

# PERSPECTIVE

WINTER 2010 | VOLUME 120



## The Amazing Strides in Tuberous Sclerosis Complex Research

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**Kari Luther Carlson**

President and Chief Executive Officer

**Jaye D. Isham**

Managing Editor,  
Senior Director of Communications

If you have opinions, questions or articles for *Perspective*, we would like to hear from you. Please contact the managing editor to obtain a submissions form and guidelines.

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# CEO's Message

## Kari Luther Carlson

**President & CEO**



I recently helped celebrate the very special birthday of Anne Heilman, who turned 100 years of age in January 2010. Anne's grandson has TSC, and she has been a tireless supporter of the TS Alliance for many, many years. She's literally witnessed the incredible growth and success of our organization from a vantage point not many of us have. I'm touched not only by her remarkable life, but also by her unwavering commitment to this organization.

The support of people like Anne truly comprises the heart and soul of the TS Alliance and the very important work we do. One way to easily get involved is to become an official member of the TS Alliance. The organization now offers several levels of membership, including one that's absolutely free. Those who choose a higher level of membership receive additional benefits based on their donation. For example, Bronze, Silver and Gold members gain exclusive access to several upcoming educational teleconferences taking place in February, March and April. Participants in these special calls will have the opportunity to speak directly with the presenters and ask questions. These will be recorded and posted on our website for anyone to listen to after they occur.

Another important component to membership is the election of the Board of Directors and Annual Membership Meeting as mentioned in the Board Chair's Column. Members of all levels have the opportunity to vote on new and renewing Board members. For more information about becoming a member of the TS Alliance, visit [www.tsalliance.org](http://www.tsalliance.org) and click "Become a Member" in the top navigation bar.

This issue's cover story focuses on the tremendous progress that's been made in TSC research as well as a snapshot of current science projects. Of course, one of the TS Alliance's key objectives is to provide you with the most-up-to-date information on research and science. I'm pleased to report that a new educational grant from Novartis will allow the TS Alliance to launch a series of Town Hall Meetings via our Community Alliances. These Town Hall Meetings will provide information on how basic science feeds into the discovery of potential new treatments. We will provide more specific information once these are finalized.

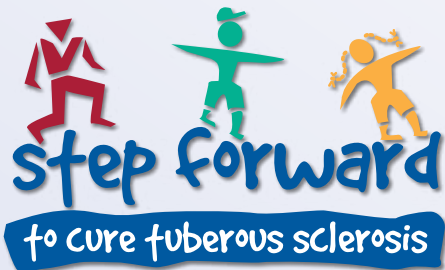
Yes, there is much to be thankful for in the TSC community, but none of these accomplishments would be possible without the synergy of our tremendous volunteers, scientists, researchers, constituents, donors, staff and board members all working together toward the common goal of defeating TSC.

Thank you for reaching out to your Congressional Representatives and Senators, hosting events in local communities, placing articles in your local papers or even just telling one new person about our cause. Each of your individual efforts, no matter how small or large, makes a true difference.

**On the Cover: Manuel R. Gomez Award Presented to Drs. Jódźwiak and Thiele**

Sergiusz Jódźwiak, MD, PhD, Head, Professor, Department of Child Neurology, The Children's Memorial Health Institute of Warsaw, Poland and Elizabeth Thiele, MD, PhD, Director, Pediatric Epilepsy Program and the Director of the Carol and James Herscot Center for Tuberous Sclerosis Complex at Massachusetts General Hospital, Boston, MA received the Manuel R. Gomez Award in September 2009 at the International TSC Research Conference. This award is given in memory of Dr. Gomez who spent his career providing clinical care and studying tuberous sclerosis complex at Mayo Clinic in Rochester, MN. Drs. Jódźwiak and Thiele received the award for their extraordinary clinical, scientific and humanitarian efforts to find a cure for TSC while improving the lives of those affected.

# Special Events



## Fall 2009 Walks

### TS Alliance of Delaware/Lehigh Valley

**Date:** September 12, 2009

**Location:** Gring's Mill

Wyomissing, PA

**Event Chair:** Shelly Richards

**Amount Raised:** \$19,500

### TS Alliance of New York/New Jersey

**Date:** September 26, 2009

**Location:** Onondaga Lake Park

Liverpool, New York

**Event Chair:** Stephanie Claxton

Langstaff

**Amount Raised:** \$49,000

### TS Alliance of the Heartland

**Date:** October 3, 2009

**Location:** Raccoon River Park

West Des Moines, IA

**Event Chair:** Cindy & Ryan Blackard

**Amount Raised:** \$10,000

### TS Alliance of Wisconsin

**Date:** October 3, 2009

**Location:** Grant Park

South Milwaukee, WI

**Event Chair:** Pam Sztukowski

**Amount Raised:** \$10,000

### TS Alliance of Metro D.C.

**Date:** October 4, 2009

**Location:** Plaza at Downtown

Silver Spring, MD

**Event Chair(s):** Nathalie Simoneau

**Amount Raised:** \$15,000

### TS Alliance of the Ohio

**Date:** October 4, 2009

**Location:** Bur Oak Park

Elyria, OH

**Event Chair:** Michelle Blood and

Frank Gritti

**Amount Raised:** \$8,000

### TS Alliance of Florida (Jacksonville and Miami)

**Date:** October 10, 2009

**Location:** Friendship Fountain

Jacksonville, FL

**Event Chair:** Joy Graydon

**Date:** October 24, 2009

**Location:** Crandon Park

Key Biscayne, FL

**Event Chair:** Vanessa Vazquez

**Amount Raised:** \$21,400

### TS Alliance of Middle Tennessee

**Date:** October 24, 2009

**Location:** Centennial Park

Nashville, TN

**Event Chair:** Amy Hobbs

**Amount Raised:** \$37,500



**Comedy for a Cure Atlanta** was held October 20 at the Punchline Comedy Club, raising \$14,000. The

attendees had a fabulous time laughing with comedian Jamie Bendall and honoring Dr. J. Robert Flamini for his hard work and dedication to TSC families in the Atlanta area.



Reiko Donato, Dr. J. Robert Flamini and Dee Triemer

**Comedy for a Cure Chicago** took place October 22 at the Improv Comedy Club, raising \$19,000. We were joined by

Honorary Chairs Sean Nolan, CEO, and Beth Dean, Vice President of Epilepsy, from Lundbeck and thanked them and their team for the time and dedication spent in getting Sabril (vigabatrin) FDA-approved in the United States. The evening concluded with nothing but laughter from comedian Mark Curry from the hit television sitcom "Hangin' with Mr. Cooper."

**Comedy for a Cure Boston** was held November 1 at Giggles Comedy Club, raising \$9,000. The attendees had a fabulous time with comedians

Tony V, Bob Seibel and Johnny Pizzi. Special thanks to our emcee, Tim Kelley. We were joined by Honorary Chairs Elizabeth Thiele, MD, PhD and Mustafa Sahin, MD, PhD along with our Honorary Committee Members Tim Kelley, The Honorable Robert Hedlund and Sean McDonough. The 2009 Honorees included Mr. and Mrs. Tom Gwinn, who have been extraordinary in their dedication and compassion in raising revenue and awareness for TSC.



On **September 12**, the **2nd Annual Drive Fore a Cure – Tournament for TSC Champions** at Brookstone Meadows in Anderson, South Carolina, raised \$7,800. Special thanks to Ole Country Smokehouse owned by Glenn Hardy who donated the BBQ dinner, Chic-Fil-A managed by Jon Holmes for breakfast and lunch, and Mighty Mouths Martin Pediatric Dentistry, LLC for its generous sponsorship. A very special thank you to event chair Karen Sims and her entire committee of volunteers for making this day possible!



On September 19, the **6th Annual Tournament for TSC Champions** took place at Maple Creek Golf & Country Club in Indianapolis, Indiana,

raising \$15,000. We would like to thank the following sponsors: Modular Devices, Inc., Indiana Wholesale Supply, and to Koers Hilltop North for hosting the event. A very special thank you and congratulations to Mark Koers, his family, friends and committee of volunteers who continue to raise funds and awareness for the TS Alliance!



The TS Alliance extends a special thank you to the Wentworth Charities family of supporters and volunteers. The **14th Annual Wentworth Charities Golf Classic Tournament** was held September 25-27 at The Samoset Resort in Rockport, Maine. Three days of golf, comedy, auctions and friend-making helped raise awareness and support for the TS Alliance and those living with TSC. Participants even signed letters to Congress in support of the TSC Research Program at the Congressionally Directed Medical Research Program at the Department of Defense. The TS Alliance receives a portion of the proceeds each year, in honor of Trey Gwinn, son of Tom and Sharon Gwinn. With this year's gift, more than \$750,000 has been donated since from Wentworth Charities since 2002. The TS Alliance honored our long partnership with Wentworth Charities at the TS Alliance's 35th Anniversary Gala last May. Thank you!

The **21st Kenvo Golf Tournament** took place back in June raising \$5,350. A very special thank you to Mark and

Maria Votta along with Joe and Dan Flaherty for their continued support of the TS Alliance.

## 35 Dinners Across America

Help us continue to mark the TS Alliance's 35th anniversary by hosting one of our **35 Dinners Across America**, which celebrate this milestone while raising funds in the social setting of your choice, such as a backyard BBQ, homemade buffet, theme party, cocktails and dinner or wine tasting -- the options are endless. For more information please contact Jenny Smiley at [smiley@tsalliance.org](mailto:smiley@tsalliance.org).



The **4th Annual Youman's Family and Friends BBQ for TSC** took place September 19 and was a huge success! With more than 90 people in attendance, and the help of many family and friends, the event raised \$9,535. A very special thank you goes out to Bill, Nancy, Ron and Jackie Youman, and also to the Colorado Springs Civitan Club for its generous donation. The Colorado Springs Civitan Club has closed its doors but chose the TS Alliance as its last benefactor. The club's members have supported the TS Alliance since the local Step Forward to Cure TSC walk started several years. We would also like to salute sponsors Gary Gressett and Deer Creek Corporation for supplying the food and beverages and Buffalo Wild Wings for their wings and door prize donations.

