



www.braintrust.org/news

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Welcome to the first issue of *The Healing Exchange BRAIN TRUST News!* Our organization's primary goal is grass roots community building and increasing communication, rather than finding a cure for any one disease or condition. That makes us different from many other organizations. To make this newsletter more accessible we use large type fonts, and publish it on our web site with even more details. T.H.E. BRAIN TRUST is not run by professional managers or fundraisers, but by those of us who are directly affected by brain tumors and other neurological disorders.



Photo by W.R. (Roger) Lyle, Beaumont, TX

My name is Samantha Jane Scolamiero. In 1990 I was a "brain tumor victim", and for the first few years I felt like a "brain tumor patient." After about 5 years I felt I had earned the title "brain tumor survivor." Now, after more than a decade, I feel lucky to be working on thriving in my life – not just surviving – in spite of all the challenges! Based on my own experiences and the many stories of people I have met on the Internet and in person, I believe that everyone who has a brain injury, tumor, or similar neurological disorder is a survivor for his or her lifetime. This newsletter is dedicated to increasing communication among survivors of such brain disorders, their families, caregivers, researchers, and health professionals, and to sharing our concerns with the general public.

During my own search for information and, more importantly, for support, I founded the Internet-based BRAINTMR mailing list at the Massachusetts Institute of Technology in 1993. Because it became essential to support the volunteers who run this online support group and to address wider concerns, I founded T.H.E. BRAIN TRUST, a nonprofit organization, with dedicated community members whom you can "meet" on our web site and in our newsletters.

If you are reading or hearing this sentence, we encourage you to join us in building a healing community. We look forward to acting on your ideas with your help and participation. I hope that you will find useful information contained here, regardless of your personal health concerns. Please share this document with your family, friends, health care team, neurologist, local support group, public or hospital library, and anyone that you think would benefit. Don't hesitate to contact us if you would like additional copies! Thank you all for helping us build greater understanding about brain disorders by communicating about them. As always, ONWARD with courage!

Love, Samantha Jane

Feature Articles
pages 3-5 and 7

Spotlights
pages 2, 4 and 6

Events
pages 2 and 5

Volunteer Spotlight

Thank you Sandy Barnes!



Dennis and Sandy Barnes

Without volunteers T.H.E. BRAIN TRUST would not exist! In every issue we'll honor someone making an outstanding contribution to our community. In this issue, we'd like to recognize **Sandy Barnes** of Seattle, WA, for more than 5 years of dedicated service helping to maintain and develop the BRAINTMR mailing list.

T.H.E. BRAIN TRUST is a volunteer effort! This newsletter was written and produced entirely by our volunteers and MIT student intern. Please keep this in mind as you read. We'd love to have you join us and support us in our grassroots efforts. Thank you!

Support Group Spotlight

BTHHealthyKids@braintrust.org

Meet **Jenny Lyons** and her kids!

Jenny created an amazing e-mail support group for families in which one member has a brain tumor, but there are healthy children. These families face unique challenges in their everyday life. From addressing kid's difficult questions about the health of a parent or sibling with a brain tumor to coping with more simple "owies," BTHHealthyKids is a safe place for parents to share ideas and experiences and to ask their own questions. Jenny says, "There is true comfort in having others to 'talk to' who are living the experience with you."



Shopping online? Help us with your Holiday Purchases at Amazon.com!

Amazon.com, one of the largest online vendors, has partnered with us! We'll receive a percentage of every Amazon.com purchase referred through our web site. Next time you, your family, friends or colleagues, plan to shop online for books, music, movies, toys, electronics, and more, please go first to our web page **www.braintrust.org/amazon** and follow the link to Amazon.com so we can get credit for referring your purchases! This program works anytime of year, so please tell all your friends about it so they can help too!

Join us in Sunny Florida!

T.H.E. BRAIN TRUST is hosting a **PARTY** at the South Florida Brain Tumor Association's Fifth Bi-Annual Brain Tumor Conference, January 19-21, 2001, in Fort Lauderdale, Florida. The conference is for brain tumor survivors, their families, friends, and health professionals.

