

Synapse

Volume 13, Issue 3 Summer, 2010

Newsletter of the Spastic Paraplegia Foundation



Liz Lepper playing soccer



Conference Chair Marlin Dollinger



Welcome



Frank Davis being fitted with a WalkAide



Registration



Up close and personal with Dr. Fink



SPF Board

*Front: Linda Gentner, Chris Brocchini, Mark Weber, Malin Dollinger
Back: Corey Braadstad, Frank Davis, Jim Sheorn, Jean Chambers,
Mike Podanoffsky, Jim Campbell, Annette Lockwood, Ashton Hecker*



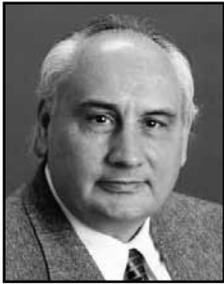
Audience participation with Corey



Jennifer Thomson using her new Dashaway walker

President's Letter:

A GOOD PROBLEM TO HAVE



Mike Podanoffsky
SPF President

As you probably already know, each year we ask for research proposals from the medical community. These proposals are then evaluated by our very own Scientific Advisory Board. They determine which proposals make the most sense. It is all part of our effort to understand the root causes of our conditions, HSP and PLS.

Usually we fund four proposals, two for PLS and two for HSP. All of these are all part of research to discover what is "broken" with our motor neurons. Our research funding has helped us to learn a great deal.

Funding more research projects would literally accelerate progress until we reach that date when medical science says "Aha, we know what's going on and how to fix it."

Up until this year there have been two reasons why we haven't funded more research, too few medical researchers and too little money. This year, we finally have their attention. We are receiving very good research proposals. If we had the money, we could fund many more.

It's a good problem to have and it is one that you can help us with. If you and two other people commit to \$10 per month, each month for a year, we could fund one, two, possibly up to six additional research projects. It all depends on how many actually sign up for the challenge. Just go to http://sp-foundation.org/monthlygiving.htm.

In the next issue of Synapse, I'll describe some of the research in lay terms and what it means for our future.

Mike Podanoffsky,
SPF President

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The Spastic Paraplegia Foundation Inc. (SPF) is a national, not-for-profit, voluntary organization. It is the only organization in the Americas dedicated to Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP).

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National Conference Report

The 130 attendees at the Los Angeles SPF Conference were greeted warmly, treated royally, educated and inspired thoughtfully, and socialized abundantly.

Friday Night

Weekend toastmaster/MC, Craig Gentner kicked off the event by introducing Dr. Malin Dollinger, Conference Chair and SPF Board Member.

Welcome to the Conference you Wish you'd Rather not Qualify for

Success in life is not in achieving a goal, but rather in being able to overcome adversity and failure, and from them to establish new worthwhile goals. These new goals may be things that we never thought about before. This conference should help everyone recognize fears, consider positive new goals, and find new directions for our lives.

FREEDOM FROM FEAR

"The most important thing we have to fear is fear itself" (FDR)

Common fears include:

What will happen to us?
Will we become incapable of caring for ourselves?
Will we become bedridden?
Will we be totally dependent on others?
Will our life change in a permanent and awful way?
Will our loved ones still be there for us?
Will we no longer be the person we are now?

The paraplegia club – rules

No invitation to join
Membership is compulsory
No rules of attendance
Club is unknown to others
Members cannot resign
No list of qualifications
No officers or meetings
Membership term indefinite
Everyone instantly knows we belong to this club

We each are able to:

Love and be loved
Smile and help others who need help
Continue our lives, despite the adversities

The Paraplegia Club Offers

New goals
New opportunities
New directions
And freedom from fear

Craig concluded the evening by expanding on some of Malin's points. Craig, noted some of the positive things we've experienced only because of our situation – such as new friends we'd never have met, and getting into Fenway Park for a Red Sox' no hitter, thanks to handicapped seats. His expansive manner whetted our appetites for the program for the rest of the Conference.

Saturday Morning

SPF President, Mike Podanoffsky presented to the group the results of a recent e-survey. The purpose of the survey was to find out what people use now, and what they'd like SPF to do for them.

Survey results:

1. Most read *Synapse*. Most want hard copy even though it is posted on the website.
2. Peoples' interests in descending order are – finding a cure; learning treatment options; meeting others; finding support groups
3. At local and regional Connections people want to learn about - research and treatment
4. The forums people use are – HSP List, PLS Friends, and Facebook

The updated website should be up by time you receive this issue

Gary Karp gave the Keynote Speech.

He learned that we are adaptive beings after a paralyzing spinal cord injury at age 18. When struggling to adapt, we work, some is hard, some easy, but we must move forward with this work. Funding and medical community can cause frustrations, but our brain is our main hurdle – i.e. we resist how we must make transition from the walking mind to the wheeling mind. An individual must come to realization wheeling is now the means of your life. Look for possibilities rather than what has been lost.

Often, people don't know how to relate now, so you must be stronger in yourself. Get beyond stereotypes - e.g. the angry cripple; I am dependent. The world only sees us in extremes. Often language implies that any accomplishments are 'despite a disability.' We are part of a continuum of society learning to understand the disabled. The history of disability from Biblical times, through medieval times when it was thought the disabled cause plagues set the disabled apart, often vilifying them. Attitudes began changing after the US Civil War, as amputees were heroes. Polio epidemics, were setbacks however, as the emphasis became solely a struggle for the cure, not the acceptance of cripples in society. Thanks from all should go to Ed Roberts, who sued CA, got into UC Berkley, became a disability leader and was instrumental in the creation of the ADA.

Today, we are much more mobile, more educated, in hired productively in the workplace, and healthier.

Thanks to the ADA, universal design has made accessibility better not just for the handicapped, but others. - i.e. curb cuts benefit strollers, deliveries

Technology empowers us.

Family plays a huge role in adapting to a disability. The needs of the non-afflicted need support, as does the disabled.

For yourself, set appropriate goals; reach out to others who have been there before; there will be mistakes. Mistakes aren't failure, but information. With new information, new possibilities flow into your life.

He concluded this motivational speech with skillful juggling, while continuing his smooth flow of summary thoughts.