CONTINUED ON PAGE 23

## From the Board Chair . . .

Happy New Year to All My Dear Friends,

As we enter a new decade I see bright horizons for the Tuberous Sclerosis Alliance (TS Alliance) and the TSC community. Interest in TSC research is stronger than ever as other diseases recognize the science of TSC as a pathway to their own cures, as well as ours. Thanks to the foresight of the TS Alliance's leadership, our organization's many alliances include a close-knit grassroots community, a dedicated clinical and scientific network and both the National Institutes of Health (NIH) and the Department of Defense (DoD). We continue to build our database, which is capturing the patient information needed to keep our research efforts moving forward. As the TS Alliance lays the foundations necessary to find a cure, it will be of the utmost importance that we continue to work with all our alliances toward our common goal of finding better therapies and treatments for everyone affected by this disease.

I have seen first-hand how the efforts of our grassroots community have literally changed people's lives. Our online discussion groups provide an abundance of information and an open heart to all those in need of a guiding hand. Our Community Alliances have selflessly become stewards of vital information and resources. They support their surrounding communities and local clinics and raise awareness among their elected officials in Washington, D.C. Through their special events they raise a significant part of our organization's funding. By operating under one national umbrella, our communities ensure the information provided is up to date with the progress of TSC research being conducted here in the United States and around the world.

The commitment of TSC physicians and scientists in trying to lessen the impact of this disease goes far beyond the status quo. Their dedication and involvement creates a special bond between them and our community. I am sure you join me in thanking these TSC heroes for all they do to improve our lives. Their commitment in helping us fulfill our mission is one I feel is unsurpassed in any other medical community.

The TS Alliance diligently advocates for increases in the amount of federal funding focused on TSC research. Throughout the year, we meet with the relevant institutes at NIH and work to organize the annual grassroots March on Capitol Hill. See the Government Advocate Update on page 13 to learn more about our legislative initiatives and successes.

The seed grants the TS Alliance awards from its own research program helps many scientists gather the data needed to apply for the larger federal grants funded by the NIH and the DOD. The TSC Natural History Database, which was started a little over five years ago, will soon become international in scope. This collection of vital patient information is documenting the lives of TSC individuals and will be used to test viable new therapies.

On February 24-25, 2010, members of the Board of Directors and the Chairs of each of our Community Alliances will gather in Washington, D.C. for the TS Alliance's March on Capitol Hill, its Annual Membership and Board Meeting and the D.C. Food & Wine Tasting event. If you are unable to join in us in Washington, call the TS Alliance or your Community Alliance Chair and ask about how you can still help in our government advocacy efforts.

Our volunteers truly make all the accomplishments of our organization possible. Each and every one of you has an opportunity to help the TS Alliance achieve its mission. One important way to support our organization is by helping to raise the funds that allow us to keep delivering our vital services. Visit our website to make an online donation or to look for a Step Forward to Cure TSC walkathon, a Comedy for a Cure event or other fundraiser in your area.

Together, we have made huge strides in improving the lives of all those affected by TSC, and by continuing to work together, we can cross the finish line to a cure.

**Celia Mastbaum**

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As the TS Alliance lays the foundations necessary to find a cure, it will be of the utmost importance that we continue to work with all our alliances...

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# The Amazing Strides in Tuberous Sclerosis Complex Research

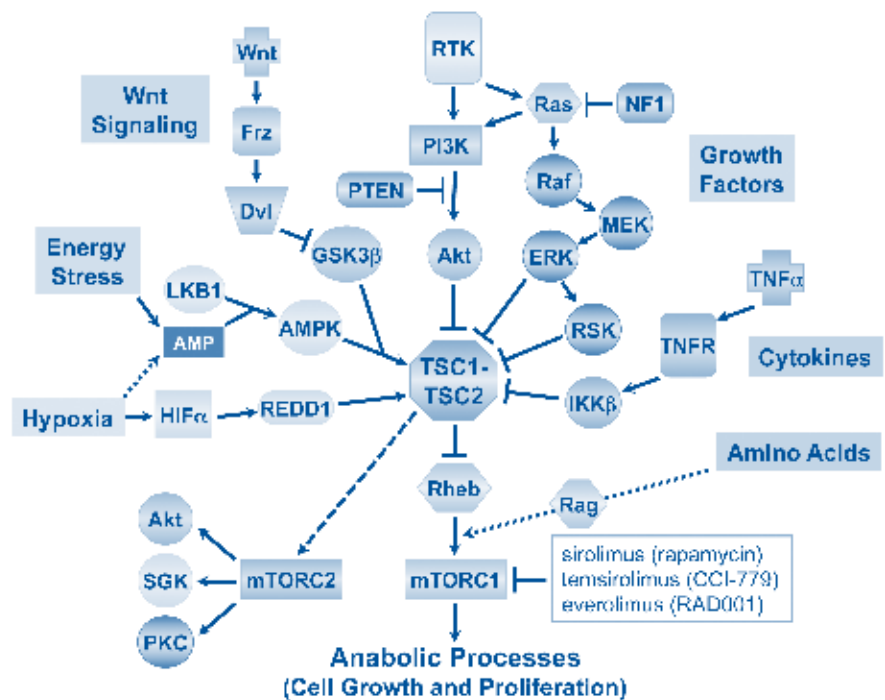
COVER STORY

Winston Churchill once said, "Never, never, never give up." Those who have supported tuberous sclerosis complex (TSC) research have never given up, and 2009 brought with it new hope for individuals living with TSC and for those who will come after us. For the first time, evidence exists that research will help not only the newly born and the newly diagnosed, but will also have an impact on the lives of those living with TSC today.

The strides made in TSC research are truly amazing for a genetic disease that affects 1 million people worldwide. In a relatively short period, TSC research has identified the two genes that cause TSC, discovered what these genes do in the human body, and launched clinical trials. We know that failure to regulate the protein mTOR (mammalian target of rapamycin) is critical to the manifestations of TSC and lymphangioleiomyomatosis (LAM), in other diseases where the genes are involved in the mTOR pathway (for example, Peutz-Jaegher Syndrome, Cowden's Disease, Birt-Hoff-Dube Syndrome). Clinical trials for Peutz-Jaegher, Sarcoma, Neurofibromatosis 1, autosomal dominant polycystic kidney disease (ADPKD), Cowden's Disease, and many types of malignant cancers (kidney, brain, pancreatic, lung, etc.) are all enrolling study participants (go to [www.clinicaltrials.gov](http://www.clinicaltrials.gov)).

## Clinical Trials for Tumors in TSC and LAM

Drugs that inhibit or suppress mTOR (called mTOR inhibitors) are in use as immunosuppressants, anticancer agents and antiproliferative agents in



The mTOR signaling pathway. (Provided by Brendan Manning, PhD, Harvard School of Public Health, Boston, MA)

drug-eluting coronary artery stents. These medications are also candidate therapies to address the underlying molecular pathology in these diseases. Early clinical trials (Phase I/II clinical trials) using rapamycin (Rapamune, Sirolimus) showed reduction in the size of TSC- and LAM-associated kidney tumors (renal angiomyolipomas) and some evidence for reversible improvement in lung function in women with LAM. Brain tumors were also shown to decrease in size in individuals with TSC while on rapamycin in a published case series. These studies showed that the tumors decreased in size while on rapamycin, but regrowth was observed when the medication was discontinued.

In 2009, multicenter, international Phase III clinical trials were launched to study the efficacy and safety of treating individuals with TSC with RAD001 (Everolimus) to treat brain

tumors (subependymal giant cell astrocytomas) and to treat kidney tumors (renal angiomyolipomas) in TSC and LAM. Both trials are blinded, randomized, placebo-controlled studies and will enroll 99 study participants worldwide. A multicenter clinical trial to study the efficacy and safety of rapamycin to treat LAM has completed enrollment, and study results are currently being analyzed. For more information about enrolling in a clinical trial, see the sidebar.

## Intellectual Disability, Autism Spectrum Disorder and TSC

Autism spectrum disorder (ASD) is a severe neurodevelopmental disorder with many different causes. Individuals with genetic syndromes (like TSC), defined mutations and metabolic disorders account for less

than 20% of individuals with ASD. However, interest is growing in the study of syndromic ASD because the genetic or metabolic alteration is known. One hypothesis suggests that an imbalance of the excitatory and inhibitory input in the cerebral cortex and changes in the development of a class of brain cells called interneurons may lead to ASD in Fragile X Syndrome and TSC. The study of genetic and environmentally modulated epigenetic factors may soon provide clarity to the complexities of ASD.

The susceptibility genes for the majority of cases of ASD are not known, but two major pathways have emerged as potentially playing a significant role. The genes that lead to syndromic ASD are known for TSC (TSC1 and TSC2), neurofibromatosis (NF1) and Cowden's Disease (PTEN) – all of which play a role in the mTOR/PI3K pathway which is associated with abnormal cell growth and synapses. Mutations in another set of genes (NLGN3/4, SHANK3 or NRXN1) alter synaptic function and lead to intellectual disability, ASD or Asperger syndrome. As Moss and Howlin (2009) appropriately point out, recognition of ASD-like characteristics in individuals with genetic syndromes is critical to ensure that they receive appropriate behavioral management and educational placement. They also point out that further research in this field is needed to more accurately define the behavioral characteristics, including ASD, in genetic syndromes like TSC and Fragile X.

Research in the laboratory of Michael Gambello, MD, PhD at the University of Texas Health Science Center in Houston and funded by the TS Alliance shows that the loss of the TSC2 gene in a specific brain cell, radial glial progenitors, may lead to the development of the brain lesions seen in individuals with TSC. This model system



Michael Gambello, MD, PhD

will help researchers identify the underlying causes of the behavioral disorders in TSC, as well as to test potential new treatments.

