Synapse

Volume 12, Issue 1 Winter, 2009

Newsletter of the Spastic Paraplegia Foundation

SAVE THE DATE!

2009 National SPF Conference

June 12 – 14, 2009

Plans are under way for the 2009 National Conference which will be held in St. Louis, MO at the Renaissance St. Louis Airport Hotel. www.marriott.com/hotels/travel/stlsa-renaissance-st-louis-hotel-airport/. 314-429-1100

Here's a snapshot of what you might expect to see at our 2009 Annual Conference;

- Our own Medical Advisor, Dr. John Fink from the University of Michigan will share the latest information about groundbreaking discoveries, the most effective treatments and the best, targeted therapies and host a series of question and answer sessions for both Hereditary Spastic Paraplegia and Primary Lateral Sclerosis.
- See the latest in equipment, live demonstrations, and services available to the HSP and PLS communities.
- Meet and greet the board of directors from the Spastic Paraplegia Foundation and learn what initiatives are being focused on for the future.
- Participate in a series of informational roundtables and make your voice heard as it relates to the entire SP community.
- Learn how you can become a part of our ***growing*** nationwide TeamWalk effort.

It's a new and improved agenda including more interactive breakout sessions with better, more relatable, information than ever before!

Stay tuned for more updates at www.sp-foundation.org.

PLS Awareness Month February 2009

Sarah Witt, PLS Awareness Month Committee

Your PLS Awareness Month Committee and Tiber Creek Associates are currently planning a major media event for February 2 in Washington, DC. Congressman Joe Baca of California, who sponsored the PLS resolution, will headline. He will be joined by members of the medical profession and representatives of SPF. The final details are still being worked out but we are extremely close

In addition, we will be pushing hard to make PLS Awareness Month permanent. The current legislation applies only to 2009. Come February, we will need to make our voices heard in the House and Senate to make this a recurring event. Finally, we hope to use this opportunity to raise money from the private sector as well as garner federal funds for research into upper motor neuron disorders.

Repositioning: My PLS Story

By Hardy Brown

Ed. Note: Hardy Brown was the inspiration for Rep. Baca proposing PLS Awareness Week.

I first noticed a limp in my left leg back in the summer of 1999 and was diagnosed with ALS in October 2002. Then in 2007 I was given the diagnosis of a second opinion of PLS from UCLA. I have held on to my faith which has sustained me and my family which is a story in itself.

(Continued next page)

Repositioning: My PLS Story - *Continued*

While I have moved from a walking cane, to a walker and now a power chair I still write a weekly column for the family newspaper (www.blackvoicenews.com), head up a statewide organization and am treasurer to another. I shared a story recently with the community that this condition has forced me to reset my priorities. I said in this satellite age we have our signals interrupted by storms sometimes knocking the picture from our televisions. When that happens the satellite has to reposition its self for the picture to return. The thing we must remember is the television, the satellite and the program still exist, so we just wait until the repositioning has taken place and the picture returns. Well with the notification of ALS then PLS I did not give up. I have repositioned my way of living while waiting for a full healing from God. As a person I like to go, but since I have physical limitations I now send my wife and children. I love to talk but since I have speech limitations, I get my wife and children to talk instead, especially since they love to talk.

I have trouble swallowing food so I make sure I concentrate while eating. I eat before I go out because any distraction can lead to food getting lodged in my throat. I also notice that being in crowds while in the power chair makes it harder to breath. I also had to finally move downstairs this year so it would be easier on my wife.

My word to those who have PLS is, "Don't give up because you still have much to offer." My faith teaches me that God can remove any thorn in a person's side or He can leave it in while giving you the grace and strength to endure the thorn. So far I still have the thorn (PLS) but I have not let it stop me from moving forward with the work I have to do. It has allowed my family, friends and community to move on with living while getting inspiration from the situation. It is allowing others to reposition their thinking in facing their situation.

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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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Published quarterly for the HSP/PLS community
Available online at www.sp-foundation.org

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A Message from the President

Jim Sheorn
President

Fundraising in 2008

We have just finished a successful year for the Spastic Paraplegia Foundation. As of our most recent financial statement, we have raised over $360,000. That is unfortunately down a little from the prior year. Hopefully this year will have a better financial outlook. The Board will be meeting soon to decide how much money will be allocated for research. The amount allocated will put us over $2 million that the SP Foundation has spent for research since we started. Once the total amount raised has been confirmed, we will compile the 2008 Annual Report that will list specifically what each event raised. It will be mailed in early Spring.

Professional Help is on Board

TIBER CREEK ASSOCIATES *of capitol hill, inc.*

We have hired a consulting company, Tiber Creek Associates of Capitol Hill, to assist in our organizational and fund raising efforts. Please feel free to check out their web-site at www.tiberdc.com. Their first initiative is to make PLS Awareness Month a great success and get support to have every February associated with PLS Awareness. They are planning a meeting in Washington, DC with all of the Congressmen the first week of February. We hope to have at least one of our PLS researchers attend as well as some Board Members to discuss the need for government funding. Currently there are so few affected, the government has not granted any research funds. Tiber Creek Associates will also be working on the 2009 National Conference, TeamWalks and Board Development.

New Board Member

We would like to welcome our newest SP Foundation Board Member. Corey Braastad, PhD is a scientist for Athena Diagnostics. His main focus is to design new clinical diagnostic tests for HSP. We are very excited to have him as a Board Member and to build a better relationship with Athena. If you are interested in serving on the Board of Directors or a committee, please let us know by logging onto www.sp-foundation.org and clicking How to Help.

Donation Opportunity

In the center of your newsletter is a response envelope. *Synapse* costs lots of money to produce and mail, and we need your help to keep it going for another year. If you would like to help with the operational expenses associated with *Synapse*, please use the enclosed response envelope to make a donation. Every little bit helps. We greatly appreciate the support received.

Once again, we would like to thank Jim & Thurza Campbell as well as all of the contributors for another fantastic year of *Synapse*. We have received many compliments on what a great job they do.

The SP Foundation Board of Directors would like to wish you a safe and Happy New Year. We hope that you will join us in St. Louis.

Jim Sheorn,
SPF President

SUPPORT SPF WHILE YOU SEARCH

Raise money by using GoodSearch as your default **search engine** which will donate about a **penny per search** to SPF. You use it just as you would any search engine, and it's powered by Yahoo!, so you get great results. Just go to http://www.goodsearch.com/ and enter Spastic Paraplegia Foundation as the charity that you want to support.

