



TBI TODAY

News, Ideas, and Resources from the Virginia TBI Model System

Planning for Your Financial Future with a Special Needs Trust

By Joanne Marcus, MSW, Executive Director, Commonwealth Community Trust

THE VIRGINIA TBIMS TEAM

EDITOR

Matthew Wetsel, B.S.

PRINCIPAL INVESTIGATOR AND PROJECT DIRECTOR—FAMILY RESEARCH

Jeffrey Kreutzer, Ph.D.

CO-PRINCIPAL INVESTIGATOR

David Cifu, M.D.

PROJECT COORDINATOR

Jenny Marwitz, M.A.

PROJECT DIRECTOR — ACUTE CARE RESEARCH

Janet Niemeier, Ph.D.

PROJECT COORDINATOR—FAMILY RESEARCH

Taryn Stejskal, Ph.D.

PROJECT COORDINATOR—CULTURAL COMPETENCY

Juan Carlos Arango, Ph.D.

MEDICAL DIRECTOR

William Walker, M.D.

BIostatistician

Jessica Ketchum, Ph.D.

PROGRAM EVALUATOR

Allen Lewis, Ph.D.

RESEARCH ASSOCIATES

Victoria Powell, B.A.

Matthew Wetsel, B.S.

Nancy Hsu, Psy.D.

Sarah Hanks, B.S.

DIRECT CORRESPONDENCE TO:

Matthew Wetsel

P.O. Box 980542

Richmond, VA 23298-0542

(804) 828-3703

Email: wetselme@vcu.edu

TBI Today is published by Virginia Commonwealth University's Dept. of Physical Medicine and Rehabilitation's Neuropsychology Service. This newsletter is a project of the Virginia Model System, funded by the US Department of Education's National Institute on Disability and Rehabilitation Research (NIDRR). The views, opinions, and information presented herein are those of the publisher and are not necessarily endorsed by the US Dept of Education.

Recovering from a traumatic brain injury is a life-long commitment that requires your all-encompassing focus. It may be difficult to think ahead and plan for your financial well being, but there are practical aspects that can be helpful and should be considered.

You may be receiving a settlement as a result of the injury. Maybe a loved one plans to give you money or will you money. If you are not employed or could become unemployed as a result of you injury, you may need to rely on government benefits such as Supplemental Security Income (SSI) and Medicaid. The settlement or inheritance would cancel your government entitlement because the maximum amount allowed to qualify for benefits is \$2,000 in income and assets.

You need to have a financial plan in place that will ensure the continuation of these benefits and make sure

that you can maintain your independence and quality of life. The good news is that there is a way to secure government benefits by placing your money in a trust.

There are two types of trusts depending on the situation of the individual. A **Special Needs Trust (SNT)** is funded by a third-party like a parent or grandparent. It may be part of a will or an outright gift of money. The SNT holds money that the grantor leaves for the beneficiary's benefit and can be used, for example, to purchase a wheel chair, dental services, eye glasses, hearing aids, education, recreation and travel, transportation, furniture, and clothing. A **Pooled Disability Trust (PDT)** is self funded by the individual with a disability generally through a personal injury award and can be used for the same types of expenditures.

(continued on page 2)

VCU's Brain Injury Family Intervention Project

Virginia Commonwealth University has developed the Brain Injury Family Intervention (BIFI) program directed toward both TBI survivors and their family members. This program is available to families regardless of how long it has been since the TBI. The purpose of the program is to strengthen families and promote long-term recovery after TBI.

Many families have described the program as very helpful. A decrease in depression symptoms and an increase in independence of the TBI survivor are just a couple of the positive outcomes some participants in the BIFI program have experienced.

Families are welcome to participate in the BIFI program, and the program is free. If you would like to participate in the BIFI program or learn more, please contact Jenny Marwitz at (804) 828-3704 or toll free at (866) 296-6904.



(*Financial Future...* continued from page 1)

When setting up a trust, you will choose a Trustee who will manage the trust for the sole benefit of you, the Beneficiary. The Trustee will manage and invest the funds and approve disbursements. The Trustee will monitor the changing rules and regulations and report to government agencies for those receiving SSI and Medicaid so as not to jeopardize benefits. This is a crucial role because the Trustee needs to be knowledgeable about not only your needs but also the complicated, ever-changing regulations of government benefits.