Intellectual disability and learning deficits are an important aspect of TSC.

In 2008, publications showed that animals with a TSC2 mutation had improvement in memory and learning deficits following treatment with rapamycin. Plans are underway for clinical trials that will carefully examine the effect(s) and safety of treatment with an mTOR inhibitor on memory and learning deficits in individuals with TSC. Anecdotal reports and a small series of adults in the UK who were treated with rapamycin indicate the results may be mixed – improvements in some areas, but worsening of skills in other areas. Very little is known about the impact of long-term treatment with the mTOR inhibitors in individuals with TSC, particularly in young children. Although the side effects of the mTOR inhibitors are tolerable, they are not insignificant. Members of the TS Alliance International Scientific Advisory Board and Professional Advisory Board recommend participation in a clinical trial for the use of the mTOR inhibitors so all effects of the medication can be closely documented. Without the data from these clinical trials, medications can not be accurately tested for efficacy and safety, and the TS Alliance wants to ensure the safety of all individuals with TSC.

### Epilepsy and TSC

In a recent Critical Review and Invited Commentary in *Epilepsia*, Michael Wong, MD, PhD discussed the role of mTOR in epileptogenesis including TSC and common acquired epilepsies. Several animal models of TSC show abnormal neurological phenotypes, which are responsive

to treatment with mTOR inhibitors. Notably, rapamycin has been shown to be effective in preventing or reversing brain abnormalities in these animal models that may relate to the generation of epilepsy (Meikle et al., 2008; Zeng et al., 2008) and learning deficits (Ehninger et al., 2008). This is very important for individuals with TSC, because the effects of the mTOR inhibitors may be antiepileptogenic rather than simply seizure-suppressing. In other words, the mTOR inhibitors may actually prevent epilepsy rather than stopping seizures.

This is encouraging because it suggests individuals with TSC who already have epilepsy may benefit from



Michael Wong, MD, PhD

treatment with the mTOR inhibitors. In addition, clinical trials are needed to determine if individuals with TSC would respond to early treatment with mTOR inhibitors that would prevent the onset of infantile spasms and/or other types of seizures. Because of the concerns about the adverse effects of the mTOR inhibitors on growth and development, especially for chronic, long-term use as might be needed to treat an individual with TSC, controlled clinical trials are necessary to establish the efficacy, safety and indications of mTOR inhibitors in TSC and for other types of acquired epilepsies.

### Summary

TSC research has come so far since the first TS Alliance research grant was awarded in 1984. There's every reason

to be hopeful that new research will find better treatments for individuals with TSC, and we will one day be able to prevent the variety of manifestations for newborns with the disease. In the words of the late Christopher Reeves, "Once you choose hope, anything's possible."

TSC research has come so far, and with more hard work and focused research we will find new treatments for TSC – treatments we never imagined would happen in our lifetime!

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# How You Can Get Involved in TSC Research

It almost goes without saying, but TSC clinical research requires participation from people with the disorder. Luckily, if you're interested in taking part, you have several choices, including signing up for the TSC Natural History Database Project or enrolling in a TSC clinical trial.

Because TSC affects everyone differently, the TS Alliance launched the TSC Natural History Database Project five years ago to document how the disorder progresses over a lifetime in a large number of individuals with TSC. The information provided by the database will help TSC researchers better understand how the disease affects people over time, perform research studies using the collected data

and, just as important, easily identify appropriate people with TSC for other research projects and clinical trials.

The TSC Natural History Database Project is administered at 15 U.S.-based TSC clinics and one in Belgium. Males and females of any age or race who have TSC may volunteer for the project if they are cared for by one of the participating clinics (see a list of participating clinics on our website). The TS Alliance is truly excited about this project's possibilities and urges anyone who is able to enroll. If you have questions or want to receive a project brochure with more detail, simply contact Jo Anne Nakagawa at (800) 225-6872 or [inakagawa@tsalliance.org](mailto:inakagawa@tsalliance.org).

As mentioned in this month's cover article, TSC-focused clinical trials are yielding meaningful information for researchers and clinicians. While it's not possible to list every clinical trial in this article, the TS Alliance website features an entire area devoted to clinical trials that explains what a clinical trial involves, why you might want to participate, what happens during the trial, what are the benefits of a clinical trial, and much more. The website also includes a link to a complete list of current clinical trials related to TSC.

You can easily find the "Clinical Trials" area of the website under the "For Individuals with TSC" tab on the left navigation menu.





## Obtain Lifelong Payments with a Charitable Gift Annuity

As the events we've witnessed in the past few years begin to stabilize, you may be looking for something dependable and secure. Fortunately, a means exists to help you earn lifelong payments and provide security for your favorite charitable organization: the charitable gift annuity.

A charitable gift annuity is a simple contract between a donor and the TS Alliance. The donor makes a donation and we, in turn, pay the donor a fixed amount of payments each year for life. With this type of gift, the donor feels secure receiving a stable annuity that won't vary from year to year.

The donor's age and the dollar value of the donation determine the amount the donor receives. The donor can collect these payments for his or her life, and if the donor chooses, he or she can have the payments continue for the life of a second individual. That way, for example, if the more-financially minded spouse dies first, the widowed spouse can have peace of mind knowing that the charitable gift annuity will continue to provide a fixed amount for his or her lifetime.

Gift annuities offer additional benefits besides secure and stable lifetime payments. They provide an income tax deduction for the charitable portion of the gift; a portion of each payment is actually income tax-free to the donor; and, depending on the type of asset donated, part of the payment may be taxed at a lower capital gains rate.

To illustrate these benefits, consider the hypothetical situation of Pete and Deloris, who are both 65 years old. They make a \$30,000 cash gift to the TS Alliance in exchange for a charitable gift annuity at a rate of 4.9 percent.\* The couple receives \$1,470 each year for as long as either one is living. Pete's and Deloris' payments do not stop at the death of the first spouse. Additionally, approximately \$917 of each \$1,470 payment is income tax-free to them—leaving only approximately \$553 of ordinary income. (After 24.5 years, when they reach their combined life expectancy, the entire annuity becomes ordinary income.) The couple can also deduct approximately

\$7,537 as an income tax deduction on their tax return. Pete and Deloris are happy with their choice of a gift annuity. They are able to donate a meaningful gift to the TS Alliance and give themselves stable and secure lifetime payments.

If you have further questions regarding gift annuities or are considering making a gift to the TS Alliance, please contact your professional advisor or call Kari Luther Carlson, President & CEO, at (800) 225-6872. You may also visit [www.tsalliance.org/plannedgiving](http://www.tsalliance.org/plannedgiving) for more information.

\*This example is based on American Council on Gift Annuities suggested rates, annual payments and a 3.4 percent charitable midterm federal rate.

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# Don't Learn the Hard Way . . .

## A Story of Struggle and Persistence

BY PAT DELORENZO

*Editor's Note: On May 25, 2002, Aina and Pat DeLorenzo welcomed a healthy little girl named Gianna into their family; she joined her 16-month-old brother Patrick. Aina and Pat were overjoyed to have two beautiful children. However, by the fall of 2004, Gianna was staring a bit more than one would expect, followed by full-blown, nearly constant seizures threatening her life. She was soon diagnosed with tuberous sclerosis complex (TSC). In 2007, the family began planning for Gianna to attend kindergarten, determined that she would be educated despite having TSC and ongoing seizures. This is the story of their multiple confrontations with the school system to ensure Gianna's safety.*



Aina and Pat DeLorenzo with Gianna and brother Patrick.

In the summer of 2007, we arranged a meeting at the local school with the principal, health aide and teacher to inform them about Gianna's TSC and to make sure they understood Gianna may have seizures in class, so they had to protect her. Although we were told Gianna wasn't the only student who experienced seizures at this school, panic quickly set in when we were informed they would not administer Diastat at school since there was no staff nurse. Instead, the school planned to call us and 911. Of course we were shocked but what choice did we have? At least we lived near the school.

On the second day of kindergarten the school health aide called, saying she was going to call 911 because Gianna had a seizure. Luckily, Gianna was okay, so why call 911? The principal insisted we remove Gianna from class immediately so they can prepare a

plan to handle her seizures. We were in disbelief as we thought the initial meeting would ensure none of this would happen.

Soon Gianna was back in class but she was not able to academically handle the work. IEP testing began and confirmed the need for special education, which was good news, because Gianna would obtain the help we knew she needed! We certainly began to understand what other parents meant when they said, "Beware, because schools will not do anything for your child unless forced to."

Unfortunately, our nightmare had only just begun. Since our local school provided no special education classes, Gianna was transferred to a school in the next town. We met with its principal, special ed teacher, regular class teacher, other specialists and the district nurse. We handed them the Diastat but it was refused. The nurse said they couldn't administer

the medication but would call 911 if needed. Discouraged, we could only pray Gianna would not need her Diastat while at school.

How could this be possible? We lived each day in fear. What if a prolonged seizure occurred – would 911 get there in time before any permanent damage or worse?

In March 2008 during an IEP meeting, I pleaded, pounding on the table for school officials to "please administer the Diastat. I don't care if the janitor uses it on her; just save my daughter's life if need be as waiting for 911 may kill her." Unfortunately, we were told time and again that school policy didn't allow them to administer the medication.

Later, when we attended an Epilepsy Alliance of Orange County monthly support meeting, we were clearly told, "It's the law: your school must provide someone in the absence of a nurse to administer medication." My wife and I were stunned, wondering

why the school and the district nurse didn't inform us about Gianna's rights or, just as important, provide the proper documents for our doctor to complete?