SUPPORT SPF WHILE YOU SHOP

Shop online utilizing the SPF Shopping Mall at

http://www.sp-foundation.org/shopping.htm

GoodShop, Buy For Charity and The ClubShop Mall feature a multitude of popular stores for all your needs. The percentage donated varies by store and appears on the website. There is no additional cost and you can still take advantage of sales and coupons!

2008 TeamWalks And Connections

Pennsylvania Connection and TeamWalk
Knoebels Amusement Resort, Elysburg, PA

Submitted by Beth Anne Shultz

The Pennsylvania Connection and TeamWalk, which was held on September 19-20, was a fun time for all. Several of us dined at The Pine Barn Inn in Danville on Friday evening. Saturday morning, we all met at Knoebels Amusement Resort for lunch.

Afterwards, we walked through the park and had several group photos taken. The rest of the afternoon and evening were spent catching up with old friends and meeting new ones. A few of us even braved the amusement park and enjoyed the rides, music and food.

A special thanks to Sue Meholick and Helen Kienlen for taking the time and energy to organize such an important event. Thanks also go to the walkers and to those who opened their hearts and wallets for the SPF. We have raised $24,000 so far and money is still trickling in.

Northern California Connection and TeamWalk
Pleasanton, CA

Submitted by Linda Gentner

On the evening of Friday, October 3rd, 17 people with HSP or PLS and their spouses gathered for a nice dinner and social time to kick-off the Northern California Connection. After dinner, we adjourned for dessert and coffee and held our private "Birds of a Feather" discussion. We decided that although we are "birds of a feather", we all fly differently. People shared their challenges and successes.

Saturday morning, more than 100 family and friends of PLS/HSPers gathered to make our 5th California TeamWalk another success. We made new friends and reconnected with old ones. After our registration and "meet and greet", we headed out under perfect skies and leisurely walked and rolled through downtown Pleasanton. Many enjoyed the local Farmer's Market. A family that deserves special mention is the family of Adele Pence. Unbeknownst to Adele, her daughter and son sent a flyer to many of their family and friends and the family enjoyed a reunion at the TeamWalk. Many thanks go to our lead sponsor Brocchini Farms, Inc., as well as other generous donors of raffle items. New helpers made the setting up and taking down much easier. Ken Auer, Ryan Banks, Kay Brady, Kris Brocchini, Jean Chambers, Diane Dobrowolski, Malin Dollinger, Linda Gentner, Mary Mailloux, Jane Mitchell, Adele Pence, Cheryl Schmidt and Jennifer Thomson were the PLS/HSPers who came from as far as Vancouver and southern California. Our entire weekend should add approximately $30,000 toward our research fund.

Idaho Connection
Boise, ID

Submitted by Patricia Bernhard

The Idaho Connection was held on October 4, 2008 at the Idaho Elks Rehabilitation Hospital in Boise. There were five people with either HSP or PLS and four people who were either caregivers or friends or family – nine in all. This year's crowd was the largest we've ever had.

After lunch, Dr. Mark Harris, a neurologist at the hospital, gave an excellent presentation that covered all facets of HSP and PLS. He also answered many question. After Dr. Harris spoke, Stephanie Nyman, a nurse and representative from Medtronic, a medical equipment manufacturer, spoke about the benefits of the implanted Baclofen pump. We look forward to this lunch each year and to seeing the people who are fast becoming friends.

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.sp-foundation.org/donate.htm

NE Ohio Connection
Mentor, OH

Submitted by Maryann Mayer

Belinda Poole and her sons at NE Ohio Connection

A casual lunch connection was held in northeast Ohio on Oct. 11, 2008, at Panera Bread in Mentor. Thirteen people attended: Gordon and Mary Jane Westerfield, as well as their son and daughter-in-law, who drove about an hour from Cuyahoga Falls to join us; Sandy Slater (whose mother lives in Dayton and has PLS) came from Bedford; JoAnn Potter (HSP) and her daughter; Kathy Wilde and her daughter Anna (HSP); Belinda Poole (PLS) and her two young sons; and Maryann Mayer (HSP). It was an especially exhilarating experience for the three people who had never met anyone else experiencing the same challenges.

During the course of our time together two additional attendees joined us via cell phone. Sandy called her mom and dad in Dayton, and we were able to say hello and add some joy to their day. There was so much spontaneity and sharing of experiences, it was hard to believe that three hours had already passed when we said our goodbyes. We all agreed that we should meet again and would look forward to others joining us. We are open to suggestions for a meeting place that would bring more of us together. Email Maryann Mayer at mayersms@oh.rr.com with any suggestions.

Cookout Connection – Tampa, Florida

Submitted by Bruce Maser

On Saturday, October 14, fourteen people gathered for a delightful Cookout Connection afternoon around the pool at Bruce Maser's home on Davis Islands (Tampa). The "oldies" (Bruce, Kathi and Ed, Karen and Jim, Flora and Doug, and Callie and Rudy) enjoyed re-connecting as well as welcoming "newbies" like Myrna (PLS) from Tampa who brought her two daughters and Steve (PLS), who drove all the way from Naples to participate.

Myrna on a trike at the Tampa Connection

Individuals shared stories, treatments and concerns regarding managing life with PLS or HSP. Bruce grilled hamburgers and hotdogs which everyone enjoyed along with the assortment of side dishes and desserts that people brought. Bruce also demonstrated his recumbent trike bike, which he rides several times a week for exercise. Several people took rides. It was the first time Myrna and Steve had met other people with PLS and they, along with everyone else, look forward to future Florida Connections.

Tennessee TeamWalk Connection
Nashville, TN

Submitted by Jim Sheorn

Ten people joined us for a TeamWalk Connection meeting on Saturday, November 1st. One gentleman who has HSP and his wife attended for the first time. It was also the first time they had met others with HSP. We spent about two and a half hours sharing information. Eddie Adcock and Terry Merritt, who have attended many Nashville Connections meetings over the years, were a big help in sharing helpful ideas. Not all money has been turned in yet, but we hope that the Nashville Connection group will raise close to $10,000. All participants left with a goody bag and a TeamWalk t-shirt.

RGM Golf Classic – Queenstown Harbor, MD

The 6th Annual Richard G. Milbourne Memorial Golf Classic was held on Saturday, November 8, at the Queenstown Harbor Golf Course on Maryland's Eastern Shore. Known as the RGM fore SPF Golf Classic, it was another huge success both in terms of enjoyment and funds raised for the Spastic Paraplegia Foundation. Mr. Milbourne was an avid golfer who played the game well into his 90s and whose three children have HSP.