The party is **Friday, January 19th from 3:00-5:00 PM** (before the conference registration) at the Fort Lauderdale Airport Hilton hotel. It will be a wonderful chance to have a "family reunion" for our online groups, to match email addresses with faces, make new friends, exchange REAL hugs, and continue to build the wonderful community we have begun online. We hope to meet many of you there! Call or e-mail us to RSVP.

Rooms are filling up, so make your reservations now! (call Hilton Hotels at 1-800-426-8578) Don't forget to register for the conference by contacting our gracious hostess **Sheryl Shetsky** at 954-755-4307, e-mail Bt1Diva@aol.com or conference organizer Lkornfeld@aol.com, 561-798-9434. Further information is available online at **www.braintrust.org/events** or **www.angelfire.com/fl3/SFBTA/events.html**

When Illness Comes Calling

by Rosalene M. Dixon, SmartNurse Advocate



The holidays are upon us and illness can often be called the “uninvited guest”. Whether it’s a brain disorder or another malady, how do we incorporate illness into the framework of our lives? No matter how unwelcome the “guest”,

we, the hosts and hostesses, can benefit from getting to know the nature of our illness and shepherding “it” through our bodies, our relationships, and our daily lives.

Are you and your illness or “uninvited guest” ready for the holidays?

Do you know enough about your “guest”?

If not, perhaps you can:

- Communicate with your healthcare team
- Do some research at the library or online
- Contact people in a local or online support group like those offered by T.H.E. BRAIN TRUST (visit www.braintrust.org/services/support).

Are your “guest’s” needs being met, so you can continue to nurture yourself and your loved ones within your lifestyle?

I’ve often found that when people can manage their illnesses successfully, they balance their lifestyles. To prepare for the holidays or other stressful events, consider how you might incorporate your illness or disability into the framework of your life.

It’s not easy, and it takes time. It’s a process of integration. Plan to take things step by step.

First, take a deep breath! Accepting illness, the “uninvited guest”, into our lives at any time of year is not easy. The added stress and excitement from the holidays can make it more difficult. However, learning to accept the illness instead of ignoring it may help you to cope more successfully in the long term. If the “guest” is not acknowledged, it may

continue to knock at your door louder and louder, becoming even more unpleasant.

This does not mean that you should meekly accept your illness into your home and serve it obediently. Nor should you allow it to dictate how you live your life. On the contrary, chronic illness can be accommodated and integrated into your life as a patient or caregiver. When the unexpected comes calling your fate is not sealed! You have options. Learning to accept that the illness exists in your life can simply help you make the best personal decisions for your set of circumstances.

Know that there are many people out there in similar situations and you can network with them in person or online.

Here are some goals for successful coping:

- Be well informed, organized and well rested
- Stock up on medication/treatment, support and understanding
- Learn to live independently with the services you need
- Build your self-esteem and enjoy the esteem of others
- Maintain healthy relationships and advocate for yourself
- Nurture your “uninvited guest” in order to lessen the impact of illness on your lifestyle.

When you begin to achieve these goals, you may discover you can more easily manage illness, balance your lifestyle and realize dreams.

HAPPY and HEALTHFUL HOLIDAYS!

From The SmartNurse Advocate

Rosalene M. Dixon, MS, RNC, NP, PA-C, is a consumer advocate working to help people with illness and disability facilitate life improvements, manage illness and balance their lifestyles. Email <smt nurse@gis.net> She coordinates our Boston area online peer support group for women overcoming disability, <Woman@braintrust.org>.

We know that it isn’t easy to reach such goals. To help you through the process, invited authors will discuss specific strategies and offer tips in a series of articles in future issues of www.braintrust.org/news.

Board Member Spotlight

Our Board members are an integral part of T.H.E. BRAIN TRUST. In each newsletter we will introduce you to a Board member, so that you can get to know the people who stand behind this organization. We hope you will find that their stories inspire you as much as they inspire us.