We immediately had Gianna's doctor sign the forms. Once signed, the school would have train people to administer Gianna's Diastat as per the authorization forms. We took the forms as well as copies of the state and federal requirements into an IEP meeting in November 2008 with the same previous people representing the school and the same nurse. The room was silent, like a poker game with everyone looking around at each others' eyes, and no one said a word as I handed over the paperwork and Gianna's Diastat once again. All along they could have, and should have as required by Federal guidelines, protected our child but chose not to until we became educated parents.

In December 2008, after a year and 3 months of the school and or district nurse risking our child's life, we believed our nightmare was finally over. More forms were signed and three people were trained to administer Diastat! Relieved, our daily stress began to subside knowing Gianna would be properly protected at school.

This past summer prior to taking our first family vacation in years, we had Gianna's Independent Student Health Plan (ISHP) paperwork signed, updated and sent to the district nurse. We enjoyed a fabulous family trip to Hawaii, something Gianna spoke of in the months prior like she had been there before and could not wait to return!

When we got back from vacation, I got email upon with a vague notice from the same district nurse that included a letter from a local hospital. The nurse asked for "our thoughts and plans for Gianna based on the letter." I simply replied that we were content with our existing signed IEP and ISHP and expected them to be followed. The IEP, at least in California, is like a signed contract, not to be broken

or changed without mutual written agreement. Nonetheless, we were concerned and wanted an explanation but it never came.

On the second day of class Gianna had a major seizure. Her long-time teacher knew the seizure was stronger and more violent than usual. Unbeknownst to us, however,

The peaceful calm of that tropical family vacation was shattered. The unbearable stress was back, along with extreme anger. The principal again said, "Sorry, it's just school policy and nothing personal. I will hold your daughter's Diastat, but unless a nurse happens to be here we can't use it." Immediately I began to bombard the district superin-

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Relieved but incredibly shocked, and fearful for all the other children state-wide whose parents may not be aware of the subtle but potentially deadly implications of that vague ambiguous email, Aina and I took it upon ourselves to get the word out.

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all schools in California had been instructed about a new state-wide policy restricting anyone previously trained by a district nurse from administering Diastat. The teacher called 911, but the seizure luckily stopped before paramedics arrived 5 minutes and 21 seconds later per their report.

tendent and its health and safety director with protestations, as it was clear this principal was not willing to honor the signed documents and follow the law.

I then contacted state and federal agencies about the Americans with Disabilities Act and was finally directed to the Epilepsy Foundation of America,



which referred me to the local office of Disability Rights California, an organization that assists in civil rights issues and special education law. I also contacted an attorney familiar with our school district. Within two days, a licensed nurse was placed at Gianna's school under the premise that it was temporary until this new statewide issue got straightened out and our district came up with a plan.

Relieved but incredibly shocked, and fearful for all the other children statewide whose parents may not be aware of the subtle but potentially deadly implications of that vague ambiguous email, Aina and I took it upon ourselves to get the word out. We sent multiple emails to all we knew, anywhere and everywhere. I also began contacting media outlets and the *Orange County Register*, our local major paper. Its education reporter listened, investigated all sides of the issue, and wrote a major article, which to our surprise showed up as the front-page cover story!

At the same time, the Disability Rights staff offered several in-depth phone consults and a complete manual of special education services and rules. These conversations and state guidelines proved yet again the school

could have and should have offered us another additional protection for Gianna right upfront but chose not to do so. I wondered why this protection was not offered? In my opinion, it was because we didn't know to simply say, "You must do this, because it's the law."

We continued to gather additional facts and information for a special meeting at the district office with another district nurse, several other district officials and Gianna's principal. They informed us they were going to implement a district-wide training plan for Diastat administration and assured us a nurse would stay at Gianna's school until all was worked out.

We then requested a nurse or trained aide be placed on the bus to and from school for Gianna. Because we educated ourselves, we knew in advance that the school bus is deemed a related service and an extension of school responsibility to our child. Although a meeting participant said no other children with Diastat orders on the buses have an aide, we simply provided California code and told them we were taking Gianna off the bus until they could properly protect her as required by law.

I also got a call to do an interview on the *Good Morning LA* TV show

after the newspaper article got their attention. About 2 weeks later and the day before we were to be interviewed live at the school, the phone rang. The school district called and agreed to have a nurse ride the bus to and from school with Gianna.

Once again the stress began to subside, although our struggle was hard, long and stressful. We have now achieved everything we feel necessary to provide a fair, safe and equal opportunity for Gianna to attend school without risking her life in so doing.

Unfortunately we now know many states besides California have issues regarding Diastat administration. Calling 911 is not acceptable when a doctor's order requires Diastat sooner than paramedics can arrive. We share this story with you, because we blindly sent our child off to school believing everything we were told and that schools would always do the right thing for every child. Of course, we soon found out how very wrong we were.

In the end, it's up to parents to find the many existing tools and resources to ensure our children's safety. Please learn from our struggle. The saying, "A good defense is the best offense," could not be any truer when it comes to protecting your child at school.

## Are You an Independent or Semi-Independent Adult with TSC?

Please join the  
TS Alliance TSC Adult  
Task Force for  
Free Adult  
Informational Calls

**Call-In number:** 866-613-5223  
**Access Code:** 4334003#  
**When:** Sunday, February 21, 2010  
**Time:** 4:00 P.M. EST  
**Topic:** The Lighter Side of TSC  
**Presenter:** Mark Martin

**Future Adult Informational  
Call Dates** (*topics and speakers  
to be announced later*):  
March 21 - April 18 -  
May 16 - June 20 (4:00 P.M. EST)  
**For more information, contact**  
Dena Hook at (800) 225-6872.

# Government Advocacy Update



## **Congress Approves \$6 Million for the Tuberous Sclerosis Complex Research Program (TSCRCP)**

On December 19, the House and Senate cleared the final version of the Department of Defense (DoD) Appropriations Act for fiscal year 2010. This legislation, which was signed into law on the same day, includes \$6 million for the TSCRCP administered by the DoD. This is a truly remarkable accomplishment in a year when many federal government programs experienced steep cuts. Congress has now appropriated a total of \$29.5 million to the TSCRCP since its inception in 2002.

Our success is due in large part to the TS Alliance's year-long grassroots efforts on behalf of our "Dear Colleague" letter funding request spearheaded by Representatives Loretta Sanchez (D-CA) and Gary Miller (R-CA) and Senators Sherrod Brown (D-OH) and Mike Crapo (R-ID).

## **National Institutes of Health (NIH) Funding Finalized**

In late December, Congress also cleared the Consolidated Appropriations Act, which includes funding for many federal agencies, including the Department of Health and Human Services (HHS). This legislation provides \$31 billion (\$692 million or 2.2 percent more than last year) to allow the NIH to continue to invest in biomedical research.

As in previous years, the TS Alliance successfully advocated for the inclusion

of NIH report language in the House and Senate versions of this legislation. These committee reports recognize the potential of NIH-funded TSC research to reveal a better understanding not only of TSC, but also more prevalent disorders such as autism, epilepsy and cancer. Because of the "gateway" potential of TSC research into these disorders, the House and Senate Appropriations Committees have encouraged "a significant strengthening of TSC research at all relevant NIH institutes, and stronger coordination of this effort through the Trans-NIH TSC Coordinating Committee."

## **Annual March on Capitol Hill Scheduled for February 24**

The success stories described above are directly attributable to the grassroots actions of our patients and families. These activities are centered around our annual March on Capitol Hill, which will take place February 24, 2010. If you have not already signed up to attend, please do so. You can make a difference by coming to Washington, meeting with your elected officials, telling your personal story, and asking them directly for their help. If you are unable to join us for the March, please consider visiting the local district offices of your elected officials and sending a letter of support to your congressional representatives in D.C. Be sure to review our online Advocacy Tool Kit under the website's "Government Relations" section for sample letters and emails.

## **TS Alliance Staff Contact Information**

All staff can be contacted by email or by calling the office toll-free phone number: (800) 225-6872. Staff members are available for assistance in finding resources and/or to answer any questions you may have. Note: To email a staff member, use First Initial Last Name @tsalliance.org or Info@tsalliance.org.

**Kari Luther Carlson**  
President and Chief Executive Officer

**Gail Alexander**  
Senior Manager of Operations  
*Executive support and oversight of office operations*

**Tyler Hoffman**  
Database Coordinator  
*Database management and development support*

**Dena Hook**  
Director of Advocacy and Education  
*Constituent support and advocacy, community outreach and educational initiatives*

**Jaye Isham**  
Senior Director of Marketing and Communications  
*Strategic communications and marketing, media relations and online strategy oversight*

**Jo Anne Nakagawa**  
Director of Clinical Projects  
*Development and implementation of the TSC Clinical Database Project and TSC clinics liaison*

**Mary Jane Perraut**  
Controller  
*Financial management and oversight*

**Jenny Smiley**  
Director of Community Outreach  
*Volunteer program and special events oversight*

**Katie Smith**  
Science Coordinator  
*Science and medical administrative support and coordination*

**Dee Treimer**  
Community Outreach Manager  
*Volunteer management and support*

**Vicky H. Whittemore, Ph.D.**  
Vice President and Chief Scientific Officer  
*Scientific affairs and medical outreach*

# TSC Clinics "Up Close"

The Tuberous Sclerosis Alliance recognizes 27 medical practices in the U.S. that provide coordinated specialty care to persons with TSC through their clinic or through a network of referrals. Each TSC Clinic is directed by a licensed physician who holds a medical specialty certification, generally in a subspecialty related to a TSC-related condition. This article continues a series about these TSC Clinics with an introduction to the healthcare professionals who staff them and highlights about the clinics.

## The Tuberous Sclerosis Clinic at the University of Texas Houston (UTH)

TSC Clinic Director Hope Northrup, M.D. is professor and Director of the Division of Medical Genetics in the Department of Pediatrics at The University of Texas Medical School at Houston. Her interest in tuberous sclerosis complex (TSC) began serendipitously in 1987 while she was completing her subspecialty training in genetics at Baylor College of Medicine in Houston.