Set up and Ready for the Nov. 8 RGM Classic

The day started with heavy downpours, but the skies cleared just as it was time to tee off. The rest of the day was warm and rain free. Golfers were treated to coffee and donuts at registration, lunch on the course, and a full dinner. The day ended with live and silent auctions. The committee for this event consists of Annette Lockwood and the Easterling and Heinicke families, who are descendents of the late Richard G. Milbourne. This golf tournament has raised $100,000 for the Foundation over the past six years.

Salt Lake Valley Connection – Salt Lake Valley, UT

Submitted by Linda Gentner

Salt Lake Curt & Katie Brown, Jonnie Larson (from Idaho), Mrs. Larson (from Spoke, WA), Linda & Craig Gentner (from CA), Geneva Miera, Connie & Roy Duran

A snowy afternoon provided the perfect backdrop for the Salt Lake Valley Luncheon Connection on December 13th. We had a lively communication session with newcomers asking many questions about HSP and the SPF. Connie Duran and Geneva Miera fielded their HSP questions, and Linda Gentner talked about the SPF, its web site and the 2009 National Conference. She also did a short presentation on 2008 event and the 2008 National Conference. Linda's husband Craig provided more details about previous conferences. By the end of lunch, Connie and the Larson family started making plans for holding a TeamWalk or some other kind of a fund raiser next summer in the Salt Lake City Area.

Upcoming Events

Spring Fling
May 1-2, 2009
Berkeley Springs, WV
Ronnie Grove: frogrove@verizon.net

Details will be released closer to the date.

A special note from Ronnie: Make a special mark on your calendar for Spring Fling 2010. This will be Spring Fling number 10 and I hope to make it really special by having a "Homecoming Event" or a Ten Year Reunion. I hope to entice all of those who have attended over the years plus those who have wanted to attend. This should be a very special Connection so I am giving you plenty of time to plan. I may even recruit a few of you if you aren't on the volunteer list, so be prepared.

2009 National Conference
June 12-13, 2009
St. Louis, MO

Plans are under way for the 2009 National Conference which will be held in St. Louis, MO at the Renaissance St. Louis Airport Hotel. www.marriott.com/hotels/travel/stlsa-renaissance-st-louis-hotel-airport/ Hotel reservations can be made by calling 314-429-1100 and referencing the SP Foundation Meeting. We have a limited number of handicap accessible rooms available; please call Daphne Manning directly at 314-890-3151 for details.

It's a new and improved agenda including more interactive breakout sessions with better, more relatable, information than ever before!

Stay tuned for more updates at www.sp-foundation.org.

Movement For Living Free Teleconferences and Seminars Present Information on Spasticity Management

Medtronic's Movement for Living Seminars feature information about the Baclofen Pump. The seminars are designed to educate people about severe spasticity and ITB Therapy (Intrathecal Baclofen Therapy) as a treatment option. During the two-hour seminar, you will hear from an experienced physician who manages spasticity and a Movement for Living Ambassador who is receiving treatment for his or her spasticity. The 2009 teleconferences are listed below. Register: https://www.medtroniceducation.com/kma/www/itb_mfl/3.listing.html or call 1-888-743-8348

2009 Teleconferences -
7 pm Eastern, 6 pm Central,
5 pm Mountain, 4 pm Pacific

January 13	Focus on Spinal Cord Injury
February 10	All Indications
March 10	All Indications
April 14	Focus on Pediatrics
May 12	Focus on Stroke
June 9	All Indications
July 14	All Indications
August 11	Focus on MS
September 8	All Indications
October 13	Focus on Pediatrics
November 10	All Indications

Abilities Expo
April 17 - 19, 2009
New Jersey Convention and Expo Center
97 Sunfield Ave, Edison, NJ

May 29-31, 2009
Anaheim Convention Center, Anaheim, CA

Abilities Expo showcases the latest products and services to enhance the lives of people with disabilities.

Dr. Fink Answers your Questions

Burning the Muscles

Q. *Dr. Fink, I am a patient of yours, referred for consults by Dr. George Sachs in Rhode Island. He mentioned that working out at the gym is okay but said not to "burn" the muscles. Why could "burning" be a problem? Thanks, Michael F. Geisser*

A. I'm not sure exactly what "burning the muscles" means. If this means "don't over exert to the point of aches and pains", I agree completely. Muscle strains *(from over exercising a weak muscle)* may lead to increased muscle tightness. With exercise, it's always best to start slow, exercise every day, and slowly increase your exercise abilities.

Complicated HSP

Q. *My daughter has been diagnosed with complicated HSP and she seems to have everything everyone on the list has, but she also has been diagnosed with restricted lung disease. She has such spasticity on her limbs, but weakness in her trunk area with includes her lungs. Have you had patients with these complications and what if anything could be done? She has a baclofen pump and wants to increase the amount, but scared of the effects to the lungs. Any help? Owen Bridgeman*

A. Restrictive lung disease *(for example, from weakness or spasticity of muscles of respiration including the diaphragm and intercostal muscles)* has not been reported as a feature of HSP. Scoliosis, however, which may accompany HSP, may be associated with impaired lung volumes and contribute to restrictive lung symptoms.

Relationship of PLS and ALS

Q. *Is PLS a Variant of ALS?*
- Frank Everhart

A. Primary Lateral Sclerosis (PLS) and Amyotrophic Lateral Sclerosis (ALS) are both in the same category of neurologic disorders *("motor neuron disorders")* that also includes Hereditary Spastic Paraplegia (HSP).

Eric is Winning

Q. *What are your thoughts on the book, Eric is Winning? www.ericiswinning.com- F. Everhart*

A. I have not read this book though I have read summaries of it on the internet. This book, written by an individual who has ALS, describes opinions about the relationship between environmental toxins *(particularly heavy metals and insecticides)* and the cause of degenerative neurologic diseases *(including ALS)*. Although it is common sense to avoid these toxins, we must recognize that a role for these agents in the cause of ALS is unproven. Our laboratory is investigating a mechanism by which a certain gene variation may confer genetic vulnerability to certain environmental toxins and contribute to motor neuron disease. This could explain why among many individuals exposed to this toxin, only certain individuals develop degenerative neurologic disorders.

