



*Please consider the Tuberous Sclerosis Alliance in your estate plans.*

## PLANNED GIVING

Each year, 72 percent of Americans give to charities. But only 5.7 percent leave charitable bequests in their wills, keeping their charitable gifts alive once they've passed away.

The members of the TSC community are vital to the success of the organization by committing time, money and resources to the Tuberous Sclerosis Alliance (TS Alliance). The commitment can continue by including the TS Alliance in your estate plans. Many people believe that they don't have enough assets to make an estate gift. That is simply not the case.

All members of the TSC community, friends and relatives can help regardless of income and size of gift. Each estate gift will have a tremendous impact on endowing the Tuberous Sclerosis Alliance and its mission.

ANYONE CAN INCLUDE  
THE TUBEROUS SCLEROSIS  
ALLIANCE ENDOWMENT  
FUND IN THEIR ESTATE  
PLANNING ... INCLUDING YOU

The endowment fund ensures a permanent source of funding to better serve families touched by TSC by paying out earnings on the principal. The Tuberous Sclerosis Alliance Endowment Fund is a pool of invested funds that generates steady, ongoing income for the TS Alliance.

want to "DO SOMETHING" for everyone who lives with the challenges of TSC. Here's your opportunity.

**Take the National Family Conference local.** Last year's membership survey determined that the National Family Conference was the most valued support program we offered AND was experienced by the smallest percentage of our members. Thus, one of our goals this year is to create a "Regional" version of the same concept – a program similar in purpose and content, but more accessible economically/geographically to a larger number of constituents. We'll be doing three pilot runs (NYC Metro area, Minneapolis and Boston). We expect to roll it out to more cities the next year. Current plans are that this will NOT replace the National Family Conference – just augment it. We still intend to hold the National Family Conference.

**Better serve adults with TSC.** As I commented in the last issue of *Perspective*, TSC is not a childhood disease. 75% of those who have the disorder are adults! Early intervention (seizure control, specialized education, etc.) is obviously critical and parents of recently diagnosed children tend to be our organization's most fervent (and appreciated) recruits. Hence appropriately for a developing advocacy organization such as ours, our efforts have been focused on early life issues.

The good news is our children grow to be adults. As adults, they have a new set of issues (vocation, housing, ongoing education, transportation, relationships, insurance, new healthcare concerns, etc.). A personal example: While our organization has made terrific progress in establishing TSC clinics throughout the US, the closest TSC clinic that specializes in care of adults with TSC is 2,500 miles from our home in California. Suffice it to say, we have some work to do and it is time we get started. I urge all friends and family members of adult individuals with TSC, as well as those adults them-

selves, to become, or re-become actively involved in this organization; to make your needs known; and help us find ways to meet those needs.

**Build on science and research momentum.** Obviously, we continue to fund and direct many research efforts. New initiatives this year include the development of an overarching, long range, comprehensive TSC research plan that incorporates the results of last years medical research consensus conference and will serve as an authoritative TS Alliance statement. The plan will be used to help direct federally funded research. It will be used to guide TS Alliance funded research. And it will be used to attract funding from major institutions and trust funds to TSC research. Concurrently, we are forming a Scientific Advisory Board, comprised of high profile, very highly respected scientists, to oversee and advise us on the course of basic research.

Another major objective for the year, which we are confident we will accomplish, is to get the NINDS (National Institute of Neurological Disorders and Stroke) to sponsor a national clinical alliance and database to collect, organize and disseminate data on the clinical treatment and progress of those afflicted with TSC. This will prove hugely valuable to researchers and clinicians alike.

**Plan for the future.** I have asked former board chairman, Marion Adams, to lead an ad hoc task force to develop a three to five year strategic plan for our organization. He's accepted. It has been five years since our last long range strategic planning effort. Much has changed since then – all for the better. The opportunities before us today are far more tangible and exciting. The purpose of the strategic planning effort is to ensure that we optimize the use of our resources and focus on those opportunities that are most likely to yield important results.

Intimately related to plans for the next several years is the challenge of replacing outgoing board members with individuals that can help take the TS Alliance to the "next level". In July, 2004, six of our twenty four current Board Members reach the end of their term limit. Each of these individuals has played key roles in the leadership of the organization. They will be missed.

Knowing them well, I can assure you they would each request that we replace them with someone even more capable. It goes without saying that we are looking for individuals of high integrity, with sound judgment, proven leadership skills, and a willingness to invest significant time and efforts in pursuit of our mission. Additionally, we are looking for certain specific skills/background that collectively will provide the perspectives and expertise the organization needs to move forward. Included among these are: Medicine/Research (e.g. a researcher or clinician interested in TSC or an executive within the medical industry), Finance/Accounting (e.g., a corporate CFO/controller or a senior partner at a major auditing firm), Executive Management (e.g. a senior officer of a substantial company), Public Relations (e.g. a partner at an advertising/PR firm), Government Relations (e.g. a former elected official or lobbyist) and Law (a partner at a significant law firm). While a family connection to TSC would be a plus, truthfully, we parents are very well represented on the Board already and always will be. What we need today is more expertise, great networks of potential donors and professional objectivity. We'd appreciate your help in identifying candidates. This is a great cause. We are becoming a great organization. We can attract great people! We will achieve our mission.

Thanks.  
-Scott

# HELLO FROM THE ADULT COMMUNITY!

Since the adult advisory committee got started in July, we've been working hard to get organized and we've assembled a solid team of diverse leaders that I'd like to introduce. We've asked each of them to participate in an operating board committee as well as one of three projects that the committee agreed to take on initially.

Barbara Alvarez is an adult in Florida. She's a stay-at-home mom, serves as the vice chair of the Florida community alliance and will join the government relations board committee to help find ways adults with TSC can help in lobbying efforts.

Nicole Seefeldt is an adult in New York and works as an associate

editor. She leads the Internet project team, which develops ideas on using the Internet as a tool to spread awareness and communicate with the adult community. Nicole will also join the board's conference committee to help plan regional conferences as well as the online community alliance committee.

Gwendolyn Pryor is an adult in Michigan and mother of three adopted children. She will lead the communications project team and participate on the board's communication committee to help the TS Alliance incorporate adult issues and perspectives in newsletters, brochures and marketing materials.

Todd Tayar is an adult in Maryland and works as a pediatric dentist. He

will bring the adult perspective to the board's conference and clinic committees and will participate on the journal project team that I am leading. That team will help adapt currently available journals geared toward parents for use by adults.

All of the project teams also include many other adults with TSC that have expressed interest in participating. As you can see, we're well on our way to getting our voices better heard and all of us welcome any input from each and every one of you.

Best,

*Yukari Iwatani Kane*  
yukari@iwatani.org

## HONORARIUMS (July 2003 – August 2003)

*You can honor a friend or family member for an important occasion with a gift to the TS Alliance. It is a wonderful way to send a birthday or anniversary wish, or congratulations for retirement, a job well done, graduation, etc. Please include the name and address of the individual being honored so that acknowledgement of your kind donation can be sent.*

Henry Albers  
Steve (Caden) Barness  
Xavier Barr-Malec  
David Beldner  
Kristen Bosley  
Kerri Buonomico  
Sally Conner  
Christopher Daly  
Blanca Danos  
Julianne Delay  
Stephen Dennis  
Eleanor Ebner

Jeremy Elias  
Helen Fertig  
Kristen Fink  
Hunter M. Forry  
Bailey Roland Giannini  
Rocky Goodman  
Cort Hoover  
Benjamin Hutchinson  
Foster E. Hyde  
Annie Johnson  
Cathy Krinsky  
Lauren E. Krinsky

Hannah LaForte  
Tommy J. Lindsey  
Hannah Linsin  
Patty Littlepage  
Alyssa C. Loftus  
Irving Lotstein  
Rachel Love  
Maria Lubrico  
Charles Malatesta  
Olivia R. Malatesta  
Edith Maniker  
Marissa Martinez

Andres Marton  
Herbert Marton  
Megan Mauro  
Wendy D. McKay  
Olivia A. Moore  
MaryJane Mudd  
Ian & James Mulvey  
Katie Munneke  
Herbert Paperman  
Jack Poutasse  
Charles Regeski  
Christine Ritchie

Anna Russell  
Robert A. Seymour  
Christopher S. Sherman  
Claire Siegel  
Sydney G. Simmons  
Drew Sklarin  
Peter Starer  
William Steinka  
William G. Ward  
Murray Waxman  
Barbara Zimmerman

## MEMORIALS (July 2003 – August 2003)

*Contributions are given to the Tuberous Sclerosis Alliance at the request of family members in memory of their loved ones. We extend our sympathies to the family and friends of those memorialized below. These generous contributions support the progress of our mission to find a cure for tuberous sclerosis complex.*

Ruth A. Baker  
Dorothy J. Benaway  
Patricia M. Burmeister  
John Carrington  
Anthony J. Christiano  
Anne Clarke

Herbert Eggers  
Lillian Feingold  
Stanley Fuld  
Alfred C. Fulmor  
Lois S. Hatton  
Cynthia R. Holman

Sam Hornstein  
Nancy Lippman  
Alicia R. Lochner  
Christopher L. Mullins  
David Pattis  
John Day Peake

Ruth K. Runeborg  
Danny Sherman  
Marjorie Sturtz  
Plumer B. Tonsmeire  
Kristen Van Daele  
Janet L. Vaughn

Jean Wagner  
Brian D. Wright

## TUBEROUS SCLEROSIS ALLIANCE STAFF CONTACT INFORMATION

All TS Alliance staff members can be reached at the toll-free office number (800) 225-6872, locally at (301) 562-9890 or through their e-mail addresses.