*Keynote Speaker,
Gary Karp
Juggling*

Tips for Traveling with a Disability

Contributed by the speaker, Tim Holtz



www.flyingwheelstravel.com

The world is opening its doors to people with a chronic illness or disability. As we in the disability community mark the 20th anniversary of the Americans with Disabilities Act (ADA), we also celebrate a truly transformed travel industry. Airlines, hotels, cruise lines and tour operators finally recognize that the disabled market is a force to be reckoned with. A recent Harris poll estimates that people with disabilities spent \$13.6 billion on 31 million trips last year.

Since 1970, Flying Wheels Travel has been advocating on the behalf of people with disabilities and chronic illness to help educate the travel



industry about the needs of people with a chronic illness or disability.

As any traveler in an airport, hotel or resort or on a cruise line can testify, disabled travelers are everywhere and remain an important segment of the travel market. Major destinations such as Las Vegas and certain cruise lines have pioneered access for handicapped travelers and now more exotic destinations such as the Galapagos Islands, Egypt and Dubai are accessible to people who use a mobility device.

Travel for people with a disability, chronic illness or the mature traveler should no longer be a scary thing. With various group travel opportunities and expertise for individual travel, agencies like Flying Wheels Travel are available to open the world to you.

Even though great progress has been made in accessible travel, it is important for someone with a disability to plan ahead and ask the right questions to make sure your needs are met and that you will experience the best vacation possible.

Ed note: Here are a few of Tim's valuable tips you might not have considered.

1. If you plan to be traveling alone, get a medical certificate from your doctor stating that it's OK.
2. Be sure that the travel insurance you purchase covers pre-existing conditions.
3. All airplanes have an on-board aisle wheelchair.
4. Make copies of passports, doctor's number, emergency contacts, list of medications. Leave one copy at home.

SPF Medical Advisor, ***Dr. John Fink*** began his talk, What's New and Exciting, by sharing with us the news that treatments on horizon!

- In PLS patients, a PET scan shows low glucose usage in the brain's cerebral cortex – which means low motor neuron activity in this part of the brain. Such a scan may be able to be used both as a diagnostic tool and also to analyze variations in presentation in a specific patient.
- In HSP patients, a spastin gene abnormality is the main cause of dominantly inherited HSP. Researchers are studying the occurrence of a bovine gene abnormality, which will be of use for humans.
- There are international efforts underway to establish a database of all mutations identified in MND (Motor Neuron Disease). There are many challenges, including: genetic heterogeneity; diverse mutations in one gene which result different phenotypes; multigenetic and multifactorial causation; and clinical overlap.
- Total genetics screening will be on the market at a cost under \$5,000.00 in 2-5 years.
- There are overlapping presentations of HSP, PLS, and ALS. Overlaps are not just mutations, but also other factors, probably environmental.
- Both PLS and HSP are very rare.
- Both are syndromes, not a single disease.
- Researchers are studying ALS to try to analyze HSP and PLS. All motor neuron disease (MND) studies are crossover studies as no treatment exists yet.

- Fruit fly studies are helpful. Researchers keep cross breeding the fruit flies to try to stop impairment.
- Genetic advances in HSP are each year changing, as they are happening at such a rapid pace - new genes; new loci; new interacting proteins.

Abnormalities of the long spinal cord axons cause HSP and probably PLS. These axons have a tubular matrix.

- In the past 18 month there have been advances in stem cell technology. Embryonic stem cells had been known to be pluripotent. Now skin cells from an adult can be converted back into pluripotent stem cells then turned into motor neurons. The use of adult skin cells gets around ethical objections to use of embryonic ones.

Last year at our National Conference, Dr. Fink took skin biopsies of six people to make induced pluripotent stem cells (or cultured cell lines).

- Though some people are going abroad now for stem cell treatments, Dr. Fink says it is too early for stem cell infusions now. That therapy will come in the future.

Saturday Afternoon Sessions

Chair Yoga

Bruce Binder and Shawna Hill conducted a session explaining "Get Fit Where You Sit." After Bruce told us about the program which was founded by Lakshmi Voelker, Shawna led us in a session, focused on deep breathing and relaxation. www.getfitwhereyousit.com

Grants, Funding and our Scientific Review Process *Presented by Mark Weber, SPF Co-Founder and Board Member*

By fall, 2010, \$2.5 million will have been given out in research grants. A grant committee of SPF members works with Mark on details of the year's RFP which he sends out to researchers. Grant proposals are received by Mark. He turns them over to the Scientific Advisory Board to review. The SAB ranks the proposals for the SPF Board to vote the final grant awards. Each researcher is hoping for a breakthrough, a eureka moment, which will give all of us a cure, a eureka moment for us all.

Adaptation to Disability

An informal session led by Keynoter, Gary Karp

We each must develop our own coping style in the process of moving toward acceptance and moving on with our lives. Anger and denial have their place but best to let them go and move on. Be willing to feel what you feel, don't deny your feelings, grieve and then move on. Keeping healthy helps. Try to think how you'll think later about a negative attitude you have now.

Disabled are:

1. Whole people first.
2. We treasure independence; imposed help robs it.
3. We are experts at living with our disability.

Helping interaction involves who is in control. Helpers are well intentioned. When help is offered, we can be disrespectful or passive, or accept help. Try to be respectful. Let go of what others think and be comfortable with what you are and what you need. There is an art to pushing a wheelchair.

In response to audience input, Gary acknowledged the added challenges of unending adaptations when the patient has a degenerative disease.

Boundaries between the patient and others are necessary in order that the patient maintain as much independence as possible. Talking is necessary between the patient and the network of family and friends. Work to achieve a balance between independence and help.

The group then divided for two **Break-out Sessions**.

The summary of the **Caregivers Time**, led by Jim Campbell is to be found in the Caregiving section on P. 19.

The WalkAide System was demonstrated on volunteers in a session led by Paul Webber, Certified Orthotist Prosthetist of Hanger Prosthetics Orthotics/ Innovative Neurotronics.

<http://www.walkaide.com/en-US/Pages/default.aspx>
WalkAide is a revolutionary FDA approved medical device that leverages functional electrical stimulation (FES) to improve walking ability of people living with foot drop. It consists of a battery-operated, single-channel electrical stimulator, two electrodes, and electrode leads. WalkAide is applied directly to your leg — not implanted underneath the skin — which means no surgery is involved. A cuff holds the system comfortably in place, and it can be worn discreetly under most clothing.