PLS and Agent Orange

Q. *What are your thoughts on PLS and Agent Orange? Frank Everhart*

A. There is no evidence that indicates a relationship between PLS and Agent Orange exposure. The vast majority of individuals with PLS have had no exposure to Agent Orange.

PLS to ALS

Q. *What determines change from PLS to ALS? John Benwell*

A. Marked worsening of weakness particularly associated with significant loss of muscle bulk *(atrophy)* or visible twitching within a muscle *(fasciculations)* are consistent with ALS. An electromyograph *(EMG)* is an important diagnostic test in this context.

Patient Data Base

Q. *My question is would it be possible to have everyone answer a questionnaire with specific questions about their condition, and put the answers together to find a common denominator? Julia Walker*

A. We too would like to build this research database. Like many projects, limited resources *(particularly funding)* have delayed this project.

Editor's note: PLSers are encouraged to join PatientsLikeMe which is gathering this valuable information. www.patientslikeme.com

Pain in HSP

Q. *I'm having trouble controlling my pain. It has worsened in the past year. What is actually causing the pain from HSP? My doctors don't seem interested in learning about HSP, and there doesn't seem to be much information explaining how HSP causes pain. My family belongs to spg8. Many members in my family have fallen into a deep depression and alienated themselves from everything. I don't want that to happen to me. Mary Edwards*

A. There are many sources of pain in HSP. These include pain from muscle stretching, aching from over-use of weak muscles, and joint pain (ankles, knees, hips, and back) from the long-term consequences of an abnormal stride. It is not possible to make generalizations about the specific nature or treatment of an individual's pain. Each person should be evaluated by a specialist (neurologist) who may need X-rays of the joints involved and consultation with other physicians (such as those in physical medicine). Chronic pain is taken seriously. There are medication and non-medication approaches (including exercise, stretching, massage, and acupuncture) that alone or in combination should provide benefit for the vast majority of individuals.

Headaches

Q. *I have headaches almost everyday that the doctor has told me are probably connected with my PLS. Is there anything I can do to stop them? What should I take? Ben Free*

A. Based on my knowledge and experience with PLS, I would not attribute headaches to PLS. I would discuss with your physician other causes of headache that are unrelated to PLS.

Hand and Foot Pain and Numbness

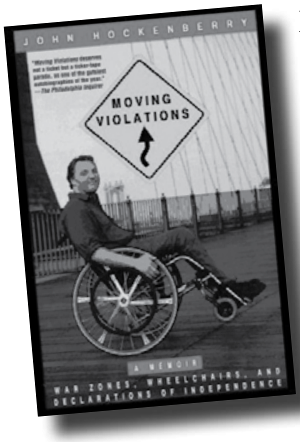
Q. *I have PLS and recently started having some symptoms that I haven't seen associated with PLS. I was hoping you could shed some light on what could be causing them. I have been experiencing excruciating pain when I touch the top of my feet a certain way along the big toe side into the toe as well as numbness. The same pain/numbness is also felt in hands along the thumb side into the fingers. Thanks.*

A. To my knowledge, these symptoms are not directly related to primary lateral sclerosis. The excruciating pain with even light touch, together with numbness in a specific region of the foot suggests the possibility that these symptoms are related to injury of a small nerve branch in the foot. I would consult your neurologist about this.

IT'S TOTALED

By Mike Ervin

Sometimes the wheelchair life is a demolition derby, and when you least expect it. The wheelchair is wiped out, but the occupant lives to tell about it. Sometimes trouble comes looking for you.



In his memoir, *Moving Violations*, gimp journalist John Hockenberry writes about the fine sunny day he was merrily rolling along the streets of downtown Chicago, and then he attempted to cross a hectic intersection. Just as he entered the street, a bus turned the corner and one of its front wheels was coming directly at him. Hockenberry managed to jump free of his wheelchair and with his gloved hands pull himself on the pavement out of the way of the oncoming wheel: "There were two sharp popping sounds as the bus tire crushed and destroyed the wheelchair. My thin high-pressured tires exploded as the bus came to a complete stop. The chair was directly under the right front tire of the bus. I was sitting on the pavement a few feet back. An ambulance arrived. Two paramedics ran over to me and asked if I had been hit by the bus. 'Yes,' I said. 'Can you walk?' they asked. 'No,' I said. 'Get the stretcher," one yelled. 'Can you feel your legs?' he asked. There didn't seem to be a way into this conversation. 'Look, I'm a paraplegic....' 'Not necessarily, son,' the paramedic said hopefully." Richard Lewis, one of my favorite wheelchair repair/sales guys is a sales manager for Permobil. But during his 20 years in the business, he's had to pronounce many chairs DOA, or, as he prefers to call them, FUBAR (F***ed Up Beyond All Repair). Lewis says in his experience airlines are by far the leading cause of FUBAR chairs, distantly followed by car and pedestrian accidents. And so the moral of the story is, if you don't want your chair totaled, don't ever fly. And don't go anywhere in a vehicle or attempt to cross the street, either. Better play it safe and never go anywhere at all. In fact, maybe you ought to just stay home and hide under the bed.

Handling HSP with Young Energy

Hello HSP'rs. I am Marina. I am 13 years old and I have HSP!! I live in Germany. When I was two years old, my mother received the diagnosis that I suffer from HSP. I would like to write my contribution and perhaps give you courage as well, to take your destiny into your own hands. Today, I have achieved a lot actually, if one considers that I am handicapped.

Since the diagnosis the health insurance company has financed my therapeutic riding. When I was three I began Kindergarten where I was one of several ill children. There all went well and I formed many friendships. The Kindergarten offered physiotherapy and I took part in it. When the therapist recognized that I still could not cycle, she taught me. My mother was very proud of me. And I was very pleased about it.

Three years later, I came into a small primary school. There were no other children who suffered from an illness. I nevertheless liked to go there to school. I had special support at that time and I also took part in the sport lessons like my classmates. Of course I was not quite as good as the other children.

When I was then 7 years old I began to dance. An appearance lay ahead. Everyone except me was allowed to go along with that. At that time I did not know the reason for that. I then learned from my girlfriend that I wasn't allowed to go along with that because I could not dance just like the other ones and I was always too slow. However I did not give up dancing and began to dance for a carnival group Little Maries. I often participated in shows. The audience was always enthusiastic about our group.

