is constructed much like a metal brace, with the base connected to a custom shoe and the upper part attached with a velcro strap. Interior springs can be added to correct "toe drop" and corrections can be accomplished with additional straps or splines. The "up side" is that this type of AFO is less constricting than the form fitting plastic, a greater amount of articulation is available, and there is no rubbing of the plastic against the foot or calf, making no special socks required. The "down side" is that the AFO is made as part of the shoe, which limits the selection and may weigh just a little more. Good walking shoes may be modified (at a cost of bout $60.00) to be work with the brace, if more than one style or color are desired.

AFO's

This is the information that Bettie Jo and I received today as she was fitted for this type of AFO.
Don Wilson
dcwilso@attglobal.net

PLSers Start Study at the NIH

Nineteen PLSers traveled to the National Institutes of Health in Bethesda, Maryland, this summer to participate in a study comparing one aspect of ALS (Lou Gehrig's disease) to PLS.

Gerry and I got back from Bethesda last night. The trip was tiring, but well worth it and very well organized. The best part was meeting and having dinner with Lavon. I can't tell you all enough how great it is to meet other PLS'ers. We had a very nice dinner and talked and talked and talked. We bumped into each other off and on while at NIH also, but didn't really have time to chat there.

The staff and doctors at NIH were very helpful and appointments went off like clockwork. There was no waiting around and the testing was not invasive or painful at all. The first day a complete history was taken. They (Drs. Floeter and Zhai) reviewed all of my medical records and decided that I had had a very complete work-up and needed no further procedures or lab work done. They then proceeded to do a complete neurological exam (you know, all the funny faces, sounds, sensory testing, reflexes, etc. etc. etc.). The next thing they scheduled for me was the magnetic imaging of the brain/muscle impulses. My brain wasn't too excited that day but they did manage to get some excitatory responses once in a while when the power was turned up to maximum. It was not painful, but I did have a dull headache for a few hours. The following day they video taped my gait as I "raced" down the hallway four times.

The next thing was the STARTLE TEST. They decided to do this test because Lavon and I told them that most of the PLS'ers we were communicating with on line had an exaggerated startle. They thought that was interesting because the startle response and PLS symptoms usually come from different parts of the brain. Anyway, they put electrodes on your face, arms and legs (try to cover all the different muscle groups). The they put earphones on your head and every once in a while they throw a beep into the earphones and you STARTLE!! At least I did.

I also had the finger-tapping test on a keyboard where they monitor how fast you can tap one key with your index finger. That was pretty easy also. All in all, things went pretty well. The people were nice, the shuttle service was very helpful and always on time and things got done. There were lots of good restaurants around the hotels in Bethesda.

Gerry and I asked Dr. Floeter about how we would hear the results of this study. At first she really didn't give us any answers but after BUGGING her about it, she said she would send all results to our doctors and then send a Newsletter to all participants. This information would, however, take weeks/months to compile. At least we'll hear something eventually. Take care everyone. And those of you going to NIH soon, have a good trip and enjoy your stay!
Sue Niquette
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I was surprised to see how young Dr. Floeter is, and she sure is brilliant. She asked me who diagnosed me and I told her Dr. Gross from the Lahey Clinic in Burlington Mass., and she knew right away that he was Chief of their Neurology Department. I was surprised that she knew of him, as she has only been in practice 10 years, and I was diagnosed by Dr. Gross long before that.

NIH is HUGE! The staff could not be more gracious. They kept us right on schedule, and there was no waiting around. I asked Dr. Floeter many questions about PLS. "THERE IS NO ANSWER, THEY DON"T KNOW" That's why the research!! So if anyone has any questions about the testing ask away.
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Even When You're Not Looking...

The passengers on the bus watched sympathetically as the attractive young woman with the white cane made her way carefully up the steps. She paid the driver and, using her hands to feel the location of the seats, walked down the aisle and found the seat he'd told her was empty. Then she settled in, placed her briefcase on her lap and rested her cane against her leg.

It had been a year since Susan, thirty-four, became blind. Due to a medical misdiagnosis she had been rendered sightless, and she was suddenly thrown into a world of darkness, anger, frustration and self-pity. Once a fiercely independent woman, Susan now felt condemned by this terrible twist of fate to become a powerless, helpless burden on everyone around her.

"How could this have happened to me?" she would plead, her heart knotted with anger.