The internet features several helpful articles about setting up a Special Needs Trust, and you can speak with other advocates such as financial planners and case managers who can give you their perspective on long-term financial planning that will best suit your "what if" scenarios. You can also contact the Commonwealth Community Trust (CCT), a nonprofit organization created in 1990 by parents of children with disabilities and concerned industry professionals to provide a comprehensive, affordable way to set up and manage trusts for individuals living with disabilities. CCT can connect you with an estate planning attorney who specializes in these types of trusts or assist you directly with setting one up. The CCT has been chosen by over 650 clients nationwide to serve as their Trustee because of their expertise in public benefit regulations, and as an organization, CCT's staff will always be there to manage the trust. To talk with CCT staff about your options and how the process works, call 804-740-6930 or visit www.commonwealthcommunitytrust.org.

Although it can seem overwhelming, choosing knowledgeable people to take you through the process will give you peace of mind knowing that your best interests will be honored.

If you have an upcoming event of interest to the Brain Injury community in Virginia, we would be glad to consider including it here. Please contact Matthew Wetsel at 804-828-3703 or wetselme@vcu.edu

Mark Your Calendar!



- ◆ **Event:** T.G.I.F.
- ◆ **Location:** Belmont Recreation Center, 1600 Hilliard Road in the Lakeside area of Henrico Co. every 1st Friday of each month
- ◆ **Description:** the local departments of recreation & parks host this monthly social event for survivors of brain injury, ages 18+
- ◆ **Contact:** Call Kariayn Smith, 804-501-5135, for more information and/or to be placed on the mailing list for monthly reminders.
- ◆ **Event:** Richmond Chapter and Support Group
- ◆ **Location:** 3rd Monday every month at 6 pm, in the Children's Hospital Auditorium at 2924 Brook Rd.
- ◆ **Contact:** Call the Richmond BIAV at (804) 355-5748 for more info!

May 17-23 and May 24-30, 2009

- ◆ **Event:** Camp Bruce McCoy
- ◆ **Location:** Triple-R Ranch, Chesapeake, VA
- ◆ **Contact:** Call 804-355-5748 or visit www.biaav.net for more information

June 4-5, 2009

- ◆ **Event:** Williamsburg Professionals Conference: Rehabilitation of the Adult and Child with Brain Injury: Practical Solutions to Real World Problems Conference
- ◆ **Location:** Williamsburg Hospitality House
- ◆ **Contact:** Call Brain Injury Services at 703-451-8881 or visit www.tbiconferences.org

June 6, 2009

- ◆ **Event:** National Caregiver's Conference
- ◆ **Location:** Williamsburg Hospitality House
- ◆ **Contact:** Call Brain Injury Services at 703-451-8881 or visit www.tbiconferences.org
- ◆ **See our ad on the back page of this issue!**

August 12-15, 2009

- ◆ **Event:** Mild Traumatic Brain Injury International Conference
- ◆ **Location:** Vancouver, BC, Canada
- ◆ **Contact:** www.mtbi2009.org for more information!

JUST THE FREQUENTLY ASKED QUESTION S

THE INFORMATION PROVIDED IN THE FAQ IS INTENDED TO FAMILIARIZE THE PUBLIC WITH ISSUES RELATED TO TBI. NO INFORMATION PROVIDED HEREIN SHOULD BE CONSTRUED AS THERAPEUTIC ADVICE OR AS A SUBSTITUTE FOR CONSULTATION WITH A COMPETENT MEDICAL OR MENTAL HEALTH PROFESSIONAL.

Q: How can I take care of myself while taking care of my husband who has a brain injury and our children? The amount of stress I am under is overwhelming!

A: It is understandable for the caregiver to feel stressed and overwhelmed following a traumatic event that affects the entire family. The changes in your husband as well as to your life can be difficult to deal with. It is important to take care of yourself during this period to avoid burnout.