A friend of mine got a new unicycle. She let me try it. My mother wanted to teach me gently that I will not be able to do it. However, I told her that I will try it and she did not stop me. My mum bought one for me for Christmas. Twins moved into my neighborhood. These certainly are my best friends today. Sometimes I do not know what I would do without them.

When I then was in the fourth grade of school, I began secondary school in another town. I must go by train daily. In school many schoolfellows asked me for my remarkable hobbling. This was not pleasant at all but most did not mean it badly. However, others then laughed at me. But my friends supported me. This was painful. I limp worst in winter when it is cold and the muscles freeze. I then run very stiffly and those are very hard days!

I have begun Videoclipdance now. This is a style like Hip Hop. I can do this well. I have recently stopped Western Riding. I then began with track and field athletics. This is not easy at all for me. But I like to have new challenges. What I resolve to do, I try to do successfully Of course some things do not turn out all right. I have a great problem now. I recently was at the public health department because they wanted to talk to me and my mother. They recognized what I do and what I have done they wonder whether they shall finance my therapeutically riding anymore. It seemed so to me as if a HSP sufferer must be unable to do sports before the health insurance company pays for therapeutically riding. But one is certain. I will not be intimidated by them! I will continue doing further sports!

I can give all of you the advice to set your goals and strive to achieve these goals.

Kind greetings Marina *Marina.Kracht@gmx.de*

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> Tell me; I'll forget
> Show me; I'll remember
> Involve me; I'll understand
>
> ~anonymous~

Synapse Appeal

Please use the enclosed envelope to make a donation. Thanks to everyone who donated in 2008 to help offset the printing and distribution expenses.

Handi-Ramp Foundation

www.handirampfoundation.org

The Handi-Ramp Foundation was formed in 2006 out of a need to provide services for people with disabilities and their families. Insurance companies *(including Medicare and Medicaid)* will readily pay thousands of dollars for wheelchairs and scooters for their clients, but they will not pay for any home modifications. The result is that thousands of people become prisoners in their own homes while others can not visit family and friends.

Handi-Ramp (www.handiramp.com) and Thom Disch recognized this and created two initiatives to help address this issue.

The Home Access Program (www.homeaccessprogram.org) is a free consulting service that works with real estate agents to help families that have a member with a disability select the right home for their needs and then Handi-Ramp can provide the right modifications prior to the purchase so that these modifications can be included in the mortgage. The Handi-Ramp Foundation will provide funding for those people that can not afford to modify their homes to meet their individual needs.

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Reasons Why I'm Grateful to ALS

By Mike Bougher

Excerpted from MDA/ALS Newsmagazine, Nov-Dec 08.

I have been living with ALS for over 10 years. In that time we have become close friends. I no longer consider this disease to be a life-robbing, horrible thing, but a life-enhancing experience. I am grateful for the new perspectives I have been given. I now understand and enjoy my existence more than I thought possible, ALS or not.

One day it occurred to me I must surrender to that over which I had no control (my body's deterioration) and begin to build on that which still had great growth potential (my mind and spirituality). I could spiral downward into misery, or use my circumstances as a catalyst for mental and spiritual expansion. I had a choice!

I use California's Blind and Disabled Library. I gorge on books that satisfy my intellectual curiosities, and others that point me toward spiritual growth. I also meditate and pray, leading me to the abundant, joy filled life I enjoy today.

Insights for which I am grateful:

- I am grateful for the ability to truly understand and be a part of the interdependent nature of our universe.
- Because of the kinship I share with all other people, I cultivate compassion and not blame others for their circumstances.
- I have found a way to help ease the suffering of others through the sale of my art. I am grateful to have been shown a purpose for my life — a purpose that feels much more meaningful than my previous self-serving goals.
- I am grateful for the timeless inner peace I experience.
- I have a physical form that from the outside appears distorted and out of proportion. I can't speak audibly or smile, and I drool. I am grateful that I have been placed in circumstances to counteract my large ego.
- I am grateful for being shown the joy of living in the NOW.
- I am grateful that I have been made to understand that I am not my body or my thoughts. I am the silent space from which all is created.
- I am most grateful for my loving wife Jen who has enthusiastically agreed to take this journey with me, and has never faltered in her love or companionship as we travel this path together.

This is only my experience, and I am in no way trying to invalidate or belittle others who are suffering through more negative circumstances. My hope is that in some small way, even one person will begin to realize that suffering is caused by the content of our thoughts, not the situations in which we find ourselves.

A former project control systems designer and project manager for Telstar, Mike Bougher, 44, of Benicia, Calif., was a self-proclaimed workaholic before his ALS diagnosis. In recent years, assistive technology has enabled him to pursue a new passion, digital painting.

Mike's Recommended Reading

The following books are selections I consider key on my spiritual path. I have used my local library to acquire the audio versions, read by the author, wherever possible. The list is in the order that the teachings unfolded for me.

The Miracle of Mindfulness by Thich Nhat Hanh

Power of Now by Eckhart Tolle

Five Classic Meditations by Shinzen Young

The Art of Happiness: A Handbook for Living by the Dalai Lama and Howard C. Cutler

Being Peace by Thich Nhat Hanh

Change Your Thoughts — Change Your Life by Dr. Wayne W. Dyer

A New Earth by Eckhart Tolle

10 Secrets for Success and Inner Peace by Dr. Wayne W. Dyer

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Chair Yoga

www.getfitwhereyousit.com

People with disabilities, inflexibility, or who just cannot get on the floor can benefit from a daily practice of yoga on a chair in the comfort of your home or office. The chair replaces the yoga mat and becomes an extension of your body allowing you to take full advantage of yoga's amazing fitness and health potential. Even if you are in a wheelchair, you can receive the many benefits of chair yoga; the integration of body, mind, and spirit that keeps the yoga practitioner at the top of their game. In addition to the postures and movements, chair yoga classes are a more complete form of exercise than most because they incorporate proper breathing. Following the breathing techniques, not only during your chair yoga, but throughout your daily life, significantly enhances your health and well-being.

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EMERGENCY PREPAREDNESS FOR HANDICAPPED AND THEIR FAMILIES

Excerpted from:The ALS Association Massachusetts Chapter

Planning for Emergencies

__Send copies of all important documents (see below) to an out-of-town contact person.

__Have a pet care plan. Shelters do not always accept pets.

__Have an extra battery for a motorized wheelchair or scooter. A car battery also can be used with a wheelchair, but will not last as long as a wheelchair's deep cycle battery. Check with your vendor to know if you can charge your battery by either connecting jumper cables to a vehicle battery or connecting batteries to a converter that plugs into a vehicle's cigarette lighter. Caution: Charge only one battery at a time.