But no matter how much she cried or ranted or prayed, she knew the painful truth...her sight was never going to return. A cloud of depression hung over Susan's once optimistic spirit. Just getting through each day was an exercise in frustration and exhaustion. And all she had to cling to was her husband Mark.

Mark was an Air Force officer and he loved Susan with all of his heart. When she first lost her sight, he watched her sink into despair and was determined to help his wife gain the strength and confidence she needed to become independent again. Mark's military background had trained him well to deal with sensitive situations, and yet he knew this was the most difficult battle he would ever face.

Finally, Susan felt ready to return to her job, but how would she get there? She used to take the bus, but was now too frightened to get around the city by herself. Mark volunteered to drive her to work each day. even though they worked at opposite ends of the city. At first, this comforted Susan and fulfilled Mark's need to protect his sightless wife who was so insecure about performing the slightest task. Soon, however, Mark realized that this arrangement wasn't working--it was hectic and costly.

Susan is going to have to start taking the bus again, he admitted to himself. But just the thought of mentioning it to her made him cringe. She was still so fragile, so angry. How would she react? Just as Mark predicted, Susan was horrified at the idea of taking the bus again.

"I'm blind!" she responded bitterly. "How am I supposed to know where I'm going? I feel like you're abandoning me."

Mark's heart broke to hear these words, but

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he knew what had to be done.

He promised Susan that each morning and evening he would ride the bus with her, for as long as it took, until she got the hang of it. And that is exactly what happened.

For two solid weeks, Mark, military uniform and all, accompanied Susan to and from work each day. He taught her how to rely on her other senses, specifically her hearing, to determine where she was and how to adapt to her new environment. He helped her befriend the bus drivers who could watch out for her, and save her a seat. He made her laugh, even on those not-so-good days when she would trip exiting the bus, or drop her briefcase.

Each morning they made the journey together, and Mark would take a cab back to his office. Although this routine was even more costly and exhausting than the previous one, Mark knew it was only a matter of time before Susan would be able to ride the bus on her own. He believed in her, in the Susan he used to know before she'd lost her sight, who wasn't afraid of any challenge and who would never, ever quit.

Finally, Susan decided that she was ready to try the trip on her own. Monday morning arrived, and before she left, she threw her arms around Mark, her temporary bus riding companion, her husband, and her best friend. Her eyes filled with tears of gratitude for his loyalty, his patience, his love. She said good-bye, and for the first time, they went their separate ways.

Monday, Tuesday, Wednesday, Thursday...each day on her own went perfectly, and Susan had never felt better. She was doing it! She was going to work all by herself! On Friday morning, Susan took the bus to work as usual. As she was paying for her fare to exit the bus, the driver said, "Boy, I sure envy you."

Susan wasn't sure if the speaking to her or not. After all, who on earth would ever envy a blind woman who had struggled just to find the courage to live for the past year?

Curious, she asked the driver, "Why do you say that you envy me?"

The driver responded, "It must feel so good to be taken care of and protected like you are."

Susan had no idea what the driver was talking about, and asked again, "What do you mean?"

The driver answered, "You know, every morning for the past week, a fine looking gentleman in a military uniform has been standing across the street corner watching you when you get off the bus. He makes sure you cross the street safely and he watches you until you enter your office building. Then he blows you a kiss, gives you a little salute and walks away. You are one lucky lady."

Tears of happiness poured down Susan's cheeks. Although she couldn't physically see him, she had always felt Mark's presence. She was lucky, so lucky, for he had given her a gift more powerful than sight, a gift she didn't need to see to believe - the gift of love that can bring light where there had been darkness.

God watches over us in just the same way. We may not know He is present. We may not be able to see His face, but He is there nonetheless! Be blessed in this thought: "God Loves You - even when you are not looking."

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PLS Resources

1. Websites:

The PLS Website:
http://www.geocities.com/freyerse/index.html

The PLS Awareness Site:
http://www.geocities.com/mdmfoo/pls.html

2. On-line PLS Discussion Sites:

For PLS chat and support:
http://www.egroups.com/group/PLS-FRIENDS

For PLS News:
http://www.egroups.com/group/PLSers-NEWS

Next Issue

I will forever need your ideas and suggestions.

For the next issue, I'd like your ideas on why you left work before retirement age--or why you've decided to stay at work in spite of your PLS. Anyone causing you problems at work because of your PLS? Let's get 'em.

Also, please send in your thoughts, stories and articles on any other subject.

Subscriptions

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