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## Rehabilitation - Then and Now

I oversee rehabilitation research in the largest healthcare organization in the world -- the Department of Veterans Affairs. The term 'rehabilitation' conjures up memories of my own experiences with cerebral palsy. Following years of progressive treatment including braces and surgery, I only had two appointments in rehab within three months of my surgery -- both just to see how I walked. Two things still confuse me about those sessions -- shouldn't the therapist have shown me how to walk correctly, and shouldn't the rehab have lasted until I walked without assistance or problems?

Twenty-five years ago, children with cerebral palsy, traumatic brain injury and other neurologic problems were given rehabilitation that constituted of disability measurement, and limited means of adaptation to it. I am elated and proud to say that in the last 25 years, the field of rehabilitation has significantly improved. Today, clinicians and scientists are focusing more on post-acute recovery and long term follow-up. This is due in part to the increasing number of children surviving neurologic insults. Anecdotal evidence and advances in molecular, cellular and bioengineering technology have increased the amount of information we have on how the brain works, and what we do with it.

We now know that the brain and spinal cord are 'plastic.' This is not to say that they are made of synthetic materials but that nerve cells in the brain and spinal cord are malleable and have

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## No Ordinary Year

Can you guess the year? "Ordinary People" won the Academy Award for Best Picture, the Philadelphia Phillies defeated the Kansas City Royals in the World Series, and "Call Me" by Blondie topped the Billboard Top 40 charts. And that same year I was diagnosed and treated for a benign pituitary tumor.



It all started during my last annual check-up with my pediatrician before heading off to "adulthood" and college in the fall. My mother noted to the doctor that the frequent mild headaches, which had plagued me since junior high school, had escalated to severe migraines by my junior year of high school. The doctor sug-

gested that just to be safe, I go see a neurologist before college started. The neurologist examined me, thought things seemed okay, but recommended an EEG and CT scan as a precaution. After those tests, we were told to call for the results on the upcoming Thursday.

That Thursday, my parents picked me up from my summer job, and we headed down to visit my grandparents in Virginia for the July 4<sup>th</sup> weekend and my 18th birthday. When my Dad called me at work to let me know they were on their way, I casually asked if he had heard my test results. He said they would tell me about it in the car. After we rode in virtual silence for half an hour, I began to suspect something was up. I asked again and was told to my complete shock that the CT scan had revealed an abnormality in my brain area, possibly a tumor or lesion of some sort. That was all the information that had been provided to my parents, and those were the words we collectively chewed on for the 3-day holiday weekend. I remember the very first thing I did upon reaching my grandparents' house was to run and get the dictionary to see exactly what a brain "lesion" was.

Upon returning to Baltimore, we headed to an

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Rehabilitation (continued from page 1)

the ability to proliferate and reorganize in response to various stimuli. An example of this is Christopher Reeve's recovery of sensory perception in 76% of his body, after experts in 1995 predicted that he would never be able to feel or move below the level of his head. Initially, researchers were convinced that the nervous system was rigid and incapable of meaningful recovery following severe trauma. But years after his accident and responses to facilitated exercise and electrical stimulation, Mr. Reeve has feeling in most of his body and can move some of his joints voluntarily. The cells of his nervous system were able to adapt and form correct connections with remaining healthy cells, resulting in restoration of his sensory perception. Mr. Reeve was not a young man at the time of his accident and he did not experience the stimuli we believe to be responsible for his recovery over one year after his injury. Through his experiences, we see the amazing hidden potential of the brain and spinal cord to recover.

Today many of our former tenets are being questioned, such as the ability of mature neurons to form new connections; persistence of neural stem cells in the brain; and the ability of technology to bypass or replace natural function. As I write this article, researchers, scientists, and regulatory agents meet with members of the National Institutes of Health and World Health Organization to discuss implementation of neural prostheses in the clinic.

Neurosurgeons, biomedical engineers, nanofabrication specialists and others can now implant small devices into the brain that record neural activity from its healthy regions, and translate them into control signals that drive external machinery. In this way, rehab specialists give severely disabled people the ability to control communication systems, keyboards and robotic arms. Similar principles were used in the development of the cochlear implant, which was responsible for giving thousands of people the ability to detect sound. Researchers funded by the Department of Defense, National Institutes of Health, and the Department of Veterans Affairs will soon compete with each other in developing the first retinal prostheses capable of restoring sight following some forms of blindness.