__Have a patch kit, can of seal-in-air product, inner tubes for a motorized wheelchair or scooter with inflatable tires.

__Have a lightweight manual wheelchair for backup.

__Have a converter for your communication device.

__Pack a low-tech communication board and preprinted key phrases in your disaster kit.

__Order an adaptor kit if you are using a BiPAP. Respironics has a kit that can be used with a car battery and a marine battery.

Important Family Documents Be sure to keep important records in a waterproof, portable container. These documents include:

__Copy of will, insurance policies, contracts, deeds, stocks and bonds;

__Copy of passports, Social Security cards, immunization records;

__Record of credit card accounts;

__Record of bank account numbers, names, and phone numbers;

__Inventory of valuable household goods, important telephone numbers;

__Family records (birth, marriage, death certificates); and

__Copy of Supplemental Security Income award letter.

Your Medical Information

__names, contact information for medical providers;

__health insurance information;

__health care power of attorney/advance directive documents;

__medications you use;

__adaptive and support equipment you use

__allergies and sensitivities;

__special care instructions;

__instructions for getting you out of your home, if necessary;

__if you have communication difficulties, the best way to communicate with you.

Items for a Disaster Supply Kit

__your current medications

__nonperishable food, including nutritional supplements if needed;

__ bottled water;

__ non-electric can opener;

__ paper/plastic utensils;

__ toiletries/personal hygiene items;

__ water purification tablets;

__ important documents (see below)

__ first aid kit;

__ flashlight and batteries;

__ insect repellent and sun-screen;

__ over-the-counter allergy and pain medications;

__ battery operated radio;

__ booster cables;

__ auto tire repair kit

Agencies for Emergency Assistance

1. Federal Emergency Management Agency (FEMA) FEMA disaster hotline at 1-800-621-FEMA (3362). www.fema.gov

The information includes *Are You Ready? An In-depth Guide to Citizen Preparedness,* FEMA's most comprehensive guide on emergency preparedness; a guide on *Preparing for Disaster for People with Disabilities and Other Special Needs,* www.fema.gov/pdf/library/pfd

Steps to take after a disaster:
www.fema.gov/news/newsrelease.fema?id=14065

How to apply for disaster assistance and a guide on how to get help after a disaster:
www.fema.gov/aboutlprocess/

2. Members of Congress -
Capitol Switchboard at (202) 224-3121.

3. The American Red Cross
1-866-GET INFO (438-4636) www.redcross.org

A comprehensive checklist for people with disabilities is available www.redcross.org/services/disaster/beprepared/apendixa.html

4. State and Local Assistance - Call your local police or fire department in advance to learn what emergency services may be available for the disabled.

5. Contact your electricity provider to see if they offer a "priority reconnection service" that will help ensure your power is restored as soon as possible.

Extend your Stay after the Conference and Explore St. Louis

www.explorestlouis.com

Here's a sample of the wide variety of things to do and places to see:

Gateway Arch-Jefferson National Expansion Memorial
The Gateway Arch Riverfront, highlighted by the majestic Gateway Arch, attracts more than four million guests each year. At 630 ft., our nation's tallest man-made monument has plenty of exciting activities. Take the tram ride to the top, see a documentary film, experience a giant screen movie, visit the Lewis & Clark exhibit in the museum and go shopping. Open daily except Thanksgiving, Christmas and New Year's. Extended summer hours.

Missouri Botanical Garden
Phone: (314) 577-9400 / Toll-Free: (800) 642-8842
Web: www.mobot.org
Founded in 1859, the Missouri Botanical Garden is a National Historic Landmark with 79 acres of scenic landscaping and elegant structures. Don't miss the Climatron® tropical rain forest, the Japanese Garden, *Seiwa-en* and founder Henry Shaw's Victorian home. $8, adults; free to children 12 and under. Seasonal narrated tram tours, restaurant, gift shop. Free parking on-site.

Gateway Arch Riverboats
One-hour sightseeing cruises, daily. Dinner cruises, private charters and specialty cruises available. Savor delicious cuisine aboard a two-hour moonlight Mississippi River cruise or lunch at the Arch View Cafe. Enjoy live music. Reservations required for dinner cruises.
Phone: (314) 982-1410 / Toll-Free: (877) 982-1410
Email: info@gatewayarch.com / Web: www.gatewayarch.com

Anheuser-Busch Consumer Hospitality Center
Phone: (314) 577-2626
Web: www.budweisertours.com
Tours include the historic Brew House, Budweiser Clydesdale stable, lager cellar, packaging plant, hospitality room and Anheuser-Busch gift shop. Open daily. FREE.

Saint Louis Art Museum
Phone: (314) 721-0072
Email: publicrelations@slam.org / Web: www.slam.org
Built as the Fine Arts Palace of the 1904 World's Fair and one of the nation's leading comprehensive art museums. Collections include works of art of exceptional quality from virtually every culture and time period. Highlights include free admission to special exhibitions on Fri. and programs that range from films to performances. FREE.

Caregiving

21 Ways to Comfort a Disabled Friend

Adapted from www.carepages.com

Provide a dose of delight. Take a disabled friend on an excursion to a "delightful place".

Drop off some food, books or videos.

Burn a CD of your friend's favorite songs.

Organize a group care network: e-mail a group of close friends and set up a rotating system for coming over and helping with cooking, household chores or caregiving.

Offer to help with the day-to-day

When you're at the grocery store, call and say, "I'm here what do you need?"

Be a stable, reliable presence in your friend's life

Keep in touch through regular e-mails.

Send a weekly care package

Take a plant or a small bouquet of flowers

Offer to arrange child care at no cost. A health crisis can create chaos in so many ways.

Send over a cleaning service

Create a gift basket

Donate your frequent flyer miles

Send a box of seasonal fresh fruit

Hire a manicurist/pedicurist to do a house call

Buy a gift membership to an online DVD rental service

Throw a feel-good get-together.

Become the wheels.

Get your friend a gift certificate for a massage.

Laugh, chat, and share as you normally would. Remember that a person is not defined by disability. They are still the same friend to you and want to continue to do their part in the give and take of friendship.