Here are some suggestions to help you cope with stress:

- Be patient with yourself. Recovery is a long process and solving big problems takes time.
- Focus on accomplishments and progress instead of failures.
- Set reasonable goals by reviewing your husband’s recent progress.
- Think positive thoughts and try to keep a good sense of humor.
- Recognize that a negative or angry emotional response may push away family, friends, and health care providers.
- Avoid putting yourself down or pushing yourself too hard.
- Seek support and help from trusted friends and family members and ask them for feedback about how you are handling stress.
- Share the burden of caregiving with trusted family and friends, and consider respite care services.
- Keep up a healthy lifestyle by exercising, eating right, and avoiding caffeine, alcohol, drugs, and tobacco.
- Breathe slowly and deeply.
- Take time for yourself and do something enjoyable...listen to soothing music, take a long bath, go for a walk, or read a book.
- Close your eyes and imagine yourself in a pleasant situation.

JUST FOR FUN!

By Matthew Wetsel

Working puzzles can help keep you sharp! Just for fun, see if you can unscramble the letters in each word or phrase taken from this issue! If you need a hand, look through the issue again and see if you can find them. Answers are at the bottom - try to peak only when you’re stumped.

1. RIRGCEAVE _____
2. NDTIAECC _____
3. ECEVYROR _____
4. OFECERCNEN _____
5. BJO LISSKL _____
6. YMIFLA _____
7. TIAUOACNFIQISL

8. OPMILAY _____
9. URVVSRIO _____
10. TIOIENENRNV

ANSWERS:

6. Family	
7. Qualifications	
8. Olympia	
9. Survivor	
10. Intervention	
4. Conference	
5. Job Skills	

JUST FOR FUN!



Questions for Pat or the FAQ column are welcomed.
Send them to: "ASK PAT" OR "FAQ"
P.O. BOX 980542. RICHMOND, VA 23298-0542
or e-mail: jhmarwit@vcu.edu





CHAT WITH PAT

Pat answers your personal questions about brain injury with compassion and practical advice. However, advice from Pat's column should not substitute for consultation with a doctor or rehabilitation specialist. The identity of individuals submitting questions to "Chat with Pat" is kept strictly confidential.

DEAR PAT: I was in a pretty bad car accident about 6 months ago. My family thought I was going to die in the hospital. I was in a coma for 10 days! Then when I woke up, the doctors said I would probably never walk or talk again. Of course I don't remember any of this. My hospital stay was a big blur.

Well, I have proven them wrong! With many hours of rehabilitation along with the support of my family, I learned to read, write, walk, and talk again. Everyone's been surprised by my recovery. I've been released by my therapists as I reached all of my goals. But I continued to do my exercises at home. I can tell I'm getting stronger every day.

So, I'm grateful for having survived the accident and getting better each day, but I'm ready for more. My frustration now is I'm getting bored being around the house! I'm not the type to sit around doing nothing. I was always working. If wasn't at work, then I was working on projects around the house. Well, frankly, I'm running out of projects. I need to go back to work. I think I'm driving my wife crazy, too.

How do I convince my doctors to let me go back to work? They don't think I'm ready to go back, but they didn't think I could walk again. I have a pretty easy job at the office. I answer people's questions over the phone. A great deal of time is spent on the computer, researching products and interacting with customers. I've been with this company for over 10 years. I can do my job in my sleep. Any advice you have would be greatly appreciated.

Sincerely,

Against All Odds



PAT'S RESPONSE:

Dear Against All Odds,

Congratulations on your accomplishments! It is difficult for the doctors to predict a precise recovery course for everyone. They are often happy when they are wrong with their predictions. As for you, it sounds like you have overcome several difficult challenges.

This past six months may seem like forever when you have been trying to get better and return to work. You're probably tired of being "sick." **However, six months is considered early in terms of recovery from a brain injury.** Typically, the majority of the recovery occurs between the first 6-12 months, though improvements continue to happen at a slower

pace. Feelings of frustration are common because people want to get back to their "normal" life.

Returning back to work prematurely will place you at risk for failure. Besides physical limitations, cognitive challenges are barriers to carrying out job responsibilities. People are often unaware of the cognitive changes because they have been focused on the physical aspects of rehabilitation. Like you, survivors are trying to regain their independence by learning to walk and function efficiently around the house. There have not been challenges to perform because others, including caregivers and family members, often keep the survivor from doing too much.

To determine readiness for return to work, a comprehensive neuropsychological evaluation is recommended. A neuropsychological evaluation assesses for cognitive changes, including attention/concentration, learning and memory, motor abilities, visual skills, and reasoning. Consult with your treating physician regarding a referral.