We are just beginning to explore the inherent capacity of the brain and our own technological limitations. In addition to addressing motor and sensory needs, we must pay attention to the educational, community and social challenges that children face after treatment. The Interagency Committee on Disability Research is discussing ways to keep children that are recovering from devastating illness in schools, with supportive environments that help them keep pace with their peers. In addition, researchers in Oregon, Ohio and Canada are exploring ways in which parents can be effective advocates in their child's education. Gone are the days of just

measuring disability and adjusting to it. Welcome to the era of restore, replace and make better!

*Danielle M. Kerkovich, Ph.D.*  
*Acting Assistant Director*  
*Rehabilitation Research and Development Service*  
*Department of Veterans Affairs*

## **Neuroscience News**

### **from the National Institute of Neurological Disorders and Stroke**

#### **Study Reveals Patterns of Gene Activity in the Mouse Nervous System**

Wednesday, October 29, 2003

The first published data from a government-funded project provide remarkable new insights into where specific genes are active in the mouse nervous system during development and adulthood. Information from this project will advance researchers' understanding of how particular genes function in the brain and spinal cord, leading to insights about how the nervous system works. It also may lead to new ways of preventing or treating disorders such as Parkinson's disease, Alzheimer's, psychiatric disorders, and drug addiction.

No Ordinary Year (continued from page 1)

appointment on Monday morning with a neurosurgeon, who was going to explain everything to us. He informed us that I had a tumor of some sort on my pituitary gland, and I checked into Johns Hopkins Hospital for five days of tests. On my very first night there around 2 a.m., a resident woke me for a physical exam, and he explained that they suspected I had a benign pituitary adenoma. That preliminary diagnosis held up through all of the tests, including one that showed a loss of peripheral vision I had not even noticed as a result of the tumor pressing upon my optic nerve. I went back to Hopkins one week later for the removal of the tumor. My parents had spent most of July researching the right doctor to perform the surgery, and of the three most experienced neurosurgeons in the country in this procedure, one was right in our backyard at Johns Hopkins.

This time my stay at Hopkins was for 10 days with most of the time spent recuperating from the procedure. I had transsphenoidal removal of the tumor, which meant the neurosurgeon cut through my gum line above my top front two teeth, went up through my nose and into the sinus cavity. There, he drilled through the sinus cavity wall and was able to reach the tumor in the pituitary gland and scoop it out. On his way out, he plugged the hole in the wall with muscle he removed from my thigh, straightened my deviated septum as a bonus (and ended 6 years of winter nosebleeds and annual cauterizations), and packed my nose for healing.

Upon waking after surgery, I was surprised at the chunk of muscle missing from my thigh (I had not been told that was coming) and upset that they had chosen my right leg, which I favored in sports. Strangely, the most difficult part of my recuperation was getting back on my feet and walking again after the muscle removal, though it didn't affect my sports life. It made for some darn good excuses plus I milked that scar pretty well over the years. I also remember that the Sudafed I was on for my congested and packed nose made me so spacey and out of it that when a hospital volunteer stopped by to ask if I wanted to play with blocks, I begged the doctor to take me off the drug.

During my recovery period, friends came by the hospital to visit, including several who juggled and would put on shows in my room. My neurosurgeon asked one of them if he would teach him how to juggle. My friend offered to in exchange for being taught brain surgery! When I was finally able to go home, nothing felt better for my still congested nose than the overwhelming heat and humidity of Baltimore in August. I recovered well and by September, I was finally off to start my freshman year of college. That fall, tests indicated that my prolactin level, which had reached 4000 before surgery (normal for a male is 1-15), had only dropped to 2000 even though the surgical procedure had removed my prolactin-secreting pituitary adenoma. Therefore, I was

placed on bromocriptine, a dopamine agonist, which very quickly reduced my levels to normal. Follow-up CT scans were not able to tell if all of the tumor was removed because the mass of muscle in my head obscured the tumor location. However, my peripheral vision loss essentially disappeared and my prolactin levels remained normal. By the end of my freshman year, I had suffered the reverse of the Freshman 15, as I lost the 20 pounds I had artificially gained during high school as a result of the tumor. Finally, the migraine headaches, which had prompted everything, disappeared after the surgery in spite of the doctors insisting the migraines had not been caused by the tumor.