One of her mentors called and asked, "What are you doing this weekend?" A few days later, she was on a plane to Utah, where she spent a day-and-a-half collecting blood samples from 45 members of a multi-generational family affected by TSC. This experience not only fueled her research interests but also motivated her to some day open a clinic to help those affected by TSC.

Nearly two decades after her weekend "TSC blood-sampling" experience,

Dr. Northrup opened the Tuberous Sclerosis Clinic at UTH in October 2006 with a core team that included a nurse coordinator, a pediatric neurosurgeon, and a pediatric neurologist. In July 2007, Mary Kay Koenig, M.D. joined the neurology faculty after completing her subspecialty training at the University of Texas in Galveston and enthusiastically assumed the role as the Clinic Co-Director.

When asked about her working relationship with Dr. Koenig, Dr. Northrup remarks, "Good chemistry! I'm more of a traditionalist, whereas Dr. Koenig is someone who thinks outside the box."

Together they follow anywhere from 80 or more children and adults with TSC in their clinic one or more times per year. Many come from West and Central Texas, as well as the southern Rio Grande Valley region. Others travel from neighboring Louisiana. Patient education is an important aspect of the clinic so when molecular (DNA) testing is performed, Dr. Northrup makes certain she spends enough time with the family to review the results and answer questions. In addition to this one-on-one meeting, each family receives a letter summarizing the information discussed. She and Dr. Koenig address any unanswered questions at the follow-up visit.

In June 2009, Joan Roberson, R.N., B.S.N. joined the clinic team as its Clinical Research Coordinator. She is the first team member who most new patients with TSC come in contact with for information

about the clinic and to schedule an appointment. Because the average "wait-time" to get a new patient appointment is two months, Joan does the initial screening to assess whether the patient's condition may require attention sooner than the next available appointment. She meets with patients in clinic, collects their medical records, coordinates the scheduling of their tests, returns their phone calls between visits, and also devotes significant time to research projects conducted by Drs. Northrup and Koenig.

One research project is the TSC Natural History Database Project sponsored by TS Alliance. Another is an investigator-initiated clinical trial called "Topical rapamycin therapy to alleviate cutaneous manifestations of tuberous sclerosis complex and neurofibromatosis 1 (NF1)."

Dr. Northrup has successfully built a network of specialists who share her interest in TSC. Her multi-disciplinary team includes pediatric and adult specialists in more than 14 clinical areas affected by TSC, such as cardiology, dermatology, epilepsy, nephrology (pediatric), neurosurgery, ophthalmology, behavior psychiatry, pulmonology, and plastic surgery. E-mails and group meetings keep everyone up-to-date on current clinical practices and new advances in TSC research.



University of Texas Medical School students also benefit from the presence of the clinic. About 25% of them spend part of their training in the clinic, where they have the opportunity to meet patients affected by TSC. Dr. Koenig reports many of them are unaware of the neurological manifestations associated with the disease, so part of their rotation through the clinic includes lectures. She and Dr. Northrup also mentor medical genetic residents and fellows as well as genetic counseling trainees who also rotate through the clinic.

To round out the services offered at the clinic, Drs. Northrup and Koenig and Joan provide information to new patients about the TS Alliance and the local Community Alliance, which serves the greater Houston metropolitan region and southeast Texas. Along with several of their colleagues, they also volunteer to take part in local fundraising events, TSC research conferences, and Meet the Expert gatherings, which benefit the TSC community.

## The Tuberous Sclerosis Clinic at the Hospital of the University of Pennsylvania

The Tuberous Sclerosis Clinic at the University of Pennsylvania in Philadelphia (TS Clinic at PENN) is co-directed by Adult Neurologist and Basic Science Researcher Peter B. Crino, M.D., Ph.D. and Medical Geneticist Katherine L. Nathanson, M.D. Nurse Practitioner Amanda Krause, M.S.N., C.R.N.P. is the Clinic Coordinator. The clinic cares for patients 12 years through adulthood and refer those under age 12 to Children's Hospital of Philadelphia.

The scarcity of medical and psychosocial services for adults with TSC motivated Dr. Crino to open a clinic

in 2001 expressly for them. He recounts, "It was really the patients who told me that once they reached 18, they were no longer able to access TSC care through their pediatricians"

His colleague, Dr. Nathanson, is board-certified in medical genetics and internal medicine. Her areas of interest span a wide spectrum of genetic disorders including TSC. She provides care to those patients and families who need counseling in genetic testing, family planning, and other related issues.

"I've been interested in TSC since my neurology residency," remarks Dr. Crino, who met patients with TSC who were undergoing epilepsy surgery and had the opportunity to examine brain tissue removed during these surgeries. His medical training not only led to his clinical interest but also is the basis for much of the research he performs in his laboratory.

When he and Dr. Nathanson initially started seeing patients, the biggest challenge was "getting the word out" about their designated TSC clinic. They hope to expand their outreach throughout Pennsylvania, New Jersey, and Delaware, where most of their current patients reside. The clinic increased the availability of follow-up appointments after Amanda joined the team a little more than two years ago. New patients contact them by e-mail, the hospital website, or through a referral from their physician.

"Any patient who is having trouble getting an appointment should call my office directly," asserts Dr. Crino. "For their first appointments, a new patient should expect to spend up to 90 minutes or longer and should bring medical records, MRIs/CT scans, clinical reports, lab work, and doctor's office notes."

He emphasizes the importance of making sure the diagnosis of TSC is correct according to published



criteria, which means a thorough history is obtained and a physical exam is performed during the first visit. Once this is confirmed, they decide what the most appropriate treatment

approaches are for the organ systems involved and refer patients to clinicians within their network of specialists who can manage almost any possible complication related to TSC. New patients and their families are given ample time to ask questions.

Dr. Crino believes the clinic is special because, "First, our patients are remarkable individuals. Each of us is continually impressed and humbled by the efforts patients make against the effects of TSC every day. Whether it is epilepsy, LAM (lymphangiomyomatosis), or kidney problems, most are continuously optimistic and hopeful. Even when things are bleak, their spirit and their family support is unparalleled."

He is also proud of the synergy between the clinicians within their network of specialists. He says they frequently discuss patients by phone, e-mail or in conference. "All of us maintain a singular mission of improving the lives of our TSC patients," he says. He adds they have joint monthly meetings with the LAM Clinic at PENN to discuss individual cases as well as new directions in clinical TSC care or research. This collaboration is one way they strive to provide the best possible care to their patients.

For the past 10 years, Dr. Crino has actively participated in TS Alliance-sponsored Meet the Expert and research meetings. "I believe these meetings provide stimulating and enjoyable opportunities to meet TSC patients and families," he says. "To be honest, I always learn something new about TSC when I talk to families at the Meet the Expert sessions. They are very rewarding."

# Tuberous Sclerosis Complex: Improving the Molecular Diagnosis

**By Corey Braastad**, Scientist and Manager of Operations, Athena Diagnostics

**Jeff Jones**, Director of Laboratory Operations, Athena Diagnostics

**Sat Dev Batish, PhD, FACMG**, Sr. Lab Director, Athena Diagnostics

You may have many questions about whether to submit a simple blood sample for molecular testing at Athena Diagnostics to confirm a clinical diagnosis of tuberous sclerosis complex (TSC). A genetic diagnosis of TSC can confirm that the clinical diagnosis was accurate, helps family planning decisions, and provides guidance for a treatment plan. The molecular testing service performed by Athena is recognized as the industry “gold standard.” The tests are accurate and reliable with technical sensitivities of >99% for the gene regions tested.

Yet some individuals with a clinical diagnosis of TSC have received

“normal” results. Why does that happen? The “clinical sensitivity” is the proportion of TSC patients in which the causative mutation is detected, and is limited by the specific gene regions tested and the limits of scientific knowledge on the full spectrum of causative factors. With the most current version of the test (launched in Jan 2010), the clinical sensitivity is up to 82%, meaning that about 18% of individuals with TSC have a mutation outside of the genetic region tested. The clinical sensitivity has increased over time as the scope of the molecular test has expanded (see the table below), thereby improving the testing service.

The earlier the testing was done, the lower the clinical sensitivity and more likely the disease causing mutation was not detected.

If the results of your Athena TSC Evaluation were “normal,” you may want to consult with your clinician to determine if additional testing is

appropriate now that clinical sensitivity is increased again. With the availability of new test components, your clinician can determine what additional testing may be right for you.

In addition to making improvements in the clinical sensitivity of the test, a program called Access Athena® was developed to make the testing process easier and more affordable. Athena works directly with insurance companies to achieve the maximum reimbursement, thereby potentially reducing the cost to the patient. The Patient Protection Plan limits a patient’s responsibility to no more than 20% and is available to most patients with commercial insurance. Access Athena also offers an optional blood draw service. Athena can send someone to the patient’s home or to a local draw site to get their specimen drawn at no additional cost. To find out more about Access Athena, visit [www.AccessAthena.com](http://www.AccessAthena.com).

| If you were tested before ...        | ...then the chances of finding the molecular cause of your TSC symptoms was... | ...because Athena testing included...  |
|--------------------------------------|--|--|
| September 2002                       | unclear  | <ul style="list-style-type: none"> <li>• Testing was only available on a research basis</li> </ul>   |
| October 2005                         | 64-75%   | <ul style="list-style-type: none"> <li>• TSC1 and TSC2 full gene sequencing</li> </ul>   |
| January 2010                         | 69-80%   | <ul style="list-style-type: none"> <li>• TSC1 and TSC2 full gene sequencing</li> <li>• TSC2 deletion testing</li> </ul>  |
| Athena’s NEW Complete TSC Evaluation | 71-82%   | <ul style="list-style-type: none"> <li>• TSC1 and TSC2 full gene sequencing</li> <li>• TSC2 duplication/deletion testing</li> <li>• TSC1 deletion testing</li> </ul> |