**Michael Coburn**  
President and CEO  
mike.coburn@tsalliance.org

**Becky Bull**  
Vice President of Development and Communications  
Fund raising programs, major gifts, special events, membership and volunteer program  
becky.bull@tsalliance.org

**Kari Luther Carlson**  
Vice President of Community Outreach  
Volunteer committee development and major gift fund raising  
kari.carlson@tsalliance.org  
alternate phone: (763) 434-3455

**Linda Creighton, M.S.W., L.C.S.W.-C.**  
Program Director, Advocacy and Outreach  
Patient and family advocacy and support  
linda.creighton@tsalliance.org

**Cheryl Dunigan, Ph.D.**  
Vice President of Scientific Affairs  
Provide direction and coordination of scientific activities  
cheryl.dunigan@tsalliance.org

**Nicole Engdahl**  
Director of Donor Relations  
Development, major gifts, annual campaigns  
nicole.engdahl@tsalliance.org

**Shanté Jones**  
Office Manager  
Oversight of admin staff and daily operations  
shante.jones@tsalliance.org

**Chasity Joyner**  
Administrative Assistant  
Reception, fulfillment, admin support  
chasity.joyner@tsalliance.org

**Holly Knorr**  
Director of Medical and Scientific Alliances  
Professional education, National Family Conference  
holly.knorr@tsalliance.org

**Marybeth Leongini**  
Director of Communications  
Publications, media relations  
marybeth.leongini@tsalliance.org

**Danielle Mayo**  
Administrative Assistant  
General administrative support  
dmayo@tsalliance.org

**Patricia Okolie**  
Gift Processing/Data Entry Administrator  
Gift processing, data entry, updating constituent records  
patricia.okolie@tsalliance.org

**Suzanne S. Peeler**  
Controller  
Finance and risk management  
suzanne.peeler@tsalliance.org

**Vicky Whittemore, Ph.D.**  
Co-Director, Center Without Walls & Senior Science Advisor  
vicky.whittemore@tsalliance.org

# THIS-N-THAT

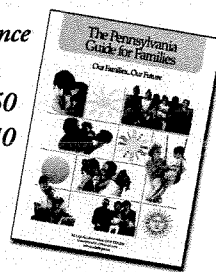
## STATE GUIDES

*The Pennsylvania Guide for Families – Our Families...Our Future*

To obtain a copy of the PA guide go to the [www.state.pa.us](http://www.state.pa.us) Web site.

If you have a state guide please share it with others by sending a copy to me:

*Tuberous Sclerosis Alliance*  
Attn: Linda Creighton  
801 Roeder Rd. Suite 750  
Silver Spring, MD 20910



## SCHOOL DAYS

It's that time again and schools are back in session. To celebrate the season, GiveKidsGoodSchool.com is planning a back to school campaign. There will be a series of actions and activities to make sure our schools and our kids have the resources they need to succeed. Once you have signed onto the site you will receive notices about congress, educational news, budgets and lots more. Eva Fox, the internet coordinator welcomes your comments. Send them to:

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

## HEALTH CARE TRANSITION FOR YOUTH DIGEST

The National Center of Medical Home Initiatives for Children With Special Needs located within the American Academy of Pediatrics has just announced a new and improved site at <http://www.medicalhomeinfo.org>. The Web site is committed to providing resources, tools and guidance to improve the systems of care by connecting parent/caregivers to a medical home.

## LARGE PRINT HELP

Many individuals with TSC have sight complications. For the constituents who have not been able to read our fact sheets,

publications and newsletters because the print is too small, there is help by downloading Adobe Acrobat (which is a free program) at <http://www.adobe.com/products/acrobat/readstep2.html>.

## ADA WATCH

Keep informed and updated by the National Coalition for Disability Rights. Receive free monthly newsletters by signing up for ADA Watch at [info@ADAwatch.org](mailto:info@ADAwatch.org).

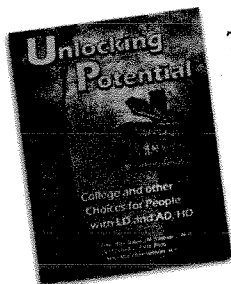
## SPEAK UP...SPEAK OUT!

The TS Alliance has volunteers who are participating in the Support Network (SN) program in 43 States. We are excited about the dedication and enthusiasm of these individuals! Our dream is to have a network of empowered volunteers who provide enhanced support to those who seek understanding and information in all 50 States.

Are you a parent and/or adult with TSC living in one of the following States: ID, MS, MT, NM, UT, VT or WV? Are you interested in sharing your personal experiences with others? Would you be available to offer emotional support to someone who is on the same journey as you? Are you aware of some community resources that may benefit a parent or adult who has just been diagnosed with TSC? If you can answer yes to the above questions then speak up and speak out as one of the SN volunteers! We offer training to you in the comfort of your home and provide you with an informational manual. As a volunteer you are not expected to be an expert; you are meant to be a caring person who has personal experiences with TSC and is willing to listen to others with an open heart. If you feel you might fit the description of a SN volunteer and want to learn more about the program contact Kari Carlson at the TS Alliance.

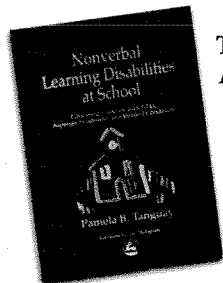
# USEFUL RESOURCES

## BOOKS



**Title:** *Unlocking Potential*  
**Author:** Taymans, Juliana, M., Ph.D., West, Lynda, L., Ph.D., Sullivan, Madeline, M.D.  
**Source:** Woodbine House, 6510 Bells Mill Rd., Bethesda, MD 20817  
 Phone 800-843-7323

**Abstract:** *Unlocking Potential* is an indispensable tool for high school students with learning disabilities and ADHD who are preparing for life after graduation.



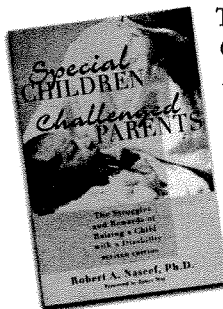
**Title:** *Nonverbal Learning Disabilities at School*  
**Author:** Tanguay, Pamela, B.  
**Source:** Jessica Kingsley Publishers Ltd, 116 Pentonville Rd., London, N1 9JB, England and 325 Chestnut St., Philadelphia, PA 19106

**Abstract:** The book is a must have tool for parents who want the best for their child with a nonverbal learning disability. The book is full of practical suggestions and ideas for appropriate, workable methods that can be utilized to meet the challenges of educating the child with a NLD.



**Title:** *Special Siblings*  
**Author:** McHugh, Mary  
**Source:** Paul H. Brooks Publishing Co., P.O. Box 1064, Baltimore, MD 21285

**Abstract:** The book captures the joy and the challenges of having and being a "special sibling." This book is a must read for teen and adult siblings of people with disabilities.



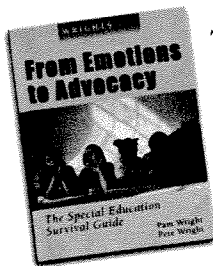
**Title:** *Special Children, Challenged Parents*  
**Author:** Naseef, Robert, A., Ph.D.  
**Source:** Paul H. Brooks Publishing Co., P.O. Box 10624, Baltimore MD 21285  
 www.brookespublishing.com

**Abstract:** When a child is born a family changes forever. If that child has special needs, the changes can be overwhelming. The book acknowledges the difficulties in dealing with emotions & recognizes that fathers and mothers deal with the child's disability differently. Dr. Naseef shares his personal journey with the readers. It's a valuable guide for parents of children with disabilities.



**Title:** *My Brother, Matthew*  
**Author:** Thompson, Mary  
**Source:** Woodbine House, 6510 Bells Mill Rd., Bethesda, MD 20817, Phone 800-843-7323

**Abstract:** The story is genuine in its depiction of the impact of a child who has special needs on family life and in its intention to help ease the way.