That year was 1980. I am now 41 years old, married with four healthy children, and doing well. I am extremely lucky that the tumor did no irreversible damage and while I will have to remain on medication for the rest of my life, my prolactin levels continue to be normal. I haven't had a migraine headache (or nosebleed!) since high school.

A lot has changed since my diagnosis that has made the treatment for these tumors even easier today. I was one of the earlier patients to receive both the transsphenoidal surgery and bromocriptine treatment. Not only did they stop using muscle in the sinus cavity wall shortly after my surgery, they now routinely treat my type of tumor solely with dopamine agonist medication (dostinex is now the drug of choice) instead of surgery. My 10-day stay at Johns Hopkins is practically unheard of today for nearly any surgery. I switched from CT scans to the no-radiation MRI years ago. The peripheral vision test I take annually has gone from the test administrator mechanically clanking the table to a computerized system in which the electronic buzzer enables the machine to give the test, analyze my accuracy, and plot my vision fields.

Other things have changed as well. My juggling friends are now teaching their kids to juggle, and it's time for me to make my reservations for my 20th college reunion. But the best change of all is that while I still see Dr. Neil Miller my neuro-ophthalmologist at Hopkins every year, I'm just a boring patient to him these days. I thank my lucky stars and the excellent medical treatment I received over the years.

*by Michael Greenspun, survivor.*

*Courage and perseverance have a magical talisman,  
before difficulties disappear, and obstacles vanish into  
air.*

*~John Quincy Adams*

## September 2003 Polaka Run

This year's Polaka Run, in memory of Steven Sliwerski, was yet another fun-filled event, thanks to the hard work and warm reception of his family. The weather was beautiful and the location this year, Hopkinton, NH was a wonderful setting for the picnic, games, and raffle that followed the challenging course of the poker run, which started at the Harley Davidson headquarters in Manchester, NH.

As the motorcyclists steadily filtered into the park after their poker run, they were greeted by many jovial family members and friends, who after weeks of preparation, made the participating bikers feel welcomed and appreciated with a big spread of home-made grilled and baked goodies. Some of the participants had relatives who had suffered from brain tumors and knew first-hand the importance of events like this; others were just good friends with members of the Sliwerski family. Their family is a large and close knit bunch -- thanks to their strong spirit, this event was truly a special celebration of Steven's life.

The event closed with a raffle of over 50 baskets, each with its own theme, such as Harry Potter, tea and biscuits, and Harley Davidson, to name a few. The event T-shirts will be our favorite souvenirs until next year's event. Our heartfelt thanks to the Sliwerski family and the participating bikers whose numbers grow more each year.



Left: Stacey and Henry, event organizers.

Right: The Sliwerski family and supporters registering bikers.



## Dress Down Day

The Birch Lenox School, NY, NY hosted Dress Down Day, an effort coordinated by Ms. Amanda Wolbrum, survivor. Students and staff enjoyed the chance to wear casual attire to school, while raising funds for the Childhood Brain Tumor Foundation. We appreciate the genuine support shown by the participants, along with the care and commitment Amanda showed for our cause.

## Ellen Elise Waldron

In appreciation to the family and friends of Ellen Elise Waldron held a walk in memory of Ellen Elise and donated the proceeds to the Childhood Brain Tumor Foundation.



## Kyle's Heroes

A big thanks goes out once again to the Killeen family, who hosted their 5th annual golf tournament in Neptune, NJ on September 22, 2003.

The Killeen family comes together with great enthusiasm to make the *Kyle's Heroes Golf Tournament* a truly enjoyable event! This year, Kaylee, survivor from NY and her Mom attended and enjoyed the activities of the day. The donations from local businesses enabled Kyle's Heroes to have a very successful raffle and offer prizes for all of the golfers. Auction items included a Fun in the Sun basket, Marvel Comics basket, Men's Golf Package, Wine Basket, Ladies Golf Package, autographed baseballs, Minolta Digital Camera, Waterford Crystal desk clock, NY Giants Tailgate Package, Grand Summit Hotel Romance Package, to name only a few of the terrific items.