# Upcoming Major Events



## **TS Alliance of Atlanta/N. Georgia**

**May 15, 2010**

Marietta Square Atlanta, GA

## **TS Alliance of Arizona**

**May 1, 2010**

El Dorado Park, Scottsdale, AZ

## **TS Alliance of Connecticut**

**June 5, 2010**

Rothberg Institute Guilford, CT

## **TS Alliance of the Dallas/Ft. Worth Area**

**May 15, 2010**

Frisco Commons Park Frisco, TX

## **TS Alliance of the Delta Region**

**May 1, 2010**

Lafreniere Park Metairie, LA

## **TS Alliance of Greater Alabama**

**April 10, 2010**

Emmet O'Neal Library Mountain Brook, AL

## **TS Alliance of Greater Chicago**

**May 22, 2010**

Busse Woods Forest Preserve Elk Grove, IL

**May 22, 2010**

Lake Storey Recreation Area Galesburg, IL

## **TS Alliance of Houston**

**May 15, 2010**

MacGregor Park Houston, TX

## **TS Alliance of Indiana**

**May 1, 2010**

Forest Park Noblesville, IN

## **TS Alliance of Intermountain West**

**May 8, 2010**

Liberty Park Salt Lake City, UT

## **TS Alliance of Michigan**

**June 12, 2010**

Granger Meadows Park, Lansing, MI

## **TS Alliance of Ohio**

**May 22, 2010**

Centerville High School Track Dayton, OH

## **TS Alliance of the Pacific Northwest Region**

**May 22, 2010**

Sand Point Magnuson Park Seattle, WA

## **TS Alliance of the Pacific Northwest Region**

**May 23, 2010**

Mt. Tabor Park Portland, OR

## **TS Alliance of Rocky Mountain Region**

**May 22, 2010**

EB Rains Park Northglenn, CO

## **TS Alliance of Southern California**

**May 15, 2010**

El Dorado Park Long Beach, CA

## **TS Alliance of St. Louis & S. Illinois**

**June 5, 2010**

Cliff Cave Park St. Louis, MO

## **TS Alliance of the Upper Midwest**

**May 8, 2010**

Pasley Park, Sioux Falls, SD

**May 16, 2010**

Como Park St. Paul, MN

## **TS Alliance of Western Pennsylvania**

**June 26, 2010**

Brady's Run Park Beaver Falls, PA

## **Are you interested in organizing a walk in your community?**

The TS Alliance needs volunteers to chair walkathons in the following locations: Sacramento/Northern, CA; Virginia; Omaha, NE; San Antonio, TX; and Sarasota, FL. If you are interested, please contact Jenny Smiley at (800) 225-6872 or [jsmiley@tsalliance.org](mailto:jsmiley@tsalliance.org).

For more information about Step Forward to Cure TSC, visit [www.StepForwardtoCureTSC.org](http://www.StepForwardtoCureTSC.org) today!

## **Comedy for a Cure Hollywood**

**April 11, 2010**

Boulevard3 – Hollywood, CA

Performances by Ray Romano

and Larry Miller

## **Comedy for a Cure New York**

**May 6, 2007**

M2 Lounge – New York City, NY

Honorary Chair Julianne Moore and special appearance

by Rachael Ray



For more information, please contact Jenny Smiley at [jsmiley@tsalliance.org](mailto:jsmiley@tsalliance.org) or visit [www.ComedyforaCure.org](http://www.ComedyforaCure.org).



Mr. Dennis Hanson  
 Mr. and Mrs. Harold Xavier  
**Tribute(s) for Patty Johnson**  
 Mr. and Mrs. Thomas Goetz  
**Tribute(s) for Stephen M. Jones**  
 Mr. and Mrs. Richard Jones  
**Tribute(s) for Michael Kelly**  
 Ms. Chris Kelly  
**Tribute(s) for Grace Kisselburgh**  
 Ms. Esther Ash  
 Chris Kisselburgh Trucking  
**Tribute(s) for Crystal Knotts**  
 Ms. Joan E. Knotts  
**Tribute(s) for Ken J. Kocher**  
 Anonymous  
 Mr. and Mrs. Paul Brunelle  
 Mr. and Mrs. Richard E. Cramer  
 Mr. and Mrs. Stephen D. Kittleson  
 Ms. Carla Rodicap  
 Mr. and Mrs. Kevin Thompson  
**Tribute(s) for Anna Koponen**  
 Mr. and Mrs. Patrick Bartsch  
 Mr. and Mrs. Mark Koponen  
**Tribute(s) for Jacob Koponen**  
 Mr. and Mrs. Patrick Bartsch  
 Mr. and Mrs. Mark Koponen  
**Tribute(s) for Andrew Koumoullis**  
 Mr. Louis DelPriore  
**Tribute(s) for Cathy J. Krinsky**  
 Mr. and Mrs. James M. Krinsky  
 Mr. Gil Ross and Ms. Cynthia L. O'Neill  
 Mr. James M. Robinson  
**Tribute(s) for Lauren E. Krinsky**  
 Ms. Eva Monastersky  
**Tribute(s) for Hannah LaForte**  
 Mr. and Mrs. Bruce M. Smith  
**Tribute(s) for Peter J. LaForte**  
 Mr. and Mrs. Philip Molstre  
 Mr. and Mrs. Joel Ratner  
**Tribute(s) for Stephen Laib**  
 Mr. and Mrs. Ronald L. Laib  
**Tribute(s) for Jude Langstaff**  
 Ms. Trish Albanese  
**Tribute(s) for Brianna LaVoun**  
 Mr. and Mrs. Arthur A. Asgian  
 Mr. Edwin Miller  
 Ms. Marie Radigan  
**Tribute(s) for Randall Lee**  
 Mr. and Mrs. William W. Lee  
**Tribute(s) for Caroline Leonard**  
 Deborah Montick and Jeffrey Jennings  
**Tribute(s) for Jacob Levine**  
 Mr. and Mrs. Jonathan Myers  
**Tribute(s) for Lauren Levine**  
 Mr. and Mrs. Jonathan Myers  
**Tribute(s) for Tommy R. Lindsey Jr.**  
 Mr. and Mrs. Charles K. Bardes  
**Tribute(s) for Hannah Linsin**  
 Katlin Family Foundation  
 Mrs. Muriel Patis  
**Tribute(s) for Heather Lowe**  
 Ms. Amy Mueller  
**Tribute(s) for Philip Mach**  
 Ms. Maria B. Wilson  
**Tribute(s) for Phillip Macri**  
 Capt. and Mrs. Roger Wilson  
**Tribute(s) for Vincent Macri**  
 Ms. Susan Harris  
**Tribute(s) for Herbert Marton**  
 Temple Emanu-el Minjan Fund

**Tribute(s) for Matthew Mastbaum**  
 Mr. and Mrs. Neil Cooperstein  
 Mr. and Mrs. Ralph L. Heumann  
 Mr. and Mrs. Abe Mastbaum  
**Tribute(s) for Genie Matthews**  
 Mrs. Julie D. Webb  
**Tribute(s) for J. Payson Matthews**  
 Mr. and Mrs. Brice C. Winfrey  
**Tribute(s) for Payson Matthews**  
 Mr. and Mrs. Alex Moore  
**Tribute(s) for Riley Mayhew**  
 Ms. Kathryn Howard  
**Tribute(s) for Sophia Mayrhoen**  
 Mr. and Mrs. Alan Marcus  
**Tribute(s) for Ashlin McFadden**  
 Mr. and Mrs. Charles McFadden  
 Mr. and Mrs. Raymond McFadden  
 Ms. Julie Peters  
**Tribute(s) for Joshua Michael**  
 Ms. Gertrude Brown  
**Tribute(s) for Makai Milton**  
 Mr. and Mrs. Peter M. Durant  
 Ms. Rachel A. Fuld  
**Tribute(s) for Danielle Mintz**  
 Mr. and Mrs. David H. Mintz  
**Tribute(s) for Nadra Mlynarczyk**  
 Mr. and Mrs. Richard D. Olson  
**Tribute(s) for Bahram Mohit**  
 Mr. John D. O'Connor  
**Tribute(s) for Farhad Mohit**  
 Mr. John D. O'Connor  
**Tribute(s) for Lindsay Moody**  
 Anonymous  
**Tribute(s) for Alex Moore**  
 Mr. Payson Matthews  
**Tribute(s) for Stephen P. Mroz**  
 Mr. Ralph D. Jacobson  
**Tribute(s) for Annika Ng**  
 Ms. Peggy Wong  
**Tribute(s) for Josephine Nicola**  
 Mr. and Mrs. Ed Crofts  
**Tribute(s) for Kaylee Noble**  
 Mr. Paul E. Noble  
**Tribute(s) for Jon Nustra**  
 Dr. and Mrs. F. Jerald Nustra  
**Tribute(s) for Marybelle Ocampo**  
 Mr. and Mrs. Rod O. Mariano  
**Tribute(s) for James Oliver**  
 Mr. and Mrs. Edward D. Stone  
**Tribute(s) for James E. Oliver**  
 Mrs. and Mrs. Kathleen D. Kos  
 Mr. and Mrs. James W. Oliver  
**Tribute(s) for Alexandra Oliveri**  
 Ms. Susan K. Summers  
**Tribute(s) for Jeremy Orr**  
 Mr. and Mrs. Donald A. Orr  
**Tribute(s) for Robb Palmer**  
 Mr. and Mrs. Stanley J. Dickinson  
**Tribute(s) for Drew Palombizio**  
 Mr. and Mrs. John Wrynn  
**Tribute(s) for Felipe Pancorvo**  
 Mr. Pablo Burbridge  
**Tribute(s) for Allison Parker**  
 Mr. and Mrs. Brian N. Belanger  
**Tribute(s) for Eric Parkes**  
 Mr. and Mrs. David W. Parkes  
 Mr. and Mrs. Jeffrey J. Siegel  
**Tribute(s) for Patricia J. Parsons**  
 Ms. M. Sharon Hurka  
**Tribute(s) for Mason Peters**  
 Mr. and Mrs. Robert Oglesby  
 Mr. and Mrs. Donald R. Peters  
**Tribute(s) for Page Pfeiffer**  
 Ms. Kay S. Dooley