**Title:** *From Emotions to Advocacy; Special Education Survival Guide*  
**Author:** Wright, Pam, Wright, Pete  
**Source:** Harbor House Law Press, Inc., Hartfield, Virginia 23071, phone 804-758-8400

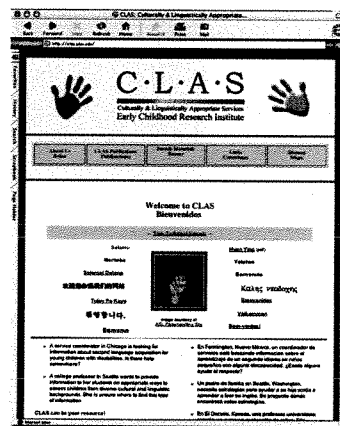
**Abstract:** The guide gives you step by step instructions on how to plan, prepare, organize and get quality special education services. It's a practical, user-friendly book.

## ONLINE RESOURCES

**Title:** *Charitable Medical Patient Air Transport HELPLINE*

**Source:** [www.patienttravel.org](http://www.patienttravel.org) and <http://www.npath.org/>

**Abstract:** The National Patient Travel Helpline provides information about all forms of charitable, long-distance medical air transportation.



**Title:** *CLAS: Culturally & Linguistically Appropriate Services*

**Source:** [clas@ericps.crc.uiuc.edu](mailto:clas@ericps.crc.uiuc.edu), 800-583-4135 and <http://clas.uiuc.edu>

**Abstract:** A collaborative effort between colleagues representing diverse cultural roots, the CLAS Early Childhood Research Institute collects and describes early childhood/early intervention resources that have been developed across the United States for children with disabilities, their families and the service providers who work with them.

**Title:** *Health Care Transition for Youth Digest*

**Source:** [transition@mchenet.ichp.edu](mailto:transition@mchenet.ichp.edu)

**Abstract:** Once you have registered for this free e-mail service you will receive monthly e-mails from The Health Care Transition for Youth With Special Needs. The e-mails give the reader new Web sites to explore, consumer updates, loads of funding information and much more.

# VOLUNTEER OUTREACH PROGRAM — BUILDING ON OUR SUCCESS

Volunteers and a grassroots movement make incredible things possible - accessing \$3 million through the Department of Defense Congressionally Directed Medical Research program for TSC research; delivering more than 4,800 packets of information on TSC to neurologists, pediatricians, nurses, geneticists/genetic counselors and school systems; increasing the visibility of TSC and the TS Alliance through incredible articles in newspapers and magazines across the country; offering a lifeline to every individual who contacts the TS Alliance looking for support and information.

All of this is possible because of the incredible 900 volunteers that have donated their time, talent and incredible passion. Thank you! Below are some volunteer spotlights and some areas where you can help make a difference.

## OUTREACH AND AWARENESS CAMPAIGN

This year, there will be two focus areas in our Outreach and Awareness Campaign. In the fall, volunteers will deliver materials to hospitals, clinics or places where individuals may receive a diagnosis of TSC in their area. Materials include a poster for each facility, resource brochures with information on the TS Alliance and our available information and services. We hope this provides more immediate help to individuals or families when they first hear the words tuberous sclerosis complex.

A physician referral list is also being created. Volunteers will be given forms that can be delivered to their recommended physicians. The

physician simply fills out the form and returns it to the TS Alliance.

The spring campaign will focus solely on congressional outreach. This has become extremely important in advocating for new and increased dollars for TSC research through the Department of Defense Congressionally Directed Medical Research Program and the National Institutes of Health. Volunteers will be asked to contact their United States Representatives and Senators. Materials include a fact sheet, talking points, sample letters and lists of United States Senators and Representatives.



## SUPPORT NETWORK SPOTLIGHT: LAURA JENSEN

This month, the TS Alliance is proud to announce

a new Fact Sheet on Infantile Spasms in TSC. The Fact Sheet was co-authored by Laura Jensen and Vicky Whittemore, Ph.D. It contains important information for both parents of children with TSC and health care providers. A copy of the Fact Sheet can be downloaded from the TS Alliance Web site or requested by phone. The publication would not have been possible without the passion and determination of Vicky Whittemore and Support Network Volunteer Laura Jensen.

Laura has lived in the Seattle area for the past 14 years. She and her husband, Pete, have two boys, Alex, 13, and Carl Eric, 11. Carl was

diagnosed with TSC at nine months. The story of his early years can be found in the TS Alliance publication, *Living with Tuberous Sclerosis*.

In 1997, Laura worked with the TS Alliance (then NTSA) to put together a Regional Medical Conference on TSC for the Pacific Northwest. She also began to coordinate a local support group for the Puget Sound region in Washington State. The following year, she participated in the TSC Consensus Conference in Annapolis. In 1999, at the National Family Conference in Washington, DC, she received the Susan Diaz Professional Education Award. She was on the planning committee for the National Family Conference in San Diego in 2001 and continues to coordinate a local support group. We are most grateful for her long-term dedication to the TS Alliance and to helping others that live with the challenges of TSC.

## SUPPORT NETWORK UPDATE

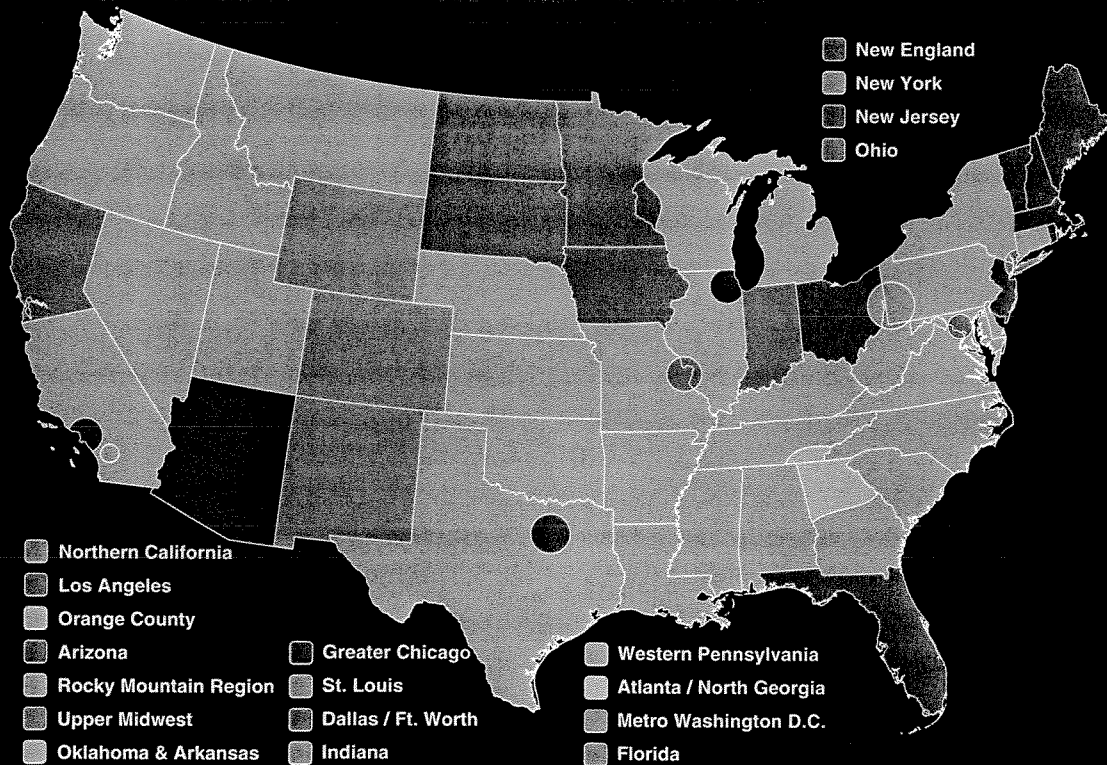
The Support Network now has 227 volunteers with representatives in 43 states and Puerto Rico. We are currently seeking volunteers from the states of Idaho, Mississippi, Montana, New Mexico, Utah, Vermont and West Virginia.

## COMMUNITY FUND RAISING

For updates on Community Fund Raising, please see pages 3-4.

If you are interested in becoming a volunteer, please contact Kari Luther Carlson at 763-434-3455 or [kari.carlson@tsalliance.org](mailto:kari.carlson@tsalliance.org)

# TS COMMUNITY ALLIANCES



Online  
Community  
Alliance

## ONLINE COMMUNITY ALLIANCE

The Online Community Alliance includes four different e-mail based list serves for Adults, Parents and Caregivers, Grandparents and Parents of Teens Transitioning to Adulthood. The list serves were created so that individuals affected by TSC would have an easy and immediate way to communicate.