Rebecca Libutti joined the Board of The Healing Exchange BRAIN TRUST in October 1998.

Rebecca is a seven-year survivor of a glioblastoma brain tumor, and the author of the book [That's Unacceptable: My Personal Story of Surviving a Brain Tumor](#) (available at www.krystalpublishing.com). She has made a personal commitment to communicating about the experience of living with a brain tumor to as many people as possible. Rebecca has spoken in many venues across the U.S. and Canada, and her story was featured in [Women's World](#) and [Town and Country](#) magazines.

As a member of T.H.E. BRAIN TRUST Board of Directors, she is particularly interested in long-term issues that brain tumor survivors face. She enthusiastically contributes to the Board the same courage, strength, and confidence with which she confronts the daily challenges of living with a brain tumor and subsequent brain injury.

**Board Members
of the Healing Exchange BRAIN TRUST**
Nancy Conn-Levin
George Hunter
Rebecca Libutti
Arky Pollokoff
Samantha Jane Scolamiero

A Different Path

by **Nancy Conn-Levin**

While on vacation recently, I had the opportunity to return to one of the most awe-inspiring places that I have ever seen. This unique site is located along the southern shore of Nova Scotia, and it features walking trails that overlook spectacular coastal cliffs. My husband and I first visited this place over five years ago, several months before my brain tumor diagnosis and neurosurgery. Fond memories of that previous visit inspired our return on this clear autumn day. My spirit was soaring as we started out toward the coastal path, and I was flooded with anticipation and memories from our previous visit.

Not long after we began to walk along the seaside trails, I began to notice some differences in my ability to manage the uneven terrain. Although most of the time I avoid thinking about the physical and cognitive adaptations that I make on a daily basis, the physical demands of traversing these paths made those changes impossible for me to ignore. I experienced a lot of difficulty keeping my balance while walking along the variable elevations of the path and climbing the roughly constructed steps. Several times, I lost my balance and needed to reach out to my husband for support.

About halfway through the trail I tripped and fell to the ground. Thankfully, I was not injured, but my self-confidence was badly shaken. While I was delighted to have my husband's companionship and his steady arm at my side, I was saddened by the realization that it was no longer safe for me to walk alone in a remote location like this.

I experienced a profound moment as I considered the changes in my life since my previous visit to this trail more than five years earlier. At that time, I had walked comfortably along the uneven surfaces with few concerns about maintaining my balance.

Brain tumors were something that I knew virtually nothing about, and back then I had no incentive for that to change.

While considering the differences in my own experience, I also thought about the variety of losses that many other brain injury survivors endure. Although some individuals experience symptoms that are obvious to those around us (i.e., paralysis, loss of vision, speech difficulties, etc.), others have less obvious deficits. Coping with challenges such as balance disorders, fatigue, cognitive changes, pain and other “invisible” symptoms can be especially distressing. Often, if we choose not to reveal details about how our lives have changed, even close friends and family members may not be aware of these residual effects that can be associated with brain tumors and treatments. For some survivors, coping with these “minor” brain injuries can have a significant impact, especially as we confront our own as well as society’s expectations about what we can – or cannot – do.

I suspect that many of us occasionally play a game with ourselves, pretending that we are “fine” and that nothing has changed, while we recognize within ourselves that our lives are fundamentally different.

This recognition is about much more than simply acknowledging losses and adjusting to challenges. It is a renewed awareness of the meaning of our survival, and a concurrent choice to make the most of our remaining abilities and opportunities.

After falling on that path and getting up again, I took a moment to reflect on the changes in my life. Yes, it was hard for me to walk along this trail as easily as I had five years ago. But another part of that reflection was a vivid awareness that I was fortunate to be able to return to this beautiful place at all. I found myself overwhelmed with feelings of profound gratitude about being alive, thankful that

most of my senses were still intact, and that I was able to appreciate the majesty of the ocean crashing against the magnificent cliffs below me.