Sunday Morning

Basic Genetics

Presented by Corey Braastad, PhD

Overview

- **The Anatomy of Genetics**
- **Genetic Function: From DNA to Proteins**
- **Mutations: altered DNA to altered Proteins**
- **Inheritance Patterns**

From our bodies to our genes...

The Anatomy of Genetics: Chromosome Facts

- Structures within the cell that contain the genetic code (DNA) for our physical and biochemical properties
 - Each chromosome contains thousands of genes
 - Humans have 46 chromosomes (23 pairs)
 - 22 pairs called autosomes; 1 pair of sex chromosomes
 - Chromosome conditions result from abnormal number or structure
- Aneuploidy: abnormal chromosomal count

Genetic Function: From DNA to Proteins

DNA structure

- Deoxyribonucleic Acid
- A-T bonds are relatively strong.
G-C bonds are the strongest.
- Dr. Brown, Dr. Mello and others use RNAi to therapeutically target RNA Genetic Function: From DNA to Protein

RNA Processing

Transcription and Translation codon is a group of three nucleotides that encodes for a particular amino acid.

Mutations

- Mutation is a failure of DNA repair.
 - In the living cell, DNA undergoes frequent chemical change, especially when it is being replicated. Most of these changes are quickly repaired. Those that are not repaired result in a mutation.
- There are several types of DNA mutations.
 - Benign vs. pathogenic
 - Point mutations
 - Insertions & deletions
 - Splice-site mutations
 - Repeat expansions
 - Somatic vs. Germline

Benign vs. Pathogenic Variants

- If a variant does not disrupt or alter the function of the protein product, it is known as a benign polymorphism.
- A pathogenic variant (mutation) is one that disrupts or alters the functional protein product and causes disease.

Single-base substitution

➤ A single-base substitution is a mutation where one base is replaced by another. A single base substitution is also called a Point Mutation.

- Missense mutation
- Point mutation that changes a codon such that it encodes for a different amino acid.
- Nonsense mutation
- Point mutation that changes a codon such that it encodes for a STOP, prematurely terminating the protein.
- Silent (synonymous) mutation
- Point mutation that does not alter the encoded amino acid.

Insertions and Deletions

- Extra base pairs may be added (insertion) or removed (deletion) from the DNA sequence of a gene.
 - The number can range from one to thousands.
 - Insertions and deletions may shift the reading frame during transcription.
- Examples
 - Splice Site Mutations Exon 1 Intron Exon 2
 - Exon 1 Intron
 - Exon 2
 - AGGTAT

Repeat Expansions

- A number of inherited human disorders are caused by the insertion of many copies of the same sequence of nucleotides.
- Examples
 - Huntington's disease – CAG repeat
 - Fragile-X – CGG repeat
 - SCA10 – ATTCT repeat
 - DM1 – CTG repeats
 - DM2 – CCTG repeats

Somatic vs. Germline

- Mutations that occur in a somatic cell may damage the cell, make the cell cancerous, or kill the cell.
 - Somatic mutations are not passed on to offspring.
- Germline mutations are in reproductive cells (gametes).
 - Every cell within offspring will contain the mutation.

Sporadic (De Novo) Mutation

- Sporadic, or de-novo, mutations occur spontaneously in an individual.
 - Pre-fertilization: Mutation occurs in germ cell prior to conception. Every cell within offspring will contain the mutation.
 - Post-fertilization: Mutation occurs in early embryonic development, leading to mosaicism.
- No previous family history.
 - Sporadic pedigrees can be confused with recessive inheritance.

Inheritance Patterns: Autosomal Dominant

- One gene in the pair contains a mutation
- All individuals with mutation are affected by or predisposed to develop condition
- 50% recurrence risk for all offspring
- Males and females equally affected
- Examples:
 - Neuro: Huntington's disease, TSC, HSP
 - Endo: OI, MEN1/2, MODY

Inheritance Patterns: Autosomal Recessive

- Both genes in a pair contain a mutation
- Individuals with one mutation are carriers and are not affected by the condition
- 25% recurrence risk for offspring when both parents are carriers
- Males and females equally affected
- Examples:
 - Neuro: SMA, Friedreich's ataxia
 - Endo: FHH, BBS, CAH

Inheritance Patterns: X-Linked Recessive

- Mutation in gene on X-chromosome
- No male-to-male transmission
- Affects primarily males
 - All daughters of affected males will be carriers
- Females are carriers
 - 50% of sons will be affected
 - 50% of daughters will be carriers
- Examples:
 - Neuro: DMD/BMD, Kennedy's disease
 - Endo: NROB1

Inheritance Patterns: X-Linked Dominant

- Mutation in gene on X-chromosome
- No male-to-male transmission
- Affects both males and females
- Affected females
 - 50% of sons and daughters will be affected
- Affected males
 - 100% of daughters will be affected
 - 0% of sons will be affected
- Examples:
 - Neuro: CMTX
 - Endo: PHEX

Inheritance Patterns: Mitochondrial

- Mutation in mitochondrial DNA (mtDNA)
- Maternal transmission
- Affects both males and females
- Affected females
 - 100% of sons and daughters will be affected
- Affected males
 - 0% of sons and daughters will be affected
- Examples:
 - Neuro: LHON, MERRF, MELAS
 - Endo: none offered

Canine Companions for Independence



Glen Gregos and Miss Bo
www.cci.org

The dogs trained for Canine Companions for Independence are bred as service dogs. From birth they are handled, then at 8 weeks, puppy volunteers keep them for 18 months.

When the young dog is returned to Canine Companions for Independence it must successfully pass 6-9 months of intensive training. Greg's black Lab knows 55 commands. She even pulls his wheelchair, carries bags, and picks up things he drops. She has become Greg's best friend. Greg has found that a service dog in public is an icebreaker with others. Thanks to the ADA, a service dog is allowed to go anywhere with it's master – planes, busses, restaurants, theaters, etc.