Three times each year, the leadership team invites a guest poster to take questions and offer their expert advice. Previous guest posters include Dr. John Bissler from the TS Clinic at Cincinnati Children's Hospital Medical Center and Dr. Bryan King, a behavioral specialist, from Dartmouth Medical School. *A dermatologist will be the next guest poster planned for late October.*

Subscription is absolutely free. You can join by visiting the TS Alliance Web site at [www.tsalliance.org](http://www.tsalliance.org), clicking on Connecting with Others and then Online Community Alliance.

## NEW TSC CLINIC IN SOUTHERN CALIFORNIA

Congratulations to Lee Ann Addison, Rose Marie Alex, April Cooper and Chris Sheffield who have worked for the past two years to open a TSC Clinic in Southern California. The dream became a reality this summer when the



*Pictured: Will Cooper, Dr. Stephen Ashwal and Alfred Cooper*

Loma Linda University Health Care Tuberous Sclerosis Clinic opened.

In tribute, the third annual Southern California TSC Family Gathering was held at Loma Linda

University Medical Center on Sunday, August 3, jointly sponsored by the TS Alliance of Orange County and the TS Alliance of Los Angeles. Presentations were given during the



*Dr. Shu talking with those that attended the Family Picnic.*

gathering by clinic director, Dr. Stephen Ashwal, adult neurologist Dr. Lori Uber-Zak and neurologist Dr. Stanford Shu.

The Southern California Clinic Committee has now expanded its membership and will work closely with the Loma Linda University Health Care TS Clinic to ensure that the needs of the community are being met. New members include Terry Merkel, Roxanne Rios and Teresa Serna (Clinic Coordinator).

# the seasons are Changing...

This Holiday  
Season, write  
a letter  
and help

**STAMP  
OUT  
Tuberous  
Sclerosis**

*Join volunteers across the  
country and take part in the  
Tuberous Sclerosis Alliance's largest  
and fastest growing nationwide event!*

## What is the STAMP OUT letter writing campaign?

During this holiday season, we are asking volunteers across the country to include a **Stamp out TS** gift envelope with their regular holiday card or letter to request a donation on behalf of the Tuberous Sclerosis Alliance (TS Alliance). **Stamp out** is an easy way to make a difference in the lives of people affected by raising vital funds. It also provides a nice way for people to make an end of the year charitable contribution. Funds raised will support family services, research and outreach programs while raising awareness of TSC. It's that simple — but we need your help.

## Sign-up Today!

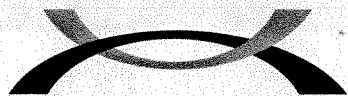
During this season of giving, you can make a difference and help **STAMP OUT tuberous sclerosis!**

To sign up to participate or for more information,  
contact Nicole Engdahl at the TS Alliance:

Phone: (800) 225-6872

E-mail: [stampout@tsalliance.org](mailto:stampout@tsalliance.org)

Web site: [www.tsalliance.org](http://www.tsalliance.org)



Tuberous Sclerosis Alliance

801 Roeder Road, Suite 750  
Silver Spring, MD 20910

Non-Profit Org.  
U.S. Postage  
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Permit No. 6041



up front

## JULIANNE MOORE

A chance meeting spurs her to action

Tom Lindsey spent three years unsuccessfully lobbying celebs to help raise awareness of Tuberous Sclerosis Complex. Then he spotted Julianne Moore on a New York City street last April. "I thought, 'This is the opportunity of a lifetime. I can't let her get away,'" he says. With his then 3-year-old son Tommy—who had been diagnosed with TSC at five weeks old—in tow, he raced up the block to talk to the actress about the genetic disorder, which causes benign tumors to form in many organs, often triggering brain dysfunction and autism. "All this information was pouring out of him," says Moore, who was drawn to Tommy, then recuperating from recent three-part brain surgery to alleviate his seizures. "I looked down at this kid, and he's got stitches all over his head. It was heartbreaking."

Moore agreed to walk to Lindsey's truck to get some more information about TSC, which afflicts more than 1 million people worldwide. There, Tommy, now 4, helped seal the deal. "The next thing I know," says Lindsey, 34, a phone company worker, "Tommy climbed out of the stroller, Julianne's holding him, Tommy's kissing her, she's cracking up and he's cracking up." A week later Moore called and agreed to attend the following month's Rock for a Cure 2003 TSC fund-raiser on Staten Island, N.Y., donating makeup, handbags and clothing as door prizes. "I was so overwhelmed," she says.

So were the Lindseys. Moore not only helped to raise \$80,000 at the event but also brought media coverage to the Tuberous Sclerosis Alliance, a non-profit organization dedicated to finding a cure for TSC for the first time in its 28-year existence. After Tommy's diagnosis in 1999 (he has been relatively seizure-free since his April brain surgery), Lindsey and wife Peggy, 34, "promised each other we would raise awareness about this disease," says Lindsey, "and it's now actually happening, all because I ran into Julianne Moore."

# Touched by a STAR

When celebrities shine their luster on a cause, small miracles and big research dollars often follow

Sure, some celebs may align themselves with charities to enhance their public image: a donation here, a photo op there. But many others take such causes far more seriously.

"The only thing celebrity is good for is to bring attention to things that need attention," says Julianne

Moore, who used her stardom to shine a light on Tuberous Sclerosis Complex, a little-known yet relatively common genetic disorder.

Stars are often persuaded to go the extra mile through a chance encounter that over time grows into a heartfelt and deeply personal connection. As the following stories show, these relationships can be both painful and poignant.

"He is a darling kid," says Moore of Tommy (at May's TSC fund-raiser on Staten Island, N.Y.). "He's so sociable. You really connect."

August 5, 2003

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By Patricia McAdams

# Colleen's Comeback

## A Family's Fight for Their Daughter's Life

OCTOBER 1986 — After days of medical testing, Sue and Burt Goodrich stood in the hallway of a hospital miles from their home, hoping for some good news about their five-month-old daughter, Colleen, who had begun having seizures earlier in the week.

The hours passed slowly until, at last, Sue spotted their daughter's physician making rounds with students. He had come highly recommended and they trusted him completely. The doctor caught Sue's eye, but turned away and continued to talk with his students. When he made no effort to speak with her, she approached him. She remembers the morning clearly. It may well have been the worst day of her life.

"What's wrong with my daughter?" she asked.

"Your daughter has tuberous sclerosis [TS]," he said, starting to walk away. Sue trailed after him.

"What exactly does that mean?"

"It means her IQ is in the teens. She will never walk or talk; she'll be profoundly retarded and autistic and never know you." TS is a genetic disorder that causes benign tumors to form in many different organs—primarily in the brain, eyes, heart, kidney, skin and lungs. The specialist had one last comment: "Put her in an institution."

This is a story not so much about how one family's life was changed forever because of a devastating disorder, but of how one grief-stricken mother refused to not love her child. It's about how she stayed positive and learned to make decisions, listening to her heart to know what was best for Colleen even when her doctors disagreed.

Before the day was over, Sue and Burt had learned that Colleen had tumors on her brain, her kidneys and her heart. The one on her heart consumed 86 percent of the right ventricle, and yet the blood had found a path around it. Thirteen specialists gathered together couldn't decide what to do, Sue

recalls. Half wanted to operate immediately. The other half agreed that Colleen was too young and would surely die on the table. Further confusing the issue was that, with TS, as the heart grows larger, the tumor sometimes recedes.

"I told them Burt and I needed 24 hours to make a decision," Sue says. "We needed time to think."

The next day Sue unhooked Colleen from her machines. Not a single doctor had offered any hope that Colleen could live beyond her first birthday. Sue decided to focus on giving her little girl a good life for as long as she could.