Looking out at the intense blue sky and the clear blue ocean, listening to the waves hitting the rocks, and feeling the fresh sea breezes on my face, I knew how many blessings I still had in my life. And now, I carry that awareness with me on the paths I encounter with each new day.



Nancy Conn-Levin
on a different path in
Nova Scotia

Nancy Conn-Levin, M.A., is a health educator specializing in brain tumor issues. During the past four years she has been a guest speaker at several national brain tumor conferences. Nancy is a member of the Board of T.H.E. BRAIN TRUST and volunteers as coordinator for The Meningioma List <Meningioma@braintrust.org>.

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The content of this newsletter is mainly editorial and is not medical advice. Please consult your personal healthcare provider regarding medical matters.

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Due to space and postage limitations we're not able to include all our news here. Please visit our website for expanded versions of articles and more!

Emily Crockett Survivor Spotlight

interviewed by Samantha Jane Scolamiero

I first met Emily at T.H.E. BRAIN TRUST's original Birthday party. The organization was less than a year old. Emily was 12. She came to sing *Happy Birthday* with her singer-songwriter parents **Valerie and Walter Crockett**.

I'd known the Crocketts for years from their e-mails on our online brain tumor support group, although we'd never met. Valerie says, "We're sure the BRAINTMR List helped keep Emily alive. We found out about treatments we would never have known existed otherwise."

At the party I told how T.H.E. BRAIN TRUST aims to serve people coping with brain disorders at each stage of the illness. I spoke about my own struggles with a brain tumor (difficulties seeing, hearing, thinking, walking, reading) and after the party, Emily gave me the biggest hug I've ever gotten from a 12-year-old.

Now she's 15 and has been living with an astrocytoma brain tumor for more than 9 years, which is both miraculous and dauntingly difficult for a teenager. She's survived 7 brain surgeries and untold hours in treatment and clinics to fight this incurable brain tumor.

I caught up with Emily the other day and had a great chat. She really enjoys talking on the phone now that she doesn't get out much except to physical therapy, acupuncture and chiropractor appointments, to improve her stamina, sleep, headaches and low vision.

I asked what she thought about being a "survivor." She said after a pause "I do think of myself as a survivor, although I'm not better or anything..." then she added playfully, "but I'm also not dead!"

It's not easy for a kid to have a brain tumor, and some people might think she is

"lucky" to have lived for so long. Emily knows it's taken much more than luck and that "being lucky" doesn't make life easier. She recalled returning to a clinic she attended daily while in treatment. She really missed the friendly people there. A volunteer told her, "You won't need us any more, you'll get better and you'll make new friends." But outside the clinic Emily says realistically, "I'm not better... and it's hard to make new friends. Most people in the world just don't understand and they don't treat you like a regular person."

Well, there is one very special new friend that Emily has made. In 1998 **The Marty Lyons Foundation** arranged for Emily to meet her music idol **Garth Brooks**. "He's amazing!" she exclaimed, *still* energized by the trip. "Sure, he was generous, but he was also so thoughtful." Whenever they were in crowded, noisy locations he arranged to turn down the lights so Emily's eyes wouldn't hurt. Later, when she was resting with icepacks on her head, he said "You're hurtin' pretty bad, huh?" then he gave her something very special, his tour guitar!

"How do you keep from getting down?" I asked her. "I play with my dogs... and I sing," she replied. Emily has written and recorded a song called "One Special Day" about her visit with Garth Brooks. Listening to it is as good as getting a hug from Emily herself! It's available on an album called *Emily's Angel* along with 11 other songs by Valerie and Walter Crockett, whose blue-grassy fancy-folk style warms the heart. You can get a copy for yourself by sending \$15 postpaid to: The Crocketts at 32 Maple Tree Lane, Worcester, MA 01602 or through their website: www.vwcrockett.com

I asked if she had learned anything about life from having a brain tumor. She said "Well, that's like asking Garth's kids what it's like to have a famous father...they've always had one."

"Garth's the best hugger in the world," Emily reports. And she ought to know, because it takes one to know one.