In addition to undergoing a neuropsychological evaluation, it is important to maintain open communication with your employer. Keeping them informed of your health and return to work status will allow them to be prepared for your return. Once your treating physician releases you, a gradual return to work is recommended (i.e., working part-time versus full-time hours). Fatigue often lingers as a residual effect of brain injury. Slowly increasing your responsibilities and work hours will increase your chance of success. Seeking feedback from your supervisor will also be key to maintaining a positive impression.

Good luck!

Work & Life After TBI:

How to Write a Winning Resumé

After a brain injury, it's common to get busy with rehabilitation or just be low on energy as you recover. Most people aren't able to return to work right away. If you're seeking a job later on, these "blank spots" may not make a job application or resumé look it's best. Putting a good resumé together when you apply for work or a volunteer position can be challenging, especially after brain injury. Many people do not know how to deal with the gaps in their work history.

Remember, a resumé is primarily a summary of your skills and abilities, so the best type of resumé will show you at your best ability and experience, time gaps or not!

There are two ways to show off your best talents in a resumé:

1. List what you have done by date, with a qualifications section that jumps out.
2. List skill categories and examples of volunteer or paying jobs you have had that helped you build these skills

Refer to the samples below to get you started on your own resumé. Think about what skills you have from prior experience - show a potential employer why you're the best person for the job!

Sample resumé #1:

List actual jobs held, starting with the most recent.

Position	Dates
Foreman	May 2005
Mail Carrier	July 2004 to August 2004
Qualifications	
<ul style="list-style-type: none"> • Assembly line work • Sort mail and forms quickly • Follow directions well • Have supervised more than two cement workers 	

Sample resumé #2:

List skills and abilities, choosing 3 or 4 categories. List examples of work or jobs you did to show you acquired skills.

Skill	How Skill Was Developed
Cleaning	Worked at a hotel cleaning rooms; January to August 2006
Typing	Worked for uncle at a car dealership typing worksheets; Summer 2005
Answering phones for business	Worked for Census Bureau, Summer 2004
Qualifications	
<ul style="list-style-type: none"> • Answering phones • Filing • 45 words per minute on typewriter or word processing • Operate waxer, steam cleaners 	

Top 10 Resumé Writing Tips:

1. Be clear about your goals. What do you want to get out of working?
2. Have someone with good writing skills help you write clear sentences and keep your resumé under 2 pages.
3. Make your resumé easy to read. Use bullets or bolding.
4. Use numbers to show off your accomplishments.
5. Begin each bullet with an action word.
6. Don't include personal information, i.e., "I am single, unmarried, and available."
7. Include any activities in which you used skills related to the job you are applying for: I was in the Parent Teachers Association, helped in the school library, etc.
8. Mention any courses or training you had relevant to the job you are applying for.
9. Only show the year and month when listing job dates.
10. Don't rely on computer spell checkers!

Survivor Story: The Life That's Waiting For Us

We'd like to present you with a unique take on a Survivor Story this issue. Reprinted with her permission, Dr. Kimberly Lees offers her story in the form of a graduation speech given on October 12th, 2006. Her life was changed forever in September, 2004, when she sustained a TBI in a devastating car wreck. Despite a long, painful, and frustrating recovery process, Dr. Lees went on to earn her doctoral degree in higher education. She offers her story to other survivors as a message of hope.

I realized 7 months after the car accident, when my brain finally had a melt down at work, just how profound a TBI really was. I began to understand the complexities and frustrations of my head trauma and its impact on my every day life. Sadly, I realized I was the one who had it and the one who had to live with it, alone, on a daily basis. Just me, myself and I. That's the stark reality of a TBI; how to survive one on your own. You see, the people closest to me weren't able to grasp the concept of my hidden disability. It's as if I was staring through a looking glass...I could see people out there living their lives like I used to do, yet tragically, they couldn't see me anymore. They knew I was there but they knew I was different. I wasn't the same person I used to be. They didn't know what to say to me, how to be around me, they didn't understand my injury and so they moved passed me as if I were invisible. And there I was, pounding on the glass trying to get their attention, knowing they saw me but they really didn't. They only saw the person I used to be and really didn't have the time to get to know the person I had become, because again, they didn't understand me. It wasn't their fault. I was now considered disabled, damaged goods and that was something difficult for even me to accept, so how could I expect someone else to do what I couldn't?