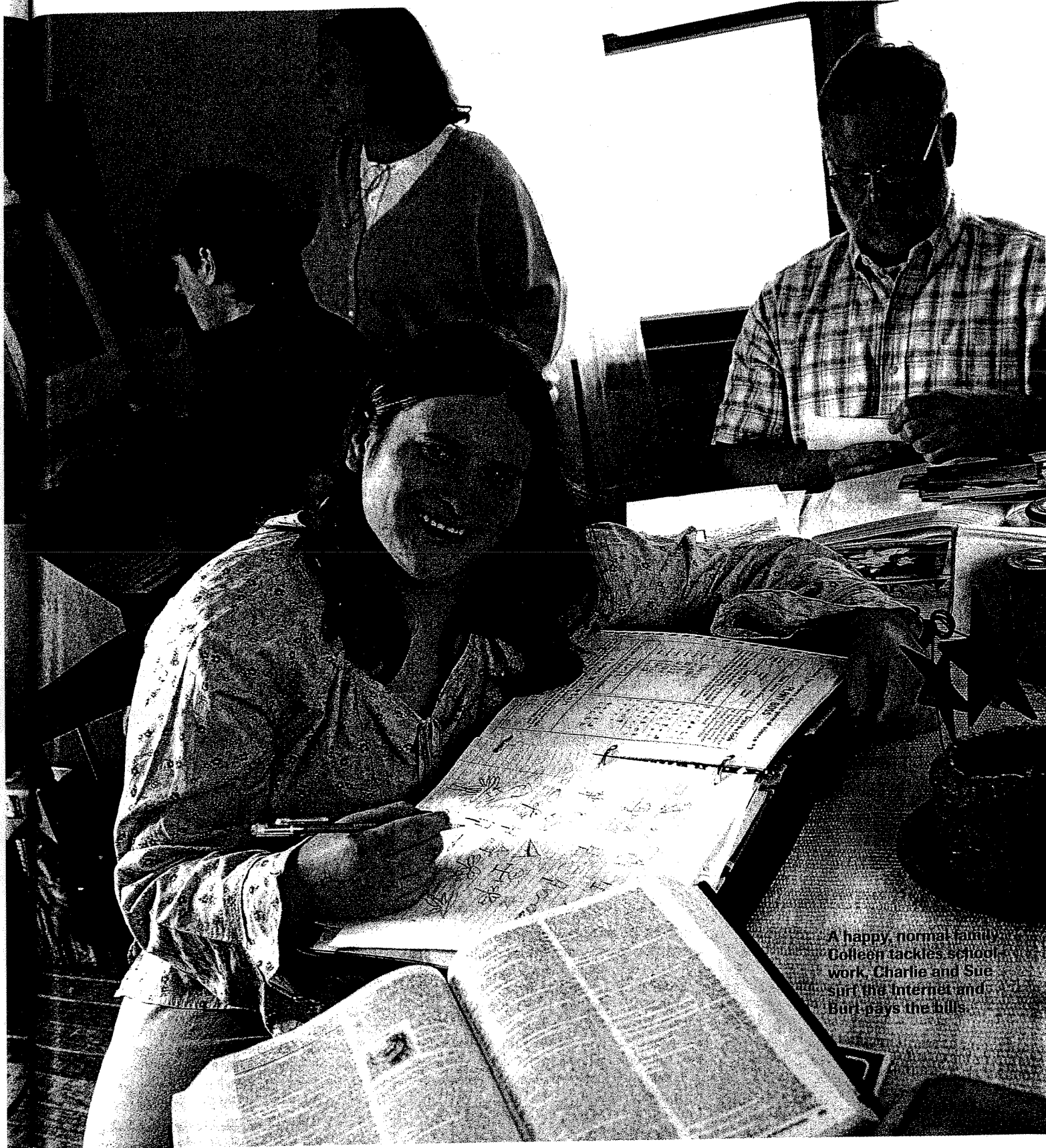
"There are things worse than dying, and one of them is living poorly," she said. "We took Colleen home so she could be with people who loved her."

An ultrasound early in Sue's pregnancy had given no indication of a problem. Everything had seemed normal. Less than a week earlier she and Burt had known only the contentment of a young couple with two beautiful children, Charlie just two, and Colleen. They had a home in Lancaster County, Pennsylvania, surrounded by Amish farms and big white barns. Everything had been perfect until quietly, while sitting on her mom's lap that last Saturday evening, Colleen had started having mini-seizures involving a rhythmic twitching of her head, lasting about three minutes.

An MRI, CAT scan and echocardiogram later, Sue knew more about TS than she ever wanted to know, and none of it was good. The disorder, which is carried by either of two known genes, has no cure. It is transmitted either through genetic inheritance or as a spontaneous mutation. The symptoms and the degree of severity of this disorder differ greatly from one person to the next, according to Sue. "People with TS include some who are doctors and attorneys and others who never get out of bed," she explains. "You can't fix the

*Patricia McAdams is a freelance science writer who lives in Pennsylvania.*

“There are things worse than dying, and one of them is livi



A happy, normal family: Colleen tackles school work, Charlie and Sue surf the Internet and Burt pays the bills.

poorly. We took her home to be with people who loved her. ”



Colleen (right) at about 2 with her brother, Charlie, 3.

**Uncommon Courage** From page 56  
 problem. All you can do is take care of symptoms."

Caring for the children kept Sue busy for part of the day but there were still too many hours for worrying. Then a few weeks later she realized she had a choice. "I could just sit there and wallow in self-pity, or I could get up and do something to help medical research for TS," she says. "Let me do something. Let me have a yard sale."

**S**ue and Burt had lots of friends who pitched in to help the family gather things to sell. Steve and Dick Hutton, the owners of the nursery where Burt worked helped too, contributing rhododendrons and roses. Although it was November, the plants were a huge hit and the sale a success. Sue knew of neurologists at the University of Chicago who were working on TS research. "I sent them a check for \$1,200 with a note: 'We had a yard sale and we did okay.'"

So the Goodriches cleaned up their yard, Colleen's first Christmas came and went, and soon it was January. Home alone with the children one evening, Sue was sitting on the rug watching TV. Colleen was moving around in the early

stages of creeping. "She came up and I said, 'Hi, Col,' and she snuggled close and put her head on my lap. Then I looked down again and I said, 'Hey, your color's not good.' I picked her up and that was it. She was gone. She had no pulse," said Sue. "She wasn't breathing."

Colleen had been at high risk for infant death and wore a monitor when she slept, but Sue had never expected anything like this. Nevertheless, a nurse by profession, she instinctively started CPR, while walking to the phone. First, she called 911 and then a neighbor to come care for Charlie. Burt was out of town and unreachable at that hour. Then she waited three...four...five minutes.

The neighbor came for Charlie, and then the ambulance pulled up. They hopped in and sped toward Lancaster, 25 miles away. Colleen was breathing, but her heart was racing and beating abnormally all the way into town.

In the emergency room the doctor shocked Colleen's chest with a paddle to stop the fibrillation and restart her heart properly. With that, the baby started having seizures, but this time they were continuous, with one cascading into the next without interruption. These were full-fledged grand mal seizures: Colleen's tiny unconscious body was literally being lifted off the cot and shaken violently, her quivering limbs flailing like a lifeless rag doll. "She can't do this," Sue said to the doctor, fearful that the convulsions would destroy her child's brain. The doctor agreed. "But I'm afraid if I give her anything, it will stop her heart again."

Sue thought back to the day when she and Burt had wrestled with the decision about open-heart surgery for Colleen. "Any choice we make," he had said at the time, "no matter what happens to Colleen—even if she dies—was the best we could do, and we were 100 percent right." His comments had crystallized her own thinking so well that it had helped her make decisions ever since.

Sue looked at the doctor. "If her heart stops again, she's

## Shopping for a Cause

Ordinarily, Jennersville, Pennsylvania, in southern Chester County is a sleepy village where the only sounds to be heard as the sun pokes its head over the horizon are the early-morning chorus of birds and maybe the clip-clop of a trotting horse pulling a buggy. But on the Saturday of Memorial Day weekend each year, a procession of varied vehicles—pickup trucks, SUVs, Amish buggies—begins wending its way into town long before dawn. Early arrivals unpack wagons and wheelbarrows and spread out colorful blankets.

By 5:30 A.M. hundreds of men, women and children line the 1,320-foot perimeter of the nursery area roped off with yellow caution tape. Finally, the megaphone shatters the silence as Sue Goodrich thanks everyone for coming to the Annual Charity Shrub Sale to benefit the Tuberous Sclerosis Alliance.

The first few minutes are like a stampede with people running for plants and dozens of volunteer cashiers in yellow T-shirts and aprons fanning through the crowd. Everyone is scrambling for shrubs as though they were being given away. Actually, with roses selling at three for \$10, they were a real bargain.

After 16 years Sue is still amazed. Beyond anyone's wildest imagination, the sale has evolved into a local legend.

Veteran shoppers Dawnmarie Ciarrocchi and her dad Carl Priemon are enthusiastic. "We came for four roses," Ciarrocchi says jubilantly, "but instead we got about twenty and three flats of annuals—so far!"

"But what better way to contribute money to a charity," says Priemon, who has been coming to the sale for more than 10 years. "We pull in about 5:30 A.M. to get a good spot. It used to be that the sale was only for the locals, but not anymore. We met some folks who got up at 3 A.M. to drive from Baltimore."

Sue and her husband, Burt, serve as the official coordinators, but the sale could never happen without the generosity of many people, especially Steve and Dick Hutton, president and former president of The Conard-Pyle Company the wholesale nursery where Burt has been working for more than 20 years. The company donates trees, shrubs, perennials and their StarBrand specialty roses for the sale.

"The Huttons' commitment is amazing. They adopted our family above and beyond



Colleen Goodrich (right) and volunteer Peggy Hart at the 2002 Annual Charity Shrub Sale.

what anyone could imagine," says Sue.

"Sue and Burt saw the potential in the plant sale and, with their energy and enthusiasm, sold us on helping to make it a bigger thing," says Steve Hutton. In addition to the Huttons, Marc and Leonie Brooks of Elverson, Pennsylvania, have been donating annuals and hanging baskets since the mid-1990s.