PS from the Conference

Contributed by Malin Dollinger

I would like to share with you my great joy and satisfaction with the SPF National Conference. I would like to express my thanks to all who attended, and shared with us their own personal situations, struggles, goals, and victories. We learned from each other as well as the speakers. Especially I wish to thank the Conference Committee. Linda Gentner [vice-chair] spent the last six months telling me which fork in the road to take, and in some cases created a fork that I should take, that I did not know existed. Craig Gentner was a masterful and effective master of ceremonies. Both of them were invaluable and essential to me. Jean Chambers, Jim Sheorn, and Will Bishop did yeoperson's duty taking care of many tasks, in particular the speaker introductions, the computer projection equipment, and the exhibitors, respectively. John Mitchell was "everywhere" taking all the important pictures. Mike Podanoffsky, in addition to his important achievements as our President, has been very important to me, assisting me in many ways, in particular making difficult or unfamiliar decisions. Almost all the speakers did me a great personal favor, and gave our organization a great contribution and gift by being there and sharing with us. Thanks to Angela Dixon, who created the wonderful program and the many clever and useful signs and posters, to the people who handled registration, Brenda, Melissa, Beth Anne and Annette, and to my two grandkids, Michelle and Gary Moton, who took care of "the desk" during the presentations. Many others contributed their time and expertise, and although I may not have mentioned them specifically, the meeting went "like clockwork" because of their help. The hotel staff and managers were especially devoted to keeping us happy and taking care of us.

SPF News

SPF Collaborates with National Medical Network

Contributed by Jim Campbell

Less than six months ago, SPF began looking for ways to establish a list of medical centers experienced in treating those with HSP or PLS. We approached NEALS, Northeast ALS consortium, to see if they were interested in helping us with the list. The NEALS leadership enthusiastically responded saying they were interested in extending their established network to upper motor neuron diseases beyond ALS and were interested in a broader collaboration with SPF. Subsequently the SPF representatives, Mike Podanoffsky, Mark Weber and Jim Campbell, have begun discussions on more extensive collaboration with NEALS. As we see it, the long term goals for SPF are as follows:

- Align SPF with an established medical network across North America for improved HSP and PLS regional accessibility to neurologists
- Provide SPF with a medical partner for:
 - Improving treatment of HSP and PLS disorders
 - Data collection leading to more focused research for our cures
 - Clinical trials for drugs aimed at detecting, arresting and eventually curing HSP and PLS

NEALS is an established network of medical clinics across North America which has a policy of strong collaboration among member institutions.

- Mission statement: To take advances in ALS research from the lab and translate them into clinical trials for patients as rapidly as possible.
- Founded in 1995, as an independent, non-profit consortium of clinical and scientific investigators who conduct research at their affiliated institutions.
- NEALS has grown to 92 member institutions in the United States, Canada, and Ireland. (NE 23: SE/Central 31: SW 23: NW 10: Canada 5: Overseas 2)

- NEALS current biomarker study includes identifying PLS and HSP disorders along with ALS.
- Biomarker patient sample collection set up to share with other consortium members.

As you can see their organization is not limited to Northeast or ALS and thus is an ideal partner for SPF.

The following SPF objectives for the collaboration with NEALS were endorsed at a recent SPF Board of Directors meeting:

1. Generate lists of hospitals and clinics that wish to treat those diagnosed with PLS or those diagnosed with HSP or both.
2. Promote physician awareness of PLS and HSP through communication with NEALS consortium network.
3. Encourage consortium members to submit proposals to the SPF Research Grant Program.
4. Encourage consortium members to publicize recommendations for treating PLS and HSP.
5. Encourage neurologists at consortium member institutions to make presentations at SPF local Connections (gatherings of SPF community members) and contribute articles to *Synapse* quarterly newsletter.
6. Investigate with NEALS the feasibility of developing regional centers-of-excellence for the treatment of PLS and HSP disorders.

The Board also authorized \$15,000 to cover NEALS working group member travel expenses for a first meeting of the working group comprised of physicians from 12 different states. We expect the first meeting to be held late September in Boston at MGH. To date we have been impressed with the enthusiasm and follow through of the NEALS leadership. We think this collaboration has great potential for providing SPF with a nationwide medical partner network.

Mike Weber's Ride Across America

In his own words

We started our 27-day journey in Costa Mesa, CA. The first stop was Newport Beach, where everyone dipped a wheel in the Pacific Ocean. Then we rode through California, Arizona (where it snowed!), and then New Mexico, Texas, and Oklahoma. The temperatures in these last three states were cool, and sometimes cold. We then crossed Arkansas, Mississippi, and Alabama, where the temperatures were warm, and finally ended in Georgia. Our last stop was the beach at Tybee Island, just east of Savannah, where we repeated the wheel-dipping ceremony. That evening, we enjoyed a sumptuous banquet. My brother Mark, one of the cofounders of the SPF, drove 14 hours from his home in Connecticut to be there.



Regarding the weather, we were very fortunate in that we were a few days behind the storms that caused flooding and some deaths in Mississippi, and we were a few days ahead of a serious storm in Arkansas.

Fifteen enthusiastic and well-prepared cyclists began and completed the trip. Two support vans accompanied us and provided food and mechanical assistance. We rode on interstate highways in California, and then mostly state highways and country roads the rest of the trip. The scenery was gorgeous – we rode through deserts, canyons, heavily forested regions, farmland, etc. In the southern states, we were constantly getting chased by dogs, which kept things exciting. Our daily mileage varied between 97 and 145 miles per day, for a daily average of 115 miles, making a total of 2884 miles. On a typical day, we arose at 5:30 a.m., ate breakfast, and then began cycling at 7 a.m. We would finish in the late afternoon, eat dinner, and be in bed by 8 p.m. It was a wonderful once-in-a-lifetime experience!



Outreach Task Force Aligned with Community Interests

Contributed by Jim Campbell

Launched in October, 2009, this SPF task force comprised of both Board Members and State Ambassadors is striving to improve communication within our SPF community and make the SPF product more valuable to our members. Recently all those with email addresses within the SPF community were asked to fill out an on-line survey indicating what they would like SPF to address.

While the response rate was only 20%, those that did respond gave us an inkling of what is important to them. The percentage of respondents identifying a particular is shown in bold. Below that is the corresponding action recommended by the task force.