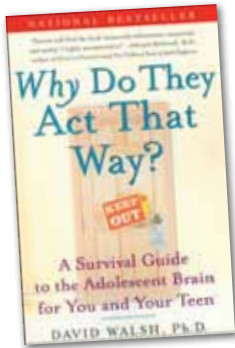
Mr. and Mrs. Jerry A. Olson  
**Tribute(s) for Sophie Phillips**  
 Ms. Allison Bursch  
**Tribute(s) for Rachel Plavin**  
 Angels on Call, Inc.  
 Mr. and Mrs. Gerald Fine  
 Mr. Ben C. Kaufmann  
 Ms. Norlean D. Moran  
 Mrs. and Mr. Barbara Reiss  
 Mr. Mark Scarr  
**Tribute(s) for Cynthia Pompeo**  
 Ms. Helen Gorman  
 Mr. and Mrs. Ronald Pompeo  
**Tribute(s) for Ronny Pompeo**  
 Ms. Helen Gorman  
 Mr. and Mrs. Ronald Pompeo  
**Tribute(s) for Carrie Post**  
 Ms. Kathy W. Scott  
**Tribute(s) for Cameron T. Powell**  
 Mr. Robert S. Webb  
**Tribute(s) for Colleen Powell**  
 Mr. Robert S. Webb  
**Tribute(s) for Rachel W. Powell**  
 Mr. Robert S. Webb  
**Tribute(s) for Rebekah M. Price**  
 Mr. and Mrs. Robert R. Price  
**Tribute(s) for Sarah M. Price**  
 Mr. and Mrs. Robert R. Price  
**Tribute(s) for TJ Quinn**  
 Mr. and Mrs. Brian J. Quinn  
**Tribute(s) for David Ram**  
 Dr. and Mrs. Dasarathi Ram  
**Tribute(s) for Martha Ratner**  
 Mr. and Mrs. Philip Molstre  
**Tribute(s) for Cameron Rawlings**  
 Mr. and Ms. John F. Rawlings  
**Tribute(s) for Lindsey Rawlings**  
 Anonymous  
**Tribute(s) for Thorpe Richards**  
 Mr. Robert P. Trout and Ms. Janet Studley  
**Tribute(s) for Colleen Rivers**  
 Mr. and Mrs. John A. Virgilio  
**Tribute(s) for Danielle Rompf**  
 Ms. Donna Carlson  
**Tribute(s) for Lillian Rose**  
 Anonymous  
 Ms. Kirsten Reach  
**Tribute(s) for Lara Rosenbach**  
 Mr. Peter Katopes  
 Ms. and Mr. Evan Zuckerman  
**Tribute(s) for Jordana A. Rothberg**  
 Dr. Jonathan M. Rothberg and Dr. Bonnie E. Gould Rothberg  
 Mr. Craig Wiener  
**Tribute(s) for Sidney Rouse**  
 Mr. Jarvis L. Cain  
 Mr. and Mrs. Roderick V. Davoud  
 Mr. and Mrs. Ronald Smith  
 Ms. Carol Thompson  
**Tribute(s) for Anna Russell**  
 Mr. and Mrs. Valentine J. Pust  
**Tribute(s) for Joel Sackett**  
 Mrs. Tracy Morgan  
**Tribute(s) for Jessica L. Sanders**  
 Mr. and Mrs. Floyd Aikens  
**Tribute(s) for Dante Saz**  
 Miss Sofia Reche Lozano  
**Tribute(s) for Hudson T. Scheck**  
 Mr. and Mrs. and Mrs. Charles Scheck  
**Tribute(s) for Madalyn Scherer**  
 Mr. Andrew M. Jaeger  
 Ms. Kelley Meyer

**Tribute(s) for Francesca Schmidt**  
 Mr. and Mrs. Nick Eitel  
**Tribute(s) for Stephen Schmitt**  
 Mr. and Mrs. Jack M. Olson  
**Tribute(s) for Sophia Schuler**  
 Mr. and Mrs. Gerald Schuler  
**Tribute(s) for Greyson R. Schwaigert**  
 Ameriprise Financial Employee Gift Matching Program  
 Mrs. Sandra Gillespie  
**Tribute(s) for Brenna Scott**  
 Anonymous  
 Mr. and Mrs. Jack D. Scott  
 Mr. and Mrs. Douglas Scott  
**Tribute(s) for Kaitlyn R. Sebedra**  
 Mr. John H. Sebedra  
**Tribute(s) for Savannah Seguin**  
 Ms. Nathalie Seguin  
**Tribute(s) for Sasha Selg**  
 Advanced Radon Mitigation, Inc.  
**Tribute(s) for Robert A. Seymour**  
 Mr. Randy Elkinson  
**Tribute(s) for Eliana R. Shahmoon-Kleinman**  
 Dr. Rebecca Shahmoon-Shanok  
**Tribute(s) for Benjamin Shapiro**  
 Mrs. and Mrs. Bardwil  
 Ms. Carol D. Hobart  
 Mrs. Melanie Landsberg  
 Mr. Kevin Yoder  
**Tribute(s) for Christopher S. Sherman**  
 Mrs. Joan Williams  
**Tribute(s) for Milton Siegel**  
 Mr. and Mrs. Alan Freeman  
**Tribute(s) for Joshua B. Sims**  
 Mr. and Mrs. Frank B. Stone  
**Tribute(s) for Harold D. Singer**  
 Dr. and Mrs. Herbert Marton  
**Tribute(s) for Meghan J. Sirinek**  
 Mr. and Mrs. Robert Peiffer  
**Tribute(s) for Drew Sklarin**  
 Mr. and Ms. Neil S. Fisher  
 Mr. Greg W. Froehlich  
 Mr. Robert Schwartz  
 Ms. Pearl Shapiro  
 Mr. and Mrs. Paul D. Simpson  
**Tribute(s) for Rylee Skodras**  
 Ms. Glenda Topp  
**Tribute(s) for Olivia Smiley**  
 Mr. and Mrs. Robert E. Apple Jr.  
 Mr. and Mrs. Robert E. Apple  
 Mr. Emanuel C. Hoover  
 Mr. and Mrs. James R. Johannsen  
**Tribute(s) for Lauren M. Smith**  
 Mr. Daniel McDonald Jr.  
**Tribute(s) for Mona Smith**  
 Mr. and Mrs. Joseph T. Smith  
**Tribute(s) for Matthew O. Sobzak**  
 Ms. Agnes Love  
**Tribute(s) for Lillian R. Solise**  
 Anonymous  
 Ms. Hilary Lowbridge  
 Mr. and Mrs. Chad Myers  
**Tribute(s) for Joseph Stammelmann**  
 Ms. Kathleen D. Dick  
**Tribute(s) for Julia Steenman**  
 Mr. and Mrs. Gerard Steenman  
**Tribute(s) for Steven Striegel**  
 Ms. Sandra Hurst

**Tribute(s) for Erin Stromeck**  
 Mr. and Mrs. Kenneth Wyer  
**Tribute(s) for Hailey Sutton**  
 Mrs. Dana Sutton  
**Tribute(s) for Sarah Sutton**  
 Mr. and Mrs. Bruce Deloche  
**Tribute(s) for Emily B. Szilagyi**  
 Mrs. Diane Burgess  
**Tribute(s) for Freddie W. Tart**  
 Ms. Barbara B. Brickman  
**Tribute(s) for Seth Taylor**  
 Mr. and Mrs. Michael A. Miller  
**Tribute(s) for Erin Thill**  
 Mr. and Mrs. Thomas J. Thill  
**Tribute(s) for Muriel Thompson**  
 Mr. and Mrs. Richard H. Blackman  
**Tribute(s) for Tyler J. Trapp**  
 Don's Body Shop  
 Mr. and Mrs. Donald Hauge  
**Tribute(s) for Andrew R. Trundle**  
 Mr. and Mrs. Randy E. Hazard  
**Tribute(s) for Ann Tyack**  
 Mr. Bruce P. Meyer  
**Tribute(s) for David C. Walker**  
 Mr. Payson Matthews  
**Tribute(s) for Marisa Wangsness**  
 Mr. and Mrs. Ted J. Montgomery  
**Tribute(s) for Jeb Ward**  
 The Kim and Erick Philanthropic Fund  
**Tribute(s) for William G. Ward**  
 Mr. and Mrs. Scott F. Bauer  
 Mr. Thomas L. McCormick and Ms. Mary I. O'Connor  
 Southern Community Bank and Trust  
**Tribute(s) for Maggie Wheeler**  
 Ms. Maggie Wheeler  
**Tribute(s) for Travis White**  
 Mr. and Mrs. Rod White  
**Tribute(s) for Luke Wickersham**  
 Mr. and Mrs. Rick Dewew  
**Tribute(s) for Amanda Wiezalis**  
 Mr. and Mrs. William P. Stebbins  
**Tribute(s) for Ashley Wiezalis**  
 Mr. and Mrs. William P. Stebbins  
**Tribute(s) for Kacee Williams**  
 Anonymous  
 Ms. Bernadette M. Esquer  
 Mr. and Mrs. Matthew Hammon  
 Mr. and Mrs. Jose A. Hernandez  
 Mr. and Mrs. David Waller  
**Tribute(s) for Florine A. Wilson**  
 Mr. and Mrs. and Mrs. David W. Coonfield  
**Tribute(s) for Lindsey A. Wilson**  
 Mr. and Mrs. Thomas Engle  
**Tribute(s) for Raven Wilson**  
 Reverend Gale Kilgore  
**Tribute(s) for Melanee Wolthuis**  
 Mr. and Mrs. Scott J. Sochor  
**Tribute(s) for Nicholas T. Wolthuis**  
 Mr. and Mrs. Scott J. Sochor  
**Tribute(s) for Harold Xavier**  
 Mr. and Mrs. Ken Johnson  
**Tribute(s) for Michael D. Yohn**  
 Ms. Linda Yohn and Mr. William Labedzki  
**Tribute(s) for Alyssa Youmans**  
 Mr. and Mrs. Douglas H. Smith  
**Tribute(s) for Maria Zoumadakis**  
 Mr. and Mrs. John P. Kapos  
 Mr. and Mrs. William L. Zoumadakis