According to Marybeth Leongini, director of communications for the TS Alliance, since 1986 the shrub sale has raised more than \$1 million for TS research programs. "Sue and Burt Goodrich are an inspiration," she says.

Please read this summary carefully, and then ask your doctor about NEXIUM. No advertisement can provide all the information needed to prescribe a drug. This advertisement does not take the place of careful discussions with your doctor. Only your doctor has the training to weigh the risks and benefits of a prescription drug for you.

## Nexium® (esomeprazole magnesium) 20-MG, 40-MG Delayed-Release Capsules

**BRIEF SUMMARY** Before prescribing NEXIUM, please see full Prescribing Information. **INDICATIONS AND USAGE** NEXIUM is indicated for the short-term treatment (4 to 8 weeks) in the healing and symptomatic resolution of diagnostically confirmed erosive esophagitis. **CONTRAINDICATIONS** NEXIUM is contraindicated in patients with known hypersensitivity to any component of the formulation or to substituted benzimidazoles. **PRECAUTIONS** Symptomatic response to therapy with NEXIUM does not preclude the presence of gastric malignancy. Atrophic gastritis has been noted occasionally in gastric corpus biopsies from patients treated long-term with esomeprazole, of which NEXIUM is an enantiomer. **Information for Patients** NEXIUM Delayed-Release Capsules should be taken at least one hour before meals. For patients who have difficulty swallowing capsules, one tablespoon of applesauce can be added to an empty bowl and the NEXIUM Delayed-Release Capsule can be opened, and the pellets carefully emptied onto the applesauce. The pellets should be mixed with the applesauce and then swallowed immediately. The applesauce used should not be hot and should be soft enough to be swallowed without chewing. The pellets should not be chewed or crushed. The pellet/applesauce mixture should not be stored for future use. Antacids may be used while taking NEXIUM. **Drug Interactions** Esomeprazole is extensively metabolized in the liver by CYP2C19 and CYP3A4. *In vitro* and *in vivo* studies have shown that esomeprazole is not likely to inhibit CYPs 1A2, 2A6, 2C9, 2D6, 2E1 and 3A4. No clinically relevant interactions with drugs metabolized by these CYP enzymes were expected. Drug interaction studies have shown that esomeprazole does not have any clinically significant interactions with phenytoin, warfarin, quinidine, clarithromycin or amoxicillin. Esomeprazole may potentially interfere with drugs metabolized by these CYP enzymes. Coadministration of esomeprazole 30 mg and diazepam, a CYP2C19 substrate, resulted in a 45% decrease in clearance of diazepam. Increased plasma levels of diazepam were observed 12 hours after dosing and onwards. However, at that time, the plasma levels of diazepam were below the therapeutic interval, and thus this interaction is unlikely to be of clinical relevance. Esomeprazole inhibits gastric acid secretion. Therefore, esomeprazole may interfere with the absorption of drugs where gastric pH is an important determinant of bioavailability (eg, ketoconazole, iron salts and digoxin). Coadministration of oral contraceptives, diazepam, phenytoin, or quinidine did not seem to change the pharmacokinetic profile of esomeprazole. **Carcinogenesis, Mutagenesis, Impairment of Fertility** The carcinogenic potential of esomeprazole was assessed using esomeprazole studies. In two 24-month oral carcinogenicity studies in rats, esomeprazole at daily doses of 1.7, 3.4, 13.8, 44.0 and 140.8 mg/kg/day (about 0.7 to 57 times the human dose of 20 mg/day expressed on a body surface area basis) produced gastric ECL cell carcinoids in a dose-related manner in both male and female rats; the incidence of this effect was markedly higher in female rats, which had higher blood levels of esomeprazole. Gastric carcinoids seldom occur in the untreated rat. In addition, ECL cell hyperplasia was present in all treated groups of both sexes. In one of these studies, female rats were treated with 13.8 mg esomeprazole/kg/day (about 5.6 times the human dose on a body surface area basis) for 1 year, then followed for an additional year without the drug. No carcinoids were seen in these rats. An increased incidence of treatment-related ECL cell hyperplasia was observed at the end of 1 year (94% treated vs 10% controls). By the second year the difference between treated and control rats was much smaller (46% vs 26%) but still showed more hyperplasia in the treated group. Gastric adenocarcinoma was seen in one rat (2%). No similar tumor was seen in male or female rats treated for 2 years. For this strain of rat no similar tumor has been noted historically, but a finding involving only one tumor is difficult to interpret. A 78-week mouse carcinogenicity study of omeprazole did not show increased tumor occurrence, but the study was not conclusive. Esomeprazole was negative in the Ames mutation test, in the *in vivo* rat bone marrow cell chromosome aberration test, and the *in vivo* mouse micronucleus test. Esomeprazole, however, was positive in the *in vitro* human lymphocyte chromosome aberration test. Omeprazole was positive in the *in vitro* human lymphocyte chromosome aberration test, the *in vivo* mouse bone marrow cell chromosome aberration test, and the *in vivo* mouse micronucleus test. The potential effects of esomeprazole on fertility and reproductive performance were assessed using esomeprazole studies. Esomeprazole at oral doses up to 138 mg/kg/day in rats (about 56 times the human dose on a body surface area basis) was found to have no effect on reproductive performance of parental animals. **Pregnancy Teratogenic Effects.** **Pregnancy Category B**—Teratology studies have been performed in rats at oral doses up to 280 mg/kg/day (about 57 times the human dose on a body surface area basis) and in rabbits at oral doses up to 86 mg/kg/day (about 35 times the human dose on a body surface area basis) and have revealed no evidence of impaired fertility or harm to the fetus due to esomeprazole. There are, however, no adequate and well-controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed. Teratology studies conducted with esomeprazole in rats at oral doses up to 138 mg/kg/day (about 56 times the human dose on a body surface area basis) and in rabbits at doses up to 69 mg/kg/day (about 56 times the human dose on a body surface area basis) did not disclose any evidence for a teratogenic potential of esomeprazole. In rabbits, esomeprazole in a dose range of 6.9 to 69.1 mg/kg/day (about 5.5 to 56 times the human dose on a body surface area basis) produced dose-related increases in embryo-lethality, fetal resorptions, and pregnancy disruptions. In rats, dose-related embryo/fetal toxicity and postnatal developmental toxicity were observed in offspring resulting from parents treated with esomeprazole at 13.8 to 138.0 mg/kg/day (about 5.6 to 56 times the human dose on a body surface area basis). There are no adequate and well-controlled studies in pregnant women. Sporadic reports have been received of congenital anomalies occurring in infants born to women who have received esomeprazole during pregnancy. **Nursing Mothers** The excretion of esomeprazole in milk has not been studied. However, esomeprazole concentrations have been measured in breast milk of a woman following oral administration of 20 mg. Because esomeprazole is likely to be excreted in human milk, because of the potential for serious adverse reactions in nursing infants from esomeprazole, and because of the potential for tumorigenicity shown for esomeprazole in rat carcinogenicity studies, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother. **Pediatric Use** Safety and effectiveness in pediatric patients have not been established. **Geriatric Use** Of the total number of patients who received NEXIUM in clinical trials, 778 were 65 to 74 years of age and 124 patients were ≥ 75 years of age. No overall differences in safety and efficacy were observed between the elderly and younger individuals, and other reported clinical experience has not identified differences in responses between the elderly and younger patients, but greater sensitivity of some older individuals cannot be ruled out. **ADVERSE REACTIONS** The safety of NEXIUM was evaluated in over 10,000 patients (aged 18-84 years) in clinical trials worldwide including over 7,400 patients in the United States and over 2,600 patients in Europe and Canada. Over 2,900 patients were treated in long-term studies for up to 6-12 months. In general, NEXIUM was well tolerated in both short- and long-term clinical trials. The safety in the treatment of healing of erosive esophagitis was assessed in four randomized comparative clinical trials, which included 1,240 patients on NEXIUM 20 mg, 2,434 patients on NEXIUM 40 mg, and 3,008 patients on omeprazole 20 mg daily. The most frequently occurring adverse events (≥1%) in all three groups was headache (5.5, 5.0, and 3.8, respectively) and diarrhea (no difference among the three groups). Nausea, flatulence, abdominal pain, constipation, and dry mouth occurred at similar rates among patients taking NEXIUM or omeprazole. Additional adverse events that were reported as possibly or probably related to NEXIUM with an incidence < 1% are listed below by body system: **Body as a Whole:** abdomen enlarged, allergic reaction, asthenia, back pain, chest pain, chest pain substernal, facial edema, peripheral edema, hot flashes, fatigue, fever, flu-like disorder, generalized edema, leg edema, malaise, pain, rigors; **Cardiovascular:** flushing, hypertension, tachycardia; **Endocrine:** gitter; **Gastrointestinal:** bowel irregularity, constipation aggravated, dyspepsia, dysphagia, dysplasia GI, epigastric pain, eructation, esophageal disorder, frequent stools, gastroenteritis, GI hemorrhage, GI symptoms not otherwise specified, hiccup, melena, mouth disorder, pharynx disorder, rectal disorder, serum gastrin increased, tongue disorder, tongue edema, ulcerative stomatitis, vomiting; **Hearing:** earache, tinnitus; **Hematology:** anemia, anemia hypochromic, cervical lymphadenopathy, epistaxis, leukocytosis, leukopenia, thrombocytopenia; **Hepatic:** bilirubinemia, hepatic function abnormal, SGOT increased, SGPT increased; **Metabolic/Nutritional:** glycosuria, hyperuricemia, hyponatremia, increased alkaline phosphatase, thirst, vitamin B12 deficiency, weight increase, weight decrease; **Musculoskeletal:** arthralgia, arthritis aggravated, arthropathy, cramps, fibromyalgia syndrome, hernia, polymyalgia rheumatica; **Nervous System/Psychiatric:** anorexia, apathy, appetite increased, confusion, depression aggravated, dizziness, hypertension, nervousness, hypoesthesia, impotence, insomnia, migraine aggravated, paresthesia, sleep disorder, somnolence, tremor, vertigo, visual field defect; **Reproductive:** dysmenorrhea, menstrual disorder, vaginitis; **Respiratory:** asthma aggravated, coughing, dyspnea, larynx edema, pharyngitis, rhinitis, sinusitis; **Skin and Appendages:** acne, angioedema, dermatitis, pruritus, pruritus ani, rash, rash erythematous, rash maculo-papular, skin inflammation, sweating increased, urticaria; **Special Senses:** otitis media, infection, esophageal ulcer, duodenitis, esophagitis, esophageal stricture, esophageal ulceration, esophageal varices, gastric ulcer, gastritis, hernia, benign polyps or nodules, Barrett's esophagus, and mucosal discoloration. Postmarketing Reports—There have been spontaneous reports of adverse events with postmarketing use of esomeprazole. These reports have included rare cases of anaphylactic reaction. Other adverse events not observed with NEXIUM, but occurring with omeprazole can be found in the omeprazole package insert. **ADVERSE REACTIONS** section. **OVERDOSAGE** A single oral dose of esomeprazole at 510 mg/kg (about 103 times the human dose on a body surface area basis), was lethal to rats. The major signs of acute toxicity were reduced motor activity, changes in respiratory frequency, tremor, ataxia, and intermittent clonic convulsions. There have been no reports of overdose with esomeprazole. Reports have been received of overdose with esomeprazole in humans. Doses ranged up to 2,400 mg (120 times the usual recommended clinical dose). Manifestations were variable, but included confusion, drowsiness, blurred vision, tachycardia, nausea, diaphoresis, flushing, headache, dry mouth, and other adverse reactions similar to those seen in normal clinical experience (see esomeprazole package insert-ADVERSE REACTIONS). No specific antidote for esomeprazole is known. Since esomeprazole is extensively protein bound, it is not expected to be removed by dialysis. In the event of overdose, treatment should be symptomatic and supportive. As with the management of any overdose, the possibility of multiple drug ingestion should be considered. For current information on treatment of any drug overdose, a certified Regional Poison Control Center should be contacted. Telephone numbers are listed in the Physicians' Desk Reference (PDR) or local telephone book.