Survey Respondents Interests / COTF Defined Action

- 81%** **Treatment options**
 - Updated portion of Website, exploring PLM
- 24%** **Finding a physician**
 - NEALS collaboration defining list of HSP and PLS institutions
- 38%** **Support groups**
 - not being addressed
- 11%** **Focus on caregivers**
 - not being addressed
- 82%** **Finding a cure**
 - Focus of existing SPF research grants
- 43%** **Meeting with others with the same condition**
 - Connections Resource Book, State Ambassador Guideline Book
- 32%** **Help with assistive devices**
 - Updated portion of Website
- 38%** **Building Awareness**
 - NEALS collaboration to increase physician awareness

The Task Force continues to believe that, in addition to the above actions, active State Ambassadors are a critical component of a more effective and relevant SPF organization. A list of the State Ambassadors can be accessed from the home page of the SPF website. If your state does not have one listed, consider talking to either of our National Coordinators if the assignment would appeal to you.

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Community Events

Peabody, Massachusetts

April 10, 2010

Submitted by Jim Campbell

A lovely garden function room at Brooksby Village, an assisted living facility in Peabody, MA, was the setting for the North East Spring Forward Connection. Thirty-three individuals from our SPF community attended, most of whom were from Massachusetts or New Hampshire. However, we did have a few folks from as far away as Maine and Long Island. After a social hour and buffet lunch, community member Liz Wroblewski led us in stretching exercises that can be done while seated. We then were treated to a very understandable presentation from ALS clinician and researcher, Dr. Nazem Atassi from Mass General Hospital.

Dr. Atassi explained how important it is to include PLS and HSP in the study of upper motor diseases. MGH is a member of the North East ALS consortium (NEALS) – a group of more than 90 hospitals across North America. These hospitals willingly share spinal fluid and blood samples with other research hospitals in the consortium. One donation of 15 ml of spinal fluid is divided into sample bottles and frozen for later use in up to 30 different studies. Dr. Atassi emphasized the need for samples from both controls and those with HSP in the current MGH ALS/HSP/PLS biomarker study. The response of the attendees was enthusiastic - 21 of them signed up to donate samples at MGH! In the first-ever on-line survey of Connection attendees, more than 80% of respondents thought this Connection was worthwhile and plan to attend the next one. Our thanks go to Joel Seidman for hosting this successful event.

Synapse Appeal

Please use the enclosed envelope to make a donation. Thanks to everyone who donated in 2010 to help offset the printing and distribution expenses.

Spring Fling

Berkeley Springs, West Virginia

May 7-8, 2010

Submitted by Sarah Witt

The second weekend of May was a milestone of great significance for Spring Fling, the brainchild of Ronnie Grove. This year's West Virginia Connection hit the decade mark and its 10th birthday was celebrated in style. Including patients, spouses, children, caregivers, and friends, nearly 50 people were in attendance. As always, Spring Fling provided plenty of time for socializing and sharing ideas. In addition, speech therapist Suzanne Mellott gave a brief but highly informative talk on augmentative communication devices. She discussed high-end devices, such as those from Dynavox, but also pointed out low-cost or free applications now available for laptop computers as well as for Apple Computer's iPod and iPad devices.

This year's landmark event was one of transition as well. Ronnie announced that this would be her last year as organizer and officially passed the torch to Jim and Barb Spencer of Frederick, MD. Jim has PLS. Though Ronnie choked up when telling those gathered of her decision, the essay she wrote for the Spring Fling program offered an eloquent close. Here are some of Ronnie's words: "Sometimes ten years seems like forever. Sometimes it seems like only yesterday. Spring Fling seems like yesterday...This has been a wonderful decade for me despite of or maybe because of PLS. I hope the good it has caused me has rubbed off on all of you. I can't imagine never having done this. You made it happen and I thank you with all my heart."



**Phoenix, Arizona
May 10, 2010**

Contributed by Wally Chase, Chair

Well, 100 Holes for Wally is over, and I was able to keep my emotions in check. It was a wonderful day. The weather, which stayed in the low 80s, was excellent, and the golfing was good too. My son had his first hole-in-one and my 6-year-old grandson made a birdie on the shortest par 3 hole. Checks are still coming in but, thanks to all, we raised more than \$20,000 for SPF. Considering we only had 32 golfers, that is outstanding.



(In the picture: left to right - Wally Chase, Bob Lord (sitting), Bill Doyle, Susan Doyle, Mandy McCormick)

My grandson and I rode backwards on the golf course to play 1 hole with each group. That way I was able to thank each person personally instead of trying to do it at the end. As much as I thanked people, they thanked me back and were so positive. Many others helped with donations but could not golf. I will be thanking people for quite some time. This event was the result of much hard work by Robert Lord, along with Bill and Susan Doyle. They are friends I have made through golfing at MVCC.

Upcoming Events

SPF Team Challenges - a.k.a. TeamWalks

In response to input from many in our community who can't walk, the Board is suggesting a new umbrella term for all local fund raising efforts—SPF Team Challenges. Please feel free to either keep using TeamWalk, or whatever other name you've used for your event and in your letters to prospective donors... or, if you want to take the plunge and organize a Team Challenge, go for it.

Learn to Windsurf Day June 26, 2010 Austin, Texas

Marlene Doolen, MDoolen512@aol.com



The Austin Windsurf Club has designated the SPF as its beneficiary for the Learn to Windsurf Day on June 26. This will be a one-day session with classes starting at 10 am and ending at 4 pm. There will be on-

land instruction, practice on land with a windsurf board simulator, and actual in-the-water windsurfing.

From Marlene: The Austin Windsurf Club has sponsored the SPF for many "Learn to Windsurf Days" over the years. I appreciate their continued support.

Pennsylvania TeamWalk September 11, 2010

Knoebel's Amusement Park, Elysburg, PA

*Sue Meholick, momofboysonly@yahoo.com,
814-653-8566*

We will have a Friday night dinner for those who can attend. We will also have a pavilion set up at Knoebels Amusement Park where we can gather and meet with others before the TeamWalk.

We will have a picnic lunch catered by the Park and then we will take a walk. For those of you who have scooters or wheelchairs, you may ride those. There are scooters available for rent at the Park as well. The Park provides us with an escort who will help anyone get a ride back to the pavilion if they get tired and don't want to go any further.

New England SPF Team Challenge September 11, 2010 (tentative)

Budweiser Grounds - Merrimack, NH

John Swain, john.swain@nemoves.com 978-387-2950

We have tentatively scheduled our event on Saturday September 11 at the Budweiser Brewery grounds in Merrimack, NH. The focus of our event will be on visiting with friends both new and old, as well as the Clydesdale horse stables which should be a treat for entire families. Please plan to come, rain or shine, as we'll have a large tent.