So, here it is two years later; did I say that already? I feel so elated that I can say that I am finally in this place of contentment, a place that I have worked so hard to achieve. I have reached the top of this voluminous mountain after climbing what seemed to be endless hours, days, months, now years of sheer treacherous rock, you know the kind that you move forward two steps and slide back ten. Yet, even so, it was through **my** perseverance along with the loyal support of my medical team at the Center for NeuroRehabilitation Services (CNS), which included my physical therapist, speech therapist, psychological therapist, group therapist, occupational therapist, my neurologist and other

medical experts, I have finally found my wings and am ready to soar into a new chapter of my life. I am now ready to climb yet a new mountain knowing that all things are possible if one believes, has faith and is determined to stretch the limits of one's soul... and it always helps if there's a knot at the end of the rope to hold onto when you can't hang on any longer.

I remember when I first came to CNS almost a year and a half ago. I was crying the whole time since I was in so much pain from the migraines, the muscle spasms, and the frustrations when trying to communicate verbally, the confusion when trying to listen to conversations, the brain overloads, cerebral traffic jams, and extreme fatigue and emotional trauma. I remember all these things, but at the time didn't know anything about what or why I was experiencing it all. It was all so foreign to me. And then realizing I was this different person in my same skin...I couldn't figure out where I had gone. I had died somewhere along the way and had to find a way to love this new person whom I had come to hate. She didn't know how to do anything that I used to be able to do. She had no energy, no mental capacity for cognitive processing, no short-term memory, no socializing skills, no word-finding abilities, and she was constantly in extreme pain from the migraines that devoured her energy and left her incapacitated for days on end. I didn't know this girl and didn't want to. She wasn't me and I wanted the "old me" back. I felt empty, numb and just plain dead inside. And yet, I didn't even realize at that point I was also in what seemed liked a never-ending depression. Who says you know when the bottom drops out? I sure didn't. I guess when you hurt so badly you stop feeling anything and become hopeless and feel very alone.

That about summed up the great impression I left on everyone when I first arrived at CNS...not a very endearing one, yet I sure felt as if nothing would help my cause at that point since I really didn't know the first thing about TBI's. I had a mild one, so to me that meant it was not so bad, right? Apparently that wasn't the truth at all. Mild was just an expression for the injury that was still a mystery to the medical field. Every person with a TBI has one that is as unique as her finger-prints. There was no MRI, CAT scan, EEG or any other magnetic mechanism that could show in my case where the damage had occurred and how bad it was or how long it would take for the head trauma to heal. There was no formula that anyone could give me to make me feel better about my mild TBI, its recovery time, when I would soon step back into my old shoes, when I would work again in the field of student services or not, when I would stay up past 7pm and only need 6 hours of sleep

Want to share your survivor story? If so, please e-mail it to jhmarwit@vcu.edu or by mail:

***TBI Today
P.O. Box 980542
Richmond, Virginia 23298-0542***

instead of 12, when I would have energy to bust loose with jogging, rock climbing, swimming, spinning, weight lifting and more to spare for going out on the town with friends. It just was what it was. It was maddening. And then there were the experimental drugs that I took in order to find just the right medications to help decrease my daily horrific migraines and night seizures, stimulate the left side of my brain, limit my sleep deprivation, and stabilize my major depression. So there was all this stress on my neurologist to help me find a cure for all my ailments and still allow me the opportunity to find myself again. No pressure there. And as days turned into months I found out in a literal way how an injury of the brain was **the** controller of every bodily function imaginable, things you took for granted in your everyday routines; your speech, word-finding, hearing, balance, vision, cognitive processes, memory, noise filtering, concentration, communication, decision-making, critical thinking, fatigue, hormones, everything!!!

Yes, a TBI required me to travel a very lonely journey for two years. Then something magical happened to me. Someone very special reached out his hand and asked if he could share the path with me. And then I began to realize there was a plan, a greater plan for me because someone had taken the time to notice me, to listen, to understand, to encourage and give me hope to live again, to love again, to heal and recover. How simple, yet so significant, the difference one distinctive person could make in my life. And to think that it only takes just one deeply caring person to help those with a TBI find their wings.

Hopefully, one day in the near future I will fulfill my dream in publishing a book from my two years of journaling that profoundly represents my life-altering journey in surviving a TBI. My prayer is that this book will encourage and bring hope to others who find themselves struggling alone with a TBI and are in search of their wings. I have been truly blessed.