Long live Emily and her hugs!

(An extended interview with Emily along with clips of her song are on our web site. See photo on page 8.)

Founder Honored



Tom Gullikson, Samantha Jane Scolamiero and Paul Flory

On August 12, 2000, Samantha Jane Scolamiero received the Tim Gullikson Spirit Award in recognition of her service to the brain tumor community. Tim's twin brother, **Tom Gullikson**, presented the award at the Tennis Masters Series Cincinnati tournament in Ohio. **Tim Gullikson**, who won the 1983 Cincinnati doubles championship and coached **Pete Sampras**, co-founded the Tim and Tom Gullikson Foundation to assist those affected by brain tumors. Tim lost his own battle with brain tumors May 3, 1996.

The Spirit Award is given annually by the Gullikson foundation to a brain tumor community member who embraces the qualities that Tim demonstrated. "Samantha epitomizes Timmy's positive attitude and fighting spirit," said Tom. "When faced with a life-changing medical problem, instead of dwelling on her fate, she used her determination ... to devote her life to providing a place for people to find compassion, support and information."

Samantha volunteers countless hours to help others. "It is my love and privilege to serve the brain tumor community," she said. "With Tim's enduring spirit and the generous assistance from the Gullikson Foundation I will continue building communications among brain tumor survivors, their loved ones and health care providers."

For more information about the Tim and Tom Gullikson Foundation, call 1-888-485-5457.

\$ Money Matters \$

Like any grassroots nonprofit we rely on fundraisers and donations from individuals to fulfill our mission. Last summer, after hearing news from **Henry Kantowitz** about the poor response to our 1999 annual appeal, **Matthew Fullerton** e-mailed his friends and suggested they donate according to their ability. His online friends raised for us more than \$6000!

Thank you Matthew and friends!



Sheryl Shetsky, Matthew Fullerton, David Bailey, Roger Lyle

Generous Grants

We are incredibly grateful to these special organizations who believe in our grassroots efforts!

The Goldsmith-Greenfield Foundation blessed us at just the right moment with a wonderful grant of \$3063 expressly to buy new computer equipment. This money could not have arrived at a better time, since our main computer had crashed beyond repair!

The Florence and Richard Koplou Charitable Foundation granted us \$4000 which enabled us to continue operating over the summer and has helped to support our new low cost office space. We are profoundly thankful to the Koplou family.

SAVE THE DATE!

On February 2, 2001, we are planning a fundraiser variety show in Boston, MA featuring **BEAN TOWN MADNESS**.

For details contact:

Kathleen McCarthy at 401-331-9511
or e-mail katedobee@aol.com

The Back Page

T.H.E. BRAIN TRUST's goal is to provide insights into living with brain injuries, brain disorders, and disability from the perspectives of everyone involved: survivors, families, parents, partners, caregivers, health care professionals, researchers, concerned friends, and others. In each newsletter we'll present a "Survivor Spotlight" describing the experiences of a member of our community who has been living with a brain injury or disorder. In this issue you'll meet **Emily Crockett**, a remarkable young woman, who has written and recorded a song about her amazing day with **Garth Brooks**. "I probably wrote my first song when I was 4, then a bunch more when I was 6 just after I was diagnosed. I knew when I was 10 I wanted to be a singer," she told us with a grin in her voice. Read more about Emily on Page 6. An extended version of the interview with her will be available on our web site soon along with audio clips of her song. Enjoy!



We'd love to hear from you!

Do you have:

- A story or experience to share?
- Coping tips for others?
- A poem or artwork to publish?
- A question that's bugging you?

Write to us or email us!!!

Party in Florida

When: January 19, 2001
From 3:00 -5:00 PM

Where: Ft. Lauderdale, FL

Who: Everyone is welcome

RSVP: Matt@braintrust.org

See page 2 for details



Don't hesitate to contact us for reprints or to join our mailing list for the next issue!
For more information, or to send us stories, comments, or questions write to us at:



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