Thanks to the continued commitment of the Killeen family, CBTF has been able to increase its contributions to scientific research and offer more in the way of information, advocacy and support to families who have children with brain tumors.

In addition to the Kyle's Heroes Golf Tournament the Knocke, Killeen, Stanton, Snodgrass and Hamilton families hosted the 3rd Grand Annual Wine Tasting in Summit, NJ on October 9, 2003. Thank you again, to Kyle and his family. Together, we will make a difference.



## Amy's Run

Thank you to all of Amy's Run supporters. We will share event photos and details in our next newsletter.

## Grants Funded by the Childhood Brain Tumor Foundation in 2003

The Childhood Brain Tumor Foundation is pleased to announce second year funding for the 2002 grant recipients, Dr. Robert Weschler Reya and Dr. Michael Sheldon. Each of the researchers were awarded grant funding last year for \$25,000 each year for up to two year.

Dr. Weschler-Reya, Duke University has made some significant progress in his study entitled, '**A New Transgenic Mouse Model.**' Dr. Wechsler-Reya has successfully generated mice whose granule cell precursor can be infected with chicken retroviruses. Once optimal conditions are established he will determine whether these genes promote tumor formation, providing insight into the molecular basis of medulloblastoma formation.

Dr. Michael Sheldon, Baylor College of Medicine, is working with genome arrays and chromosome 13 arrays in his study entitled '**Molecular Cytogenetic characterization of Pediatric Ependymoma.**' Ependymomas are malignant central nervous system tumors that affect children and young adults. Currently, there are no reliable prognostic markers for ependymoma. Dr. Sheldon's goal is to develop new tools for distinguishing different classes of ependymoma. Ultimately, given the ability to assign patients to the risk categories at the early stage of diagnosis will allow the appropriate choice of therapy, thereby, avoiding the use of potentially damaging therapies that may be unnecessary for the survival of the patient. Dr. Sheldon's works will be presented at the 2003 Meeting for the Society of Neuro-Oncology in Keystone, CO, November 13-16.



For 2003, CBTF selected two studies for funding. One study entitled, '**Preclinical Evaluation of Valproic Acid as a Novel Treatment for Medulloblastoma.**' Medulloblastoma, the most common pediatric malignant brain tumor, poses problems of long-term neuropsychological and cognitive impairments for survivors due to therapies administered to developing brains in children. Valproic Acid is a newly identified histone deacetylase inhibitor. Anti-tumor activities shown by VPA have been observed in many cancers, in vitro and in vivo. VPA has unique features making it an attractive novel treatment for medulloblastoma. This histone deacetylase inhibitor has been used in long-term therapy of epilepsy and has clinically proven records of safety and low toxicity profiles. Dr. Li's goal is to establish the anti-tumor potential of VPA and to establish a preclinical rationale for clinical trials. We look forward to learning of his progress next summer.

Funding was also granted to Dr. C. Damodar Reddy for his study entitled, '**Retinoids and Vitamin D3 analogues.**' Dr. Reddy plans to examine growth inhibitory activity of all trans-retinoic acid, 9 Cis and 20-epiD3. He

aims to characterize the molecular basis of cell death. In vivo studies will provide the benefits of combining the two agents and toxicity data. The benefits and toxicity data are important for further translational studies.

In our winter newsletter edition we will announce funding for the clinical study that is being selected for funding in November.

### Upcoming CBTF Activities

Childhood Brain Tumor Foundation  
10th Anniversary Gala  
Fund-raising Casino Night

**Saturday, December 6, 2003**  
**7:00 pm-11:30 pm**

Torpedo Factory Art Factory  
Old Town Alexandria, Virginia

Casino, buffet dinner, silent auction,  
dancing, live music, open-bar.

Call 301.515.2900 if you would like more  
information or to be an event sponsor.

Credit card donations and  
registration for the event can be made  
through our Web site. Please look for  
the event Give Button.

### Sharing Hope

A mini-conference, co-sponsored by the American Brain Tumor Association and Childhood Brain Tumor Foundation is to be held on **March 26-27, 2004.** For more information please call us and we will send a program when they become available.



**Sunday, April 2004**

**Date to be announced**

**The Dan Fiduccia Spring Biathlon,**

500 yd. Swim/5K Run to be held at  
Madeira School, McLean, VA. Participants can be as  
individuals or as a team. Top 3 male and female finish-  
ers in each age group will receive medals: 10 and under, 11-14, 20-29,  
30-39, 40-49. Have some fun, take the  
challenge. Sponsorships are encouraged.