Since earning her doctorate, Dr. Lees has been working as a Director of a U.S. Dept. of Education Grant in higher education for the past 18 months. The following is a letter she provided to us as an update on her continued journey in recovery after graduation.

Starting in September 2007, I had been fully released from rehab to go back out into society to pursue my new life as a fully functioning individual. For a year prior to that, I had been encouraged to actively pursue job applications for positions that were aligned to my doctoral degree in higher education. For the most part, I was highly motivated to get back into the working professional life I once had been so competent, confident and actively engaged in. However, at the moment, it was a daunting process, endless hours of research, portfolio building, resumé revisions, cover letter writing, and inter-

view practicing. This was a very exhausting time in my life mentally, emotionally, psychologically and socially. I had to relearn how to communicate at a professional level with academic discourse. I needed to find the confidence to "sell myself" to an interview committee. I knew they would be looking for a person of intellect and competency, as well as someone who possessed critical thinking & communication skills, leadership, global awareness, and knowledge of the university's Student Affairs and Grant protocols and procedures. I was basically being thrown under the bus and wasn't sure I could drive upside down!

But eventually, through timeless amounts of practice on the internet, word processing, thesaurus and other support mechanisms, I was able to convey who I was and what I stood for. As a survivor of a MTBI, I was fortunate to have faculties healthy enough to regain some composure for developing new strategies to compensate for the loss I had suffered so greatly. I was beginning to accept some of my challenges and learn how to overcome them... besides being stubborn and very independent, I had no one close to me to assist in my recovery. It was me or no one. I had to make this work!

Now, after working for a year and a half as the Director of a U.S. Dept. of Education Grant in higher education, I have come to realize my limitations and my potential. I am making a difference in myself by learning more about myself each and every day. My attitude has played a key role in allowing me the gracious honor of healing, and humor has been my sacred armor for giving me the freedom to laugh at my mistakes and accept myself for who I am and not who I used to be. I am me, nothing more, nothing less. I will never be the same woman that entered that car 4 1/2 years ago...she has been reshaped and molded into someone more beautiful, more giving, more empathic, loving, enjoying each moment of every day because it may be the last one she gets to experience. For both she and I am free...

Thank you for letting me share this small window of my world with you. There is so much more I wish to offer in the stages of my work-related entry of a person with a TBI. I have had to work harder, longer, be more patient, endure more exasperating circumstances, yet I delight in more moments that take my breath away. May yours be just as fulfilling!

*Kimberly Lees, Ed.D.
Olympia, WA*

March 2009

National TBI Caregiver's Conference 2009!

Saturday, June 6th, 2009 at the Williamsburg Hospitality House, Williamsburg, VA

Often, for persons with brain injury and family members, it isn't until after leaving the hospital and rehabilitation that the real journey of recovery begins. Following on the overwhelmingly positive feedback from last year's participants, this one-day national conference, will offer detailed, practical information on achieving long-term recovery. The second annual National TBI Caregiver's Conference is featuring a set of presentations or 'tracks' individualized to survivors or caregivers. Presenters include nationally and internationally known clinicians, caregivers, survivors, and advocates. Low registration fees include a continental breakfast, lunch, and conference reception. Kicking off the day, our keynote speakers are:

Cynthia A. Lefever, M. Ed. has devoted her career to advocate for Veterans with TBI and their caregivers. Her mission is to prepare both families and communities for the new generation of Veterans.

Kelli Williams Gary, Ph.D., MPH, OTR/L draws on her experience as both a TBI survivor and clinical researcher. She is recognized nationally and internationally for her work on TBI post-injury outcomes.

Sometimes, the most helpful people, are the ones that have experienced brain injury first hand, as a survivor or caregiver. Therefore, this conference will also provide opportunities for you to meet others with similar experiences, socialize, and network.

Register early for assured participation, as enrollment is limited!

Go to www.tbiconferences.org for conference details, a printable brochure, to register, and more!

Questions? Please contact Linda Nowsherwan at 703-451-8881 or via email at llee@braininjurysvcs.org

VCU, PM&R

TRAUMATIC BRAIN INJURY MODEL SYSTEM

P.O. BOX 980542

RICHMOND, VA 23298-0542