North Carolina Connection and the Magnificent Mile

September 18-19, 2010

Hillsborough St, Raleigh, NC

Sarah Witt, srwitt@yahoo.com

We will have an afternoon social hour and dinner on Saturday night to which area researchers and therapists will also be invited. The 5th Annual Magnificent Mile will be held on Sunday afternoon. Details and registration information is available at www.MagMileRace.com. If you are traveling to Raleigh for the event, discounted rooms (\$79/night) are available for Friday and Saturday nights at the Clarion Hotel. Call 919-832-0501 and ask for a room in the Magnificent Mile block.

a greater number of people. Our world is calling out to us – it is in pain and the resulting wounds are deep and will take time and considerable energy to heal.

Your Action Plan: Strategies for Managing Your Illness

By Gloria Troyer

SET GOALS Write down your goals. Choose one and ask: What do I want to achieve? What are alternative ways that I might accomplish my goal?

CREATE AN ACTION PLAN For each goal, decide on a short-term plan. You need to decide how much you are going to do, when you are going to do it, and how many times

PROBLEM SOLVING If you're having trouble achieving a goal, don't give up immediately – explore what you can do, and ask others for advice. Try these steps: - Identify the problem. - List ideas that may resolve the issue.

- Select an idea.
- Try the idea.
- Assess the results.
- If one idea doesn't work, try another
- Utilize other resources - call on friends, family, health-care professionals or organizations.

REWARD YOURSELF Reward yourself for reaching your goals – you deserve it! It could be as simple as lighting an aromatherapy candle and listening to your favorite music. Enjoy a cup of tea, have a bubble bath or go out for coffee with friends. Give yourself a pat on the back.

BE PERSISTENT You will not always achieve your goals right away. Acknowledge the setbacks and move on – this is part of self-managing a chronic condition.

Let's Play! The Importance of Having Fun

By Nancy Chamberlayne

My friends and I acknowledged our grief for the loss of how we used to play, but we didn't want to dwell on the sadness. Accepting change is not easy. Our attitude is simply to get on with life.

The majority of us have learned to play differently with creativity. We've re-created how we recreate. I

can no longer jog, but I realized I can jog in the water by wearing a buoyancy belt. Others exercised in their wheelchairs or scooters. It is not the same, but it is similar.

The computer is an excellent toy. Games such as bridge, reading, doing research and answering email are all forms of play. Talking books, movies, TV and music provide entertainment. A member who used to dance now choreographs routines in her head as she listens to music. Another challenges his intellect with the game of chess.

Learning to adapt is a key component for continuing to play. Many of us use a scooter or wheelchair to get around. Whether the mobility challenge is permanent or intermittent, the mobility aids provide us with the ability to play. In my case, to experience park trails again, I scooter-hike.

Pets bring us joy. Going for a doggie scooter walk, giving a back scratch and throwing a ball are all considered play by both the pet and the owner. This also applies to service dogs when they are not working.

Humour is an important theme in people's lives. One facet is to poke fun at the disease and what it does to the body in the form of black humour. Because MS can cause poor balance and co-ordination, it has been suggested that we need to wear a T-shirt that says we are not drunk! Laughing makes people happy, which is all part of play.

We do what we can to get out there and play. I have learned that the physical activities of play may have changed, but the emotional rewards are the same.

Ask Questions to Raise Awareness:

By John Rae (1st Vice President, Alliance for Equality of Blind Canadians)

You can help make cultural institutions in your community more inclusive by raising awareness of accessibility and expressing your needs. Below are some questions that you can present to the manager of your local art gallery or museum.

- Do your tour guides and lecturers provide enough detail during their talks for people who are blind or have low vision, and cannot see artifacts, art or slides?
- Are people with disabilities welcome in art and sculpture classes?

- Are there text descriptions of photos, and are these descriptions in plain language?
- Do you offer audio guides at exhibitions?
- Are the walkways in your exhibits wide enough to accommodate a wheelchair or scooter?
- Are you investigating the introduction of technology that may enable information to be transmitted directly to mobile phones?
- Do you provide sign language interpreters, and are accessibility features mentioned when you publicize events?
- Do your movies or films include descriptive narration?
- Is your website accessible to people with disabilities e.g., can the font be enlarged?
- Do you have a TTY service for people who are deaf or hard of hearing?

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Total Subscription Cost: \$30

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Total Subscription Cost: \$57



MEMORIAL GARDEN 2010 DONATIONS

By Diana Montague-Jackson

Hi friends. By the time you receive this issue of *Synapse*, the 2010 Forever Friends Memorial Garden should be lovely. Sharon and I generally cover much of the cost. Last year your generous donations allowed us to have a really nice garden.

This year, my youngest daughter is getting married and I haven't been able to save as much for the garden. We grow as many annuals as we can here at home and we are slowly switching to as many perennials as possible. But there is still the cost of buying annuals, soil, etc. So we will have about a \$500.00 shortfall this year.

For any of you who would like to make a donation ... large or small... any amount is fine, I have set up the following plan so you don't have to worry about

Canadian money orders and I don't have to cash a number of US checks. Dolores has kindly offered to be the recipient of American donations. She will then forward all of them on to me in one Canadian Money Order. Here is the procedure if you would like to make a donation to our memorial garden:

If you live in the USA: please make your check or US postal order out to:

Dolores Carron
139 Forest Drive
Newington, CT 06111-3119

If you live in CANADA, AUSTRALIA, THE U.K or another country, please make your cheque or CANADIAN postal order out to:

Diana Montague-Jackson
3730 Spruce Drive
Red Deer, Alberta
Canada T4N 3N9

Please make a NOTATION on the bottom of your check "MEMORIAL GARDEN DONATION." That should serve as a receipt.

For those of you not familiar with the Forever Friends Memorial Garden, it began in 2008 as a small project to remember friends and loved ones who had a Motor neuron Disease...PLS, HSP, ALS, etc. and have passed away. People send photos and sometimes soil from all over the world, especially from the USA. We planted a bush or a small flower bed and we put the photos, sealed on a wooden plaque beside the flowers and bushes. Last year, through peoples' generosity, the Garden bloomed into a huge 1/2 acre memorial garden.