# Recommended Reading



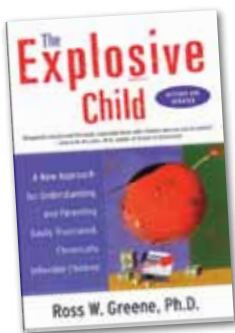
## Why Do They Act That Way?: A Survival Guide to Adolescent Brain for You and Your Teen

By David Allen Walsh Nat Bennett

**Synopsis:** In this national bestseller, acclaimed, award-winning psychologist Dr. David Walsh explains exactly what

happens to the human brain on the path from childhood into adolescence and adulthood. Revealing the latest scientific findings in easy-to-understand terms, Dr. Walsh shows why moodiness, quickness to anger and to take risks, miscommunication, fatigue, territoriality, and other familiar teenage behavior problems are so common — all are linked to physical changes and growth in the adolescent brain.

*Why Do They Act That Way?* is the first book to explain the changes in teens' brains and show parents how to use this information to understand, communicate with, and stay connected to their kids. Through real-life stories, Dr. Walsh makes sense of teenagers' many mystifying, annoying, and even outright dangerous behavioral difficulties and provides realistic solutions for dealing with everyday as well as severe challenges. Dr. Walsh's techniques include, among others: sample dialogues that help teens and parents talk civilly and constructively with each other, behavioral contracts, and Parental Survival Kits that provide practical advice for dealing with issues like curfews, disrespectful language and actions, and bullying. With this arsenal of strategies, parents can help their kids learn to control impulses, manage erratic behavior, cope with their changing bodies, and, in effect, develop a second brain.



## The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children

By Ross W. Green

**Synopsis:** Almost everyone knows an explosive child, one

whose temper and extreme noncompliance leaves his or her parents standing helpless in fear, frustration, and guilt. Now, in *The Explosive Child*, Dr. Ross Greene,

the noted therapist who has worked with thousands of these children, offers parents good news: These kids aren't bad; rather, they suffer from a physiological deficiency in frustration tolerance and flexibility. This compassionate book helps parents grasp the underlying problems of explosive children, defuse explosive episodes, and reduce tension and hostility levels for the entire family by providing invaluable tools for coping with this behavioral disorder.

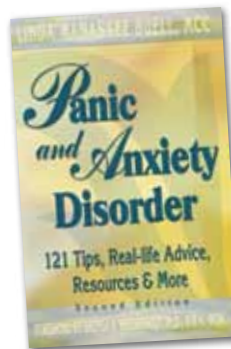


## Your Defiant Child: Eight Steps to Better Behavior

By Russell A. Barkley, Christine M. Benton

**Synopsis:** Every child has "ornery" moments, but more than 1 in 20 American children exhibit behavioral problems that are out of control.

For readers struggling with an unyielding or combative child, *Your Defiant Child: Eight Steps to Better Behavior* offers the understanding and guidance they need. Drawing on Dr. Russell A. Barkley's many years of work with parents and children, the book clearly explains what causes defiance, when it becomes a problem, and how it can be resolved. The book's comprehensive eight-step program stresses consistency and cooperation, promoting changes through a system of praise, rewards, and mild punishment. Readers learn tools and strategies for establishing clear patterns of discipline, communicating with children on a level they can understand, and reducing family stress overall. Filled with helpful charts, questionnaires, and checklists, *Your Defiant Child* helps parents get their child's behavior back on track and restore harmony in the home.



## Panic and Anxiety Disorder

By: Linda Manassee Buell

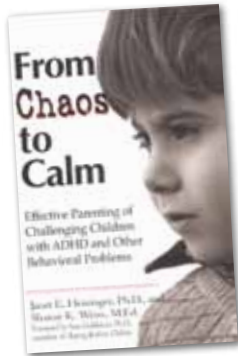
**Synopsis:** This second edition of *Panic and Anxiety Disorder: 121 Tips, Real-life Advice, Resources & More* features 40 more pages than the original. Some of them offer author

Linda Manassee Buell's personal journal entries, in which she reflects on her years of suffering, learning and joy in her battle with panic disorder and agoraphobia. As one reads these stories,

it becomes clear how this book's remarkable realistic approach and very practical tips came to be.

Adding even more value are new chapter introductions that will help the reader use the tips more effectively, along with brief yet helpful insights from mental health professionals. The resource area has also been expanded considerably.

Written from a panic sufferer's own special perspective, this unique book offers heartfelt support. It is a welcome addition to understanding and helping in the search for sensible approaches and realistic goals for people who suffer from panic and anxiety disorder as well as those who would like to better understand and help them.



### **From Chaos to Calm: Effective Parenting for Challenging Children with ADHD and Other Behavioral Problems**

By Janet E. Heininger,  
Sharon K. Weiss

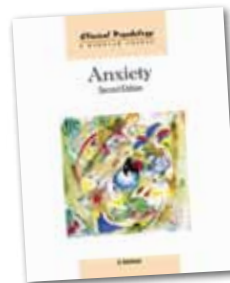
**Synopsis:** Three points of view—parent's, therapist's, and child's—make this the most practical guide on the market for raising a child with Attention Deficit Hyperactivity Disorder or other behavioral issues. Traditional parenting and discipline books aren't effective for parents who are dealing with kids with ADHD, OCD, depression or other disorders. They need a guide that will help them with the unique discipline and organization challenges kids with these issues have. When getting up, going to school, completing homework, helping with chores, and getting to bed

all become battlegrounds, the step-by-step proven techniques presented here will help parents achieve peace in their households. It will teach parents how to:

- Engage in proactive, not reactive, parenting
- Discipline consistently and effectively
- Deal with stalling, forgetting, overreacting, and other everyday behavior problems
- Work with a child's teachers, and more.

**Author Biography:** Sharon K. Weiss, M.Ed., a behavioral consultant in private practice in northern Virginia, speaks nationally and internationally on parenting and behavior management, among other topics, and has worked as a teacher of special-needs children. A founding member of ADHD Professionals Group, she has also served as a program coordinator and supervisor of an intervention program for behavior-disordered children.

**Author Biography:** Janet E. Heininger, Ph.D., is a former assistant professor at American University in Washington, D.C., and the mother of two children, including a son with ADHD.



### **Anxiety**

By S. Rachman

**Synopsis:** Unique in its combination of an introduction to the subject of anxiety with comprehensive coverage of the latest developments in research and practice, this book provides an excellent breadth and depth of coverage.

## **Lend Your Voice by Participating in the 2010 TS Alliance Online Survey**

The TS Alliance is pleased to announce an easy-to-complete online constituent survey. Through this survey, we hope to find out what the TS Alliance is doing right and identify those things we can do better. We will share survey results when they become available. Your opinions will be grouped with those of other survey participants and held in strict confidence, and

you will not be contacted by the TS Alliance unless you give us your permission in this survey.

This online survey will remain open until March 30, 2010. To participate in the survey, please go to [www.tsalliancesurvey.com](http://www.tsalliancesurvey.com).

If you do not have access to the Internet, please contact the TS Alliance at (301) 562-9890 or (800) 225-6872. One of our trusted volunteers will call

you to arrange a best time to assist you complete the survey over the phone.

Your participation is critical in gathering actionable information to help us continue to serve the TSC community and meet the needs of individuals and families affected by TSC as well as their caregivers and healthcare providers.

If you have any questions about the survey, please call Jaye Isham at (800) 225-6872.



## Other Events

On September 12, Donna Scott raised funds for the TS Alliance during a special **Benefit Hike-a-Thon**. Donna Scott led 21 friends and family members on the trail, while many more “angel hikers” supported them from home. They eventually reached Lake Alice in the Sawtooth Mountains, enjoyed each other and the view, and then completed the 12-mile hike back down. Thank you to Donna for her work in planning and organizing the benefit hike!



On September 26, the **6th Annual Crashin for the Cause Demolition Derby** was held at the Pickett Steam Engine Club in Rosendale, Wisconsin, raising \$29,361 and with proceeds donated to the TS Alliance. With 80-plus vehicles participating this year, it was the largest crowd to date! Thank you to the Kopf family: Joe, Abby, Malayna, Kinsey and Anya for all you continue to do in raising

awareness in your community and in raising funds for the TS Alliance!

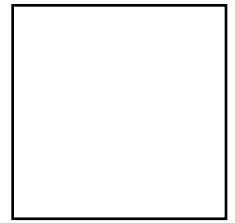
On October 17, **Raine Diaz**, whose 4-year-old nephew has TSC, reached out to her general manager at Wal-Mart in New



Caney, Texas to see if they would help lend a hand in raising money for the TS Alliance by holding a garage sale. More than 90 Wal-Mart helped raise \$1,210, while an additional \$5,000 grant was awarded from Wal-Mart due to their employees volunteering their time to make this fundraiser take place. A very special thank you to Raine, her sister Robyn, her friend Sheniqua and the entire Wal-Mart family for all you have done to raise awareness in your community and helping getting us one stop closer to finding a cure!



801 Roeder Road, Suite 750  
Silver Spring, MD 20910



Please let  
us hear  
your voice.

Participate in the 2010 TS  
Alliance Online Survey.

Available now at

[www.tsalliancesurvey.com](http://www.tsalliancesurvey.com)