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Uncommon Courage Continued from page 58

done," she said. "I want her no code. She's been through enough." The doctor nodded, then gave Colleen an injection of Valium. She stopped seizing and continued breathing.

In the months ahead Colleen was heavily medicated in an attempt to control her seizures, and yet they continued at about 65 to 100 a day. She slept as many as 20 hours a day, and her developmental progress was slow.

Meanwhile, the yard sale became a shrub sale through the generosity of the Huttons and a growing number of volunteers. It was moved to Memorial Day weekend in 1987, and the dollars for research continued to climb.

Then one evening when Colleen was a year old, Burt and Sue watched on TV a movie called *Fight for Life*, about a couple's struggle to save their 6-year-old epileptic daughter. A character referred to the ketogenic diet, which sometimes was used in treating seizures. Neither Sue nor Burt had heard of the diet before.

Sue began researching the next day, a slow process pre-Internet. She learned that the diet was a serious medical therapy developed in the 1920s to control intractable seizures. By the 1980s, however, it was rarely used because of the availability of medications that helped most people. But they didn't help her child.

"No one knows why the diet works, but the theory is that the brain works on carbohydrates," says Sue. "If you take away the carbs and substitute ketones for energy, there may be less excitability in the brain." Specifically, the ketogenic diet is a high-fat, adequate-protein, low-carbohydrate diet that mimics the effects of starvation. When there is a limited supply of glucose for the body to burn for energy, it burns fats instead. Ketones—chemical by-products of fat—build up in the blood as fat is metabolized, or broken down. Ketones appear to inhibit seizures; exactly how is unknown.

By the summer of 1988 Sue was convinced the diet was worth a try. She met with Colleen's doctor, but he was appalled. With her heart and kidney problems, the diet could kill her, he said. "I'm trying to save a child's brain," she argued. "Let's try to give her some kind of life."

Compelled to work alone, Sue believed this alternate therapy offered Colleen the only hope for a normal life. She had to see if it could help. As a medical professional, she knew it was risky, but she understood the biology and was confident she could manage the diet effectively, tailoring it very precisely to Colleen to keep her safe.

Within two weeks, something incredible happened.

"It was like Colleen woke up," her mom said.

Colleen's seizures plummeted to a fraction of what they had been and became less intense. Gradually, Sue was able to reduce her medications.

Pediatric neurologist John Freeman, M.D.—who has led the Johns Hopkins Children's Center team renowned for its expertise in managing and perfecting the diet—has seen countless lives transformed because of it since 1994, when an interest in the therapy was renewed at Hopkins.

"The diet is superb," says Dr. Freeman. "It works very effectively in half the children who are put on it." Dr. Freeman points out that recently completed research also indicates a long-lasting effect for many children. Three to six years after starting the diet, many of the children have almost complete seizure control or

are seizure free and have stopped the diet and their medication. "That is better and longer than any anticonvulsant ever studied."

Dr. Freeman cautions that the diet must be done with strict medical and dietary supervision because "there are hazards and, if it is not done properly, patients have died."

According to Dr. Freeman, desperate parents today no longer have to struggle alone with the risky administration of this diet. Excellent resources are available at many hospitals across the country. Dr. Freeman reiterates that the diet has been very effective, but you can't just put your child on a high-fat diet, he says, "because that's a recipe for disaster." This is a serious medical therapy and must be managed in a strict medical environment. Dr. Freeman and his colleagues have treated about 500 patients since 1994.

Sue understood there was nothing she could do to change her daughter's genes and the limitations they imposed. She could optimize the quality of Colleen's life, however. Now that Colleen had turned a corner with her health, Sue dreamed the dreams of any other mother. "I wanted her to have a good life, to be like any other child." More than anything else, perhaps, Sue wanted Colleen to be able to communicate.

Because she had slept through much of her earlier life, it wasn't surprising that Colleen wasn't talking at two. Sue knew, though, that some people with TS never learn to speak, and she had come to terms with this possibility.

Sue and the children watched *Sesame Street* on TV and came to know Linda Bove, a deaf actress who signed to the *Sesame Street* characters. Together, the family started signing to one another. They had a repertoire of about 50 signs when Colleen spoke her first word: She wanted "more." The family kept signing until they were sure Colleen would be verbal.

Her achievements coming fast and furious, Colleen was like a sponge, taking in everything. Soon after she learned to talk, she learned to walk. Then she learned to swim. Although she has her ups and downs and requires periodic operations to remove blood-filled tumors from her face, called angiofibromas, mostly things are good.