For more information contact:  
Gib Smith, Race Director: 540-822-4355 or check our website: <http://www.childhoodbraintumor.org>

### Remembrances

Eliana Tova Andersen  
 Stephen Boyce  
 John Boyles  
 Jeff Brown  
 Kelley Bula  
 Charles Byrum  
 Catherine Cason  
 Ryan Caspar  
 Laira Caverly  
 Joesetta Chiang  
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 Lynda Santelli  
 Luke Shahateet  
 Courtney Shelby  
 Lisa Soghomonian  
 Teresa Stargel  
 Symphony Ann Taylor  
 Jaime Vanderheyden  
 Swetha Vasudevan  
 Ellen Elise Waldron  
 Matthew Wierzbicki  
 Ian Hammond Williams  
 Josie Wynn



*Mary Butt*



*Matthew Wierzbicki*

*Let us be silent that we may hear the whisper of God.  
 ~Ralph Waldo Emerson*

**National Cancer Institute  
The Facing Forward Cancer Survivor Series**

The series is designed to educate cancer survivors, family members, health care providers and others touched by cancer about the challenges with life after cancer treatment.

Visit [www.cancer.gov/publications](http://www.cancer.gov/publications) or call 1-800-4-CANCER

*Our mission is to support and fund basic science and clinical research for childhood brain tumors. We are dedicated to heightening public awareness of this devastating disease and improving the quality of life for those that it affects.*

CBTF has a website!  
*visit us at:*  
**<http://www.childhoodbraintumor.org>**  
Thank you to our Webmaster, Tim Ratliff.

**Gift Matching Opportunities**

Many companies offer a matching gifts program to support charitable organizations. Your human resources department can tell you if such a program exists in your organization. Generally, they have a form that would be sent to the Childhood Brain Tumor Foundation reporting a contribution, stating they will match the contribution. We return the form to the employer with the proper acknowledgment and information required.

**VEHICLE DONATION PROGRAM**

CBTF now accepts vehicle donations. Donate Online or call 866-332-1778 and designate the Childhood Brain Tumor Foundation as your charity of choice.

**QUICK FACTS FOR DONATING**

You are eligible for an itemized **TAX DEDUCTION** of your vehicle's Retail Fair Market Value. The service is totally free and includes convenient pick-up of your car, truck, or RV anywhere in the U.S.

Find out details by checking the Foundation website;  
[www.childhoodbraintumor.org](http://www.childhoodbraintumor.org).



CBTF can now accept donations via stock securities through Bank of America Investment Services, Inc. Contact our Broker, Steven P. Burroughs at 301-897-7699.

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**WORKPLACE GIVING**

Thank you to those who choose us as their charity!  
CBTF is in the

- Combined Federal Campaign; (National)
- Children's Charities of America (National); and
- United Way

Campaign donations can be made for the United Way through the "donor option" or "donor choice." Please check with your employer in reference to United Way campaigns.



**Thank you for your support!**  
**The Childhood Brain Tumor Foundation, Inc.**  
**Donation Form**

Enclosed is my contribution of \$: \_\_\_\_\_  
In Memory of: \_\_\_\_\_  
In Honor of: \_\_\_\_\_  
On the occasion of: \_\_\_\_\_  
General donation: \_\_\_\_\_

Please send remembrance card to:  
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Address: \_\_\_\_\_  
City/State/Zip: \_\_\_\_\_  
Optional Phone: \_\_\_\_\_

Please make checks payable to:  
The Childhood Brain Tumor Foundation  
20312 Watkins Meadow Drive  
Germantown, Maryland 20876  
telephone: 301- 515-2900 toll free: 877-217-4166

Charge my: \_\_\_ MasterCard \_\_\_ Visa  
Card# \_\_\_\_\_ exp. \_\_\_\_/\_\_\_\_  
Note: minimum charge donation is \$20

Name: \_\_\_\_\_  
Address: \_\_\_\_\_  
City/State/Zip: \_\_\_\_\_  
Optional Phone: \_\_\_\_\_

Contributions also accepted via our Web Site's Give Button.