PLS Friends (If you are able to access the 'photos' section on the PLS Friends website here you can go in and view photos of the garden.)

Thanks friends. Come mid July I will have some awesome photos, including the new photo-plaques, to send to you! Hugs to all! And THANK YOU, Dolores, for your help!



EXERCISE and YOU

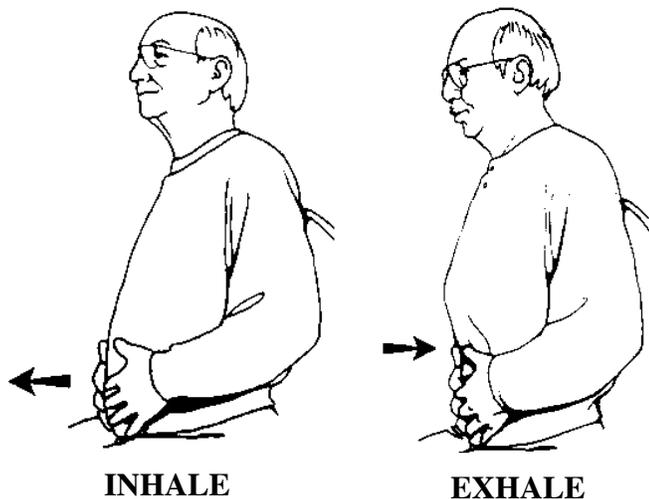
BREATHE RIGHT!

Contributed by Liz Wroblewski, MPT

Efficient optimal breathing during exercise assures getting oxygen to muscles and is one of the first steps in activating the primary core muscle, the transverse abdominis. This breathing pattern is called diaphragmatic breathing, deep breathing or belly breathing. It also promotes relaxation throughout the body and mobilizes the spine.

Take a deep breath in through the nose as if smelling a rose while lips are closed. Then slowly exhale through pursed lips as if blowing out a candle. Make that exhalation twice as long as the inhalation. Practice this as a primary exercise lying down or seated comfortably in a chair. Place one hand on the chest and the other on the belly button area. On the inhalation the belly hand should actually “rise” first followed by the upper chest to a lesser degree. Think of pouring water into a glass. The water hits the bottom first and then fills the glass. On the slow exhalation “pull” your belly button to the back of your spine. This “wakes up” the transverse abdominis muscle which is a primary core abdominal muscle.

Your real challenge is to then integrate this breathing pattern into your exercises and use it when standing and walking. Generally you want to exhale when you make the effort in exercise. Inhale as you return to the start position. Practice this throughout the day.



A MULTICENTER STUDY FOR THE VALIDATION OF ALS BIOMARKERS (BIO_ALS 01)

The Northeast ALS (NEALS) Consortium is seeking individuals to participate in a specimen collection study.

The purpose of the research study is to collect blood and cerebrospinal fluid (CSF) samples from people with all forms of motor neuron disorders such as amyotrophic lateral sclerosis (ALS), hereditary spastic paraparesis (HSP), primary lateral sclerosis (PLS), pure lower motor neuron (LMN) syndromes, multiple sclerosis (MS), other neurodegenerative diseases as well as people with no motor neuron disorders.

Through comparison of these samples, the researchers hope to learn more about the underlying cause of these motor neuron disorders, as well as find unique biological markers, which could be used to develop new therapies.

If interested, please contact one of the coordinators listed at the research sites below:

AZ Phoenix Neurological Associates, Ltd.

Nicole Hank - 602 258 2432

CA University of California, Irvine

Veronica Martin - 714 456 7760

FL Mayo Clinic Jacksonville

Amelia Piazza Johnston -904 953 9498

Pamela DeSaro - 904 953 7720

University of Miami

Donald Koggan - 305 243 7424

GA Emory University

Meraida Polak-404 778 3807

IL University of Chicago

Ismael Gutierrez - 773 834 4654

MD Johns Hopkins University

Betsy Mosmiller - 410 502 0495

MA Lahey Clinic

Stephanie Scala - 781 744 2950

Massachusetts General Hospital

Robert Lawson - 617 726 0563

MI Saint Mary's Healthcare

Brian Berryhill - 616 685 5435

MN Hennepin County Medical Center

Cindy Rohde - 612 341 7923

MO St Louis University

Susan Eller - 314 977 4867

Washington University

Julaine Florence - 314 362 6983

NH Dartmouth Hitchcock Medical Center

Dr. Brent Harris - 603 650 0889

NJ UMDNJ Robert Wood Johnson

Barbara Belsh - 732 235 7234

NY Beth Israel Medical Center (NY), New York

Theresa Imperato - 516 946 5467

SUNY Upstate Medical University

Katie Markis - 315 464 4998

Upstate Clinical Research

Suzanne Alterman - 518 533 1546

North Carolina's Medical Center

Jaime Shue - 704 446 6253

Duke University Medical Center

Karen Grace - 919 668 2844

Wake Forest University

Mozhdeh Marandi - 336 713 8577

Ohio State Research Foundation

Sharon Chelnick - 614 293 4973

OR Providence ALS Clinic

Britt Ash - 503 963 3128

Oregon Health & Science University

Diana Dimitrova - 503 494 7269

PA Drexel University

Christine Barr - 215 762 5186

Pennsylvania State University

Helen (Beth) Stephens - 717 531 0003 x 283395

University of Pittsburgh

Danielle Rowlands - 412 648 9053

TX Methodist Neurological Institute

Sharon Halton - 713 441 3420

Luis Lay, Jr. - 713 441 3057

UT University of Utah

Narneice Craven - 801 585 7876

Canada Montreal Neurological Institute

Jo WenWang - 514 398 1779

An Octogenarian's Advice

Contributed by Jim Langedijk, one of our SPF Ambassadors in Canada

I am one of the fortunate ones. I got PLS or MS which one of the two, it does not matter. I am now celebrating my 82 year of life on this wonderful planet. I live in Canada the best country in the world. Yes I have pain. Yes I cannot walk anymore. Yes it's difficult to write. But I am still here, and last year I was elected president of our 142 unit Condo Corporation, and enjoying every minute of it. I don't dwell on whatever I got, but my glass is always half full. After a sitting down nice hot shower I feel great. Stop seeing your glass half empty. Be glad you don't have dementia. I think losing your memories is the worst thing a person can get. And I have many. My wife and I celebrated our 60th wedding anniversary, living with a wonderful woman. Keep living, it's worthwhile.