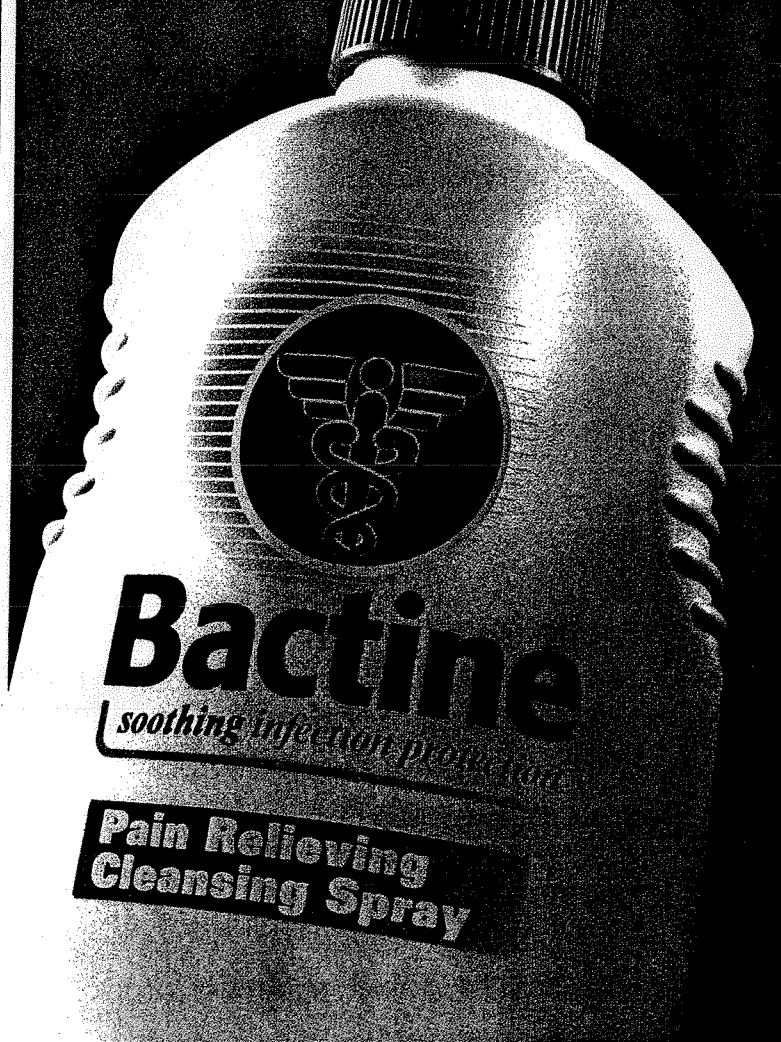
After three and a half years Sue weaned Colleen from her restrictive diet and she continued to do well. Between ages five and nine, she was off medications and had no seizures whatsoever, although they resumed after a bout of the flu. Today she has only a few a week and these are far less severe than when she was younger. Finally, the tumor on her heart now occupies a more moderate 26 percent of her ventricle and is causing no problems.

"We have been so fortunate," says Sue. "If it weren't for the seizures, I think she could drive."

Today Colleen is in the 11th grade. She attends Lampeter Strasburg High School, where she makes honor roll in her special-ed classes. At home she is a typical fighting-her-brother-for-the-computer teen. With a sunny disposition like her mother's, she has a social life, and even traveled to the Bahamas last fall with a friend and her family. In short, Colleen enjoys a normal life, just as her mom once dreamed.

According to Sue, Colleen is undecided about what she wants to do with her life. She has made one decision about the future, however. "Her idea is that we should buy a double house," says Sue, a twinkle in her eye. "She gets one half and we get the other. 'That way,' Colleen said to me one day, 'if you ever need my help, I can help you.'" **FC**

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### Moore's chance encounter sparks tuberous sclerosis awareness

By John Morgan, Spotlight Health, with medical adviser Stephen A. Shoop, M.D.

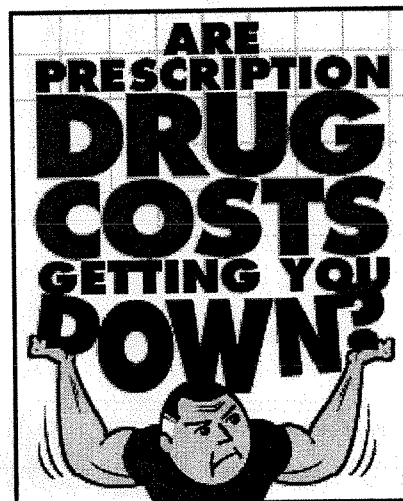
It's not every day that you meet a real life celebrity. It's even rarer still that one would call you after a chance encounter and volunteer to help your family. But that's exactly what actress Julianne Moore did for Thomas and Peggy Lindsey and their 3-year-old son, Tommy, who has tuberous sclerosis complex.



Actress Julianne Moore has bonded with Tommy, a 3-year-old with TSC, which causes benign tumors in organs.

"I think the most important thing we need to do right now is raise awareness about tuberous sclerosis," says Moore, who starred in the hit sequel *Hannibal*. "It's a genetic disorder, and it's more common than people might realize. The hope is that it can be identified and treated earlier rather than later."

TSC causes benign tumors in different organs. The most symptomatic usually involves the brain but also involves the kidneys, skin, lungs, eyes and heart. It is estimated that one in 6,000 live births has TSC or approximately 50,000 Americans; worldwide the estimate is 1 million people worldwide have the disorder. The disease afflicts all racial groups and both sexes equally. Undiagnosed and untreated TSC can be fatal.



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"I was on my way home to pick up my daughter, and I passed this guy with a little boy in a stroller and he smiles and I smiled back and he said, 'Hey, are you Julianne Moore?'" explains Moore, nominated for two Oscars in 2003 for her work in *The Hours* and *Far From Heaven*.

The dad had stopped the acclaimed actress in hopes of persuading a celebrity into helping to heighten awareness about the disorder.

"My wife and I have written so many letters to news stations and shows for years with no response," Lindsey explains. "So I decided this was an opportunity of a lifetime to help get the word out about tuberous sclerosis. We promised ourselves we would do every thing we do to raise awareness about it."

Moore recounts the encounter.

"Well, he introduced himself and started talking to me about his son, Tommy, who had just had brain surgery," Moore continues. "I looked down and there's this sweet, happy, loving, little boy who still has stitches in his head."

"Tommy climbs into her arms and starts kissing and licking her and we're all cracking up," Thomas recalls. "I showed her the photos of the surgery, and she got all welled up. She took my phone number and promised to get back to me about attending our fundraiser."

### Shining star

A few weeks later, Moore called to say she would be joining the Lindseys at the inaugural Rock for a Cure 2003. The event was held Wednesday night on Staten Island and raised money for the Tuberous Sclerosis Alliance, NYU Medical Center's Tuberous Sclerosis Center and Volunteers of America's Staten Island Early Learning Center.

"It was unbelievable," says Peggy Lindsey. "Julianne said she would do anything she could. She donated all this amazing stuff she owns for our auction. She's just been incredible. We can't get over it."

Moore has been happy to help.

"I don't have time for premieres, because I have two kids I'd rather be home with," Moore says from the set of her new film, *Marie and Bruce*. "But for something like this that deserves attention, I am happy to use whatever celebrity I have to focus people on tuberous sclerosis. I think every parent's No. 1 priority is their children's health and well-being. And to think that that could be threatened in any way has to be very difficult."

For the Lindseys, learning that their son, then 5 weeks old, had TSC was more than difficult. It was frightening and agonizing.

Tommy's first symptoms were a series of seizures.

"After a bunch of MRIs and CAT scans, they told us Tommy had a lot of tumors in his brain," Thomas says. "Our pediatrician called us and told us that the preliminary diagnosis was TSC. And the first thing we said was, 'What is that?' We even asked a bunch of the doctors and nurses and no one had even heard of it. So one of the nurses got a medical journal and we read a two-paragraph definition of it."

"The neurologist comes in the next day and says, 'It's very bad. Your son has tuberous sclerosis, and he's probably going to be both mentally and physically retarded, and you

might want to consider institutionalizing him," Thomas recalls.

"It was devastating," Peggy recalls. "Especially because weeks later we realized he had just read the definition we had read the night before and didn't have any real experience with TSC."

"Thank God our pediatrician, Dr. Ronald Kipp, stepped in and said, 'We're taking your son out of here,'" Thomas says.

### **TSC 'evolution'**

Kipp directed the Lindseys to Orrin Devinsky, a renowned specialist in TSC, who put Tommy's disease and their treatment options in perspective.

"I saw Tommy when he was 7 weeks old," Devinsky, who is the director of the New York University Epilepsy Center. "His main problems were benign tumors in the brain, developmental delays and seizures."

Other common symptoms can be:

- Learning disorders
- Behavioral problems
- Skin problems – decreased pigment and/or angiofibromas (red wart-like bumps)
- Cardiac abnormalities

Devinsky says TSC has a wide spectrum of involvement – from children with mild skin problems and some benign tumors in their kidneys, to infants like Tommy who have seizures in the first several weeks of life, to others who die in the mother's womb. Some children even will fit criteria for autism.

"Tommy was treated with antiepileptic medications but unfortunately, none of them controlled his seizures," Devinsky says. Over the next three and a half years, Tommy continued to have as many as 20 to 30 seizures a day.

Devinsky says that as a 3-year-old, Tommy functioned at the level of a 17-month-old. "So clearly the seizures were contributing to the developmental delays."

After a year of discussions, the Lindseys finally opted to have Dr. Howard Weiner perform a complicated three-stage brain surgery on Tommy.

During the first stage, Weiner removed a small