Medical Updates

As I look back on the past year, I see the footprints of a giant leap forward and a quickening pace towards triumph. We've surged in several neurological fields of research relevant to understanding the full spectrum of motor neuron disease, advancing us towards effective treatments and potential cures. Milestone discoveries have been made in the areas of genetics, cellular environment and mechanisms, causes of onset, disease predictors, stem cell research, biotechnology and nanotechnology. Research methods have been developed that transcend ethical, financial and technical barriers. Worldwide efforts have accelerated as experts across the globe work side by side, sharing resources and information to maximize research efforts. We are positioned in the starting blocks to sprint into an entirely new age of progress, with perseverance lengthening our stride and hope for the future fueling our speed towards the finish line.
Betsy Baquet, editor

GENE DISCOVERY SHEDS LIGHT ON HSP, ALS AND OTHER MOTOR NEURON DISEASES

Scientists have identified a gene in mice that plays a central role in the proper development of one of the nerve cells that goes bad in amyotrophic lateral sclerosis, or Lou Gehrig's disease, and some other diseases that affect our motor neurons. University of Rochester Medical Center scientists who normally work with the eye, in collaboration with a Harvard developmental neuroscientist, conducted the study. Lin Gan, Ph.D., Rochester and Jeffrey D. Macklis, M.D., D.HST, Harvard, demonstrated that a specific protein, Bhlhb5, is central to how the brain's progenitor cells ultimately become corticospinal motor neurons, which degenerate in Hereditary Spastic Paraplegia, ALS and other MND.

The work by the Harvard and Rochester scientists marks an important step in scientists' understanding of how stem cells in the brain eventually grow into the extraordinary network of circuits that make up the human nervous system. Understanding how the body determines the destiny of stem and progenitor cells is crucial if physicians are to ultimately use the cells to create new treatments for motor neuron diseases like ALS and HSP, as well as other conditions such as Parkinson's and Huntington's diseases and spinal cord injury.

A next step, Gan said, would be to analyze the function of the counterpart to the Bhlhb5 gene in patients. Scientists reported recently that the gene itself is not mutated in patients with HSP, but it's possible that the effect of the gene is somehow changed, perhaps by a different genetic mutation, in some patients with HSP. Already, more than 20 gene mutations are known to cause various forms of HSP, offering an array of targets to try to treat or cure the disease.

SOURCE: http://www.eurekalert.org/pub_releases/2008-10/uorm-gfs102008.php

SCIENTISTS GAIN INSIGHT INTO CAUSE AND POSSIBLE TREATMENT OF MOTOR NEURON DISEASE

LONDON—Researchers funded by the Biotechnology and Biological Sciences Research Council (BBSRC) at UCL (University College London), along with collaborators at King's College London, have identified a molecule that could be the key to understanding the cause of neurodegenerative diseases such as motor neuron disease (MND). This insight opens up the possibilities for developing new treatments to treat these devastating progressive conditions. The research was published November 17, 2008, in the *Proceedings of the National Academy of Sciences* (*PNAS*) and is funded by BBSRC with the Medical Research Council and the Wellcome Trust, the world's largest medical research charity.

Lead Researcher, Patricia Salinas, along with her husband, Dr. Simon Hughes, have found that a molecule called Wnt3 is crucial in the connectivity between nerves and muscles (synapses) by assisting another molecule called Agrin. By understanding the normal formation and functioning of synapses between nerves and muscles, scientists can start to look for elements that aren't working properly in people with MND. "The work we are publishing today puts another important piece of the puzzle in place and offers up a new possibility for developing drugs to treat MND and other neurodegenerative diseases," says Prof. Salinas.

Dr Belinda Cupid, Research Manager, Motor Neuron Disease Association (United Kingdom) said: "We know from recent research that signs of motor neuron damage on a cellular level in models of MND occur much earlier than the symptoms appear, so any new knowledge of how healthy motor neuron and muscles interact will give us new clues about what might be going wrong in those people affected by this cruel disease."

SOURCES: http://www.physorg.com/news146160994.html
http://www.bbsrc.ac.uk/media/releases/2008/081117_motor_neurone_disease.html

TRANSPLANTED CELLS SLOW DOWN NEURON LOSS AND EXTEND LIFE IN ALS ANIMAL MODELS

Johns Hopkins researchers report that transplanting a new line of stem cell-like cells (glial restricted precursors, or GRPs) into rat models with ALS clearly shifts key signs of neurodegenerative disease, in general, and ALS in particular - slowing the animals' neuron loss and extending life. The target area of the study was the parts of the spinal cord that control the diaphragm muscles largely responsible for breathing. After transplantation of cells, 47 percent more motor neurons survived there than in untreated animal models. "While the added cells, in the long run, didn't save all of the nerves to the diaphragm, they did maintain its nerve's ability to function and stave off death significantly longer," says neuroscientist Nicholas Maragakis, M.D., an associate professor of neurology at Johns Hopkins who led the research team.

The transplanted cells, called GRPs, developed into mature astrocytes. Astrocytes play a crucial role in keeping the Central Nervous System in healthy balance.

Studies have shown that diseased astrocytes may make motor neurons more susceptible to death by excitotoxicity. Although astrocytes might not be the primary cause of ALS, the idea is that they are involved in its progression. "Our findings demonstrate that astrocyte replacement, by transplantation, is both possible and useful," Maragakis explains. "This targeted cell delivery to the cervical spinal cord is a promising strategy to slow that loss of motor neurons in ALS."

SOURCE: http://www.physorg.com/news143643411.html

JAPANESE RESEARCHERS MAKE BRAIN TISSUES FROM STEM CELLS

Stem cells taken from human embryos have been used to form tissues of the cerebral cortex, the supreme control tower of the brain, according to researchers at the government-backed research institute Riken. The team's previous studies showed stem cells differentiated into distinct cells but until now they had never organized into functioning tissues. "In regenerative therapy, only a limited number of diseases can be cured with simple cell transplants. Transplanting tissues could raise hopes for greater functional recovery," the institute said in a statement.

SOURCE: http://www.physorg.com/news145171200.html

A BREAKTHROUGH, THEN A SURGE, IN STEM CELL RESEARCH

Less than a year after a Wisconsin team helped discover a major alternative to embryonic stem cells, more than 800 labs have begun using the approach, suggesting that stem-cell researchers are starting to move beyond controversial embryonic sources for their work. Last year, Researcher James Thomson and a Japanese research team shook the field when they discovered a way to reprogram adult skin cells to act like embryonic stem cells. The cells, called iPS cells, have the ability to form any of the body's tissues. Pioneer Thomson also co-discovered human embryonic stem cells a decade ago, in November of 1998.