Quips of One Person with HSP from a Multi-Generational Approach

Contributed by Geoff Kettling

My Name is Geoff and I reside in Northern Nevada. I was diagnosed at 24 mos. We've got a multi-generational history of HSP. Grandpa was nicknamed Shuffles because of his gait pattern. Mom has the condition and is 77. I have 2 sisters with HSP, a nephew with HSP, and several cousins. My daughter is 14 and has HSP. My daughter uses AFOs at night and a wheelchair for really long distances (e.g. Disney World). Thanks to my folks I am an Eagle Scout, a former member of Order of the Arrow. Thanks to my High School weight lifting instructor, I joined the swim team. Thanks to innovative people I earned a black – belt using modified forms/karate. Thanks to community support I have a hand-cycle and a racing wheelchair. *(Continued next page)*

Support SPF with One Step a Month

Consider making a monthly donation to help SPF move a step closer to a cure. Our One Step a Month Program is a win-win! Recurring gifts allow us to plan ahead with confidence, making sure we take the best steps towards finding the cures for HSP and PLS. Plus, recurring donations allow you to give in a convenient, safe and secure way. Go to <http://www.spf-foundation.org/donate.htm>

Quips of One Person with HSP from a Multi-Generational Approach

Continued from previous page

4 generations of Documented HSP and likely a 5th.

Here's 20 cents worth of lessons I've learned.

FOR THOSE WITH KIDS

- Walking funny, different is just a characteristic. Without mine, I have no idea where I would be.
- Asking what if does no good
- Asking the divine why? Is worth asking, but the answer is individualistic and answer comes in hindsight.
- Being different requires one to think outside of the box to get something done, which is a valuable skill.
- Encourage all youth to Do what they each love and love what they do.
- If kids use AFOs, call them Magic Legs – something positive.
- Keep kids active and in programs that work muscles – yoga, pilates, gymnastics, horse back riding, martial arts, fencing. Yes, there's wheelchair or sitting fencing.
- Let kids be kids. “Why do we fall? So we learn to pick ourselves up” Alfred, Butler to Bruce Wayne
- Be an Advocate, but get a Social Worker, get help.

There are two ways of meeting difficulties: you alter the difficulties, or you alter yourself to meet them.

~ Phyllis Battome ~

SYNAPSE APPEAL

Synapse costs lots of money to print and mail, and we need your help to keep it going for another year.

Please use the enclosed response envelope to make a donation. Every little bit helps.

FOR ADULTS

- Do what you love and love what you do. Find your passion.
- If you like cross-country skiing check out a sit ski
- If you like water skiing, check out body boarding
- If you like horseback riding, find an Adaptive Riding Center
- See if your city has any adaptive programs. Are City programs fully accessible to persons with disabilities – any and all? If not, get involved and make it happen.
- If you like bike riding check out handcycle or recumbent bikes.
- Go swimming. Go sailing.
- Take a culinary class.
- Take a hobby and turn it into a small income if you so desire (but not to the point of burnout)
- Network and connect with community, friends, and acquaintances.

FOR CAREGIVERS

(My mom who has HSP is my dad's caregiver as he has dementia.)

- Find a way to take a break. If the person you are caring for needs 24 hour care/observation, get assistance from family, friends, neighbors, fellow congregants of your place of worship.
- Get a Social Worker
- Take care of yourself, do things you enjoy doing.
- Rest, get good sleep (*quality not only quantity*)
- Network and connect with community friends and acquaintances.

We have aches, pains, surgeries, etc, but we are still living and can thrive instead of merely surviving. Upon waking, I have a pulse, a breath, and my feet are this side of the dirt--- it's a good start to the day.

Caregiving/Helping

Is it Caregiving or only Helping?

Jim Campbell

That was one of the questions discussed by the 20 or so people that attended the “Caregiving” breakout session at the national conference. The answer depended to a large extent on the progression of the disorder either PLS or HSP. While both disorders tend to include mobility impairment, PLS is often also associated with bulbar (*speech and swallowing*) issues and hand dexterity issues as well. Therefore, caregiving is more likely to be required.

Even though some in the room thought the subject was not applicable to their situation, I brought up the topics of a caregiver’s maxing out (*temporarily being overloaded with demands*) and the more serious condition of caregiver burn out (*numbness to patient’s needs and overall depression on the part of the caregiver*). In both cases a respite or break in terms of hours on a weekly basis, or for multiple days in a row on an annual basis is a much needed therapy. Acknowledging the reality of maxing out is a healthy thing and, over the long haul, minimizes the chance of burnout at least according to one professional therapist.

The group talked about the importance of regular daily communication between the patient and primary caregiver. In response to my question to the group of where to turn for outside help, especially when the patient or helper perceives a stigma of going to a social worker or therapist, one of the participants suggested seeing a “life coach.” This is a relatively new source of professional counseling increasingly popular with men. Life Coaching is a good alternative to those who struggle with the stigma of psychotherapy. Coaching is a very direct and effective approach to helping both the afflicted and affected. The life coach provides concrete tools to help with relationships, managing negative feelings, and decreasing stress. Coaching differs from psychotherapy in that there is a cooperative partnership between the professional and the client and a very specific plan to work toward the stated goals of the client. It is a growing profession and it can be accessed online, by phone or in person. (*The Life Coaching explanation has been contributed by Louie Hallie, CSW, who participated in this session.*)

Before I knew it the 45 minute session was over. According to several attendees the session offered some new perspectives for both “caregiving” and “helping.”



2011 SPF CONFERENCE

HOUSTON, TX

Let your hopes and dreams for a cure take-off with us. We’ll have a blast!

Look for dates and details in the Fall Synapse, and coming soon at the website!



7700 Leesburg Pike, Ste 123
Falls Church, VA 22043



The tables are all set



*Emily Brown, the
Social Director*



Corey's Talk



*Chocolate plaque awarded to
Kris Brocchini, Brocchini
Farms, the 2010 National
Conference Decorations*



MC, Craig Gentner



Chair Yoga Participation



SPF President, Mike Podanoffsky