Since this alternative for stem cell research was developed, 812 labs in dozens of countries have adopted the use of iPS cells for stem cell research. By contrast, only a half-dozen or so labs started working with embryonic stem cells in the months after Thomson's landmark 1998 discovery. Already, researchers say, iPS cells have proved easier for individual labs to make than embryonic stem cells, fueling the intense interest, and transforming stem cell research from "a select fraternity" into a field "open to the masses," says Evan Snyder, Research Director at the Burnham Institute. Many scientists said the absence of ethical concerns over iPS cells is also a draw.

SOURCE: http://www.physorg.com/news143133581.html

HUMAN STEM CELL ALS MODEL OPEN DOORS FOR RAPID DRUG SCREENING

Researchers from the Salk Institute for Biological Studies for the very first time established a human embryonic stem cell (hESC)-based system for modeling ALS. Their study confirmed that dysfunctional human astrocytes turn against their charges and kill off healthy motor neurons. But more importantly, treating the cultured cells with apocynin, a powerful anti-oxidant, staved off motor neuron death caused by malfunctioning astrocytes.

Their findings, which appear in the Dec. 4 issue of the journal *Cell Stem Cell*, provide new insight into the toxic pathways that contribute to the demise of motor neurons in ALS and open up new possibilities for drug-screening experiments using human ALS in vitro models, as well as clinical interventions using astrocyte-based cell therapies.

To date, drug trials that have been effective on mouse models have not shown efficacy in preclinical or clinical trials. Only one drug, Riluzole, has been approved by the FDA to treat ALS, and has shown to slow the disease by only two months. Researcher M. Carol Marchetto, Ph.D., says, "cell models using both human neurons and astrocytes could potentially be very useful for drug screening and, to some extent, cell replacement therapies." "We believe that we can use this system as a rapid drug screening test for oxidative damage to identify the best candidates for subsequent long-term co-culture experiments," says Marchetto.

SOURCE: http://www.eurekalert.org/pub_releases/2008-12/si-anh112608.php

PROTECTING NEURONS—NEWLY IDENTIFIED COMPOUNDS NOT TOXIC AT HIGH DOSES

DALLAS – Researchers at Southern Methodist University (SMU) and the University of Texas at Dallas (UTD) have identified a group of chemical compounds that slow the degeneration of neurons, a condition behind old-age diseases like Alzheimer's, Parkinson's and (ALS). SMU Chemistry Professor Edward R. Biehl and UTD Biology Professor Santosh D'Mello teamed to test 45 chemical compounds. Four were found to be the most potent protectors of neurons, the cells that are core components of the human brain, spinal cord and peripheral nerves.

A past study reports that the compound GW5074 has shown to prevent neurodegeneration. However, while effective at protecting neurons from decay or death, GW5074 is toxic to cells at slightly elevated doses, which makes it unsuitable for clinical testing in patients. The newly identified, second generation compounds maintain the protective feature of GW5074 but are not toxic – even at very high doses – and hold promise in halting the steady march of neurodegenerative diseases.

SOURCE: http://www.eurekalert.org/pub_releases/2008-11/smu-pnc111308.php

VEGF: A PROMISING CANDIDATE DRUG APPROVED FOR TRIAL FOR ALS TREATMENT

Leuven (Belgium), Stockholm (Sweden) – Permission has been granted to start the first safety and tolerability trial on patients for a remedy for ALS. The Swedish Biopharmaceutical company NeuroNova has already built upon this research. Together with UZ Leuven they'll start the first evaluation of safety and tolerability of the drug in patients by the end of this year. This is an important step in the development of a new treatment. It will take several years before the protein can be made available as a medicine.

VEGF is a substance that controls the growth of blood vessels. Unexpectedly, VEGF also helps neurons survive under stressful conditions. In 2001 Peter Carmeliet's team showed that too little VEGF causes ALS-like symptoms in mice. Later the group of Diether Lambrechts, Wim Robberecht and Peter Carmeliet showed that persons who produce too little VEGF (due to certain variations in the gene that codes for VEGF) have a higher risk of developing ALS. This was the starting point of a search for a possible treatment with the VEGF protein. Researchers have found that rats with severe and mild forms of ALS treated with VEGF both manifested the disease later and lived considerably longer.

SOURCE: http://www.eurekalert.org/pub_releases/2008-12/vfi-fti120108.php

NEW MOUSE MODEL INVENTED

Researchers at Northwestern University have created a unique transgenic mouse model that expressed superoxide dismutase (SOD). This is an excellent animal model for the analysis of Cu- or Zn-superoxide dismutase in amyotrophic lateral sclerosis (ALS), that results from mutations in the Cu, Zn- superoxide dismutase. These transgenic mice have already been widely used for screening therapeutic candidates for the discovery of drugs to treat ALS.

SOURCE: http://ttp.northwestern.edu/abstracts/viewabs.php?id=162&cat=169

NANOTECHNOLOGY OFFERS HOPE

Dr. Samuel I. Stupp, director of the Institute of BioNanotechnology in Medicine at Northwestern University, is one of a new breed of scientists combining nanotechnology and biology to enable the body to heal itself -- and who are achieving amazing early results. Dr. Stupp's work suggests that nanotechnology can be used to mobilize the body's own healing abilities to repair or regenerate damaged cells.

"By injecting molecules that were designed to self-assemble into nanostructures in the spinal tissue, we have been able to rescue and regrow rapidly damaged neurons," said Dr. Stupp. "The nanofibers – thousands of times thinner than a human hair – are the key to not only preventing the formation of harmful scar tissue which inhibits spinal cord healing, but to stimulating the body into regenerating lost or damaged cells."

"This research provides an early glimpse into the new and exciting places where nanotechnology can take us," said Project on Emerging Nanotechnologies Director David Rejeski. "This type of work helps us to see beyond first generation, 'gee-whiz' nanotech applications like better tennis racquets or anti-static fabrics, and reach for an end to human suffering from Parkinson's, heart disease, and even cancer."

SOURCE: www.mccormick.northwestern.edu/news/articles/265

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PEOPLE DOINGS

*Maryann Meyer and friends at the Oct. 11
NE Ohio Connection*

*Quest Middle School - Tampa, FL
Field Day - Awareness Walk December 16, 2008*

RGM Classic golfers were treated to raw oysters

*RGM Classic participants
Joan Heinicke and Ruth Easterling*

Tampa Cookout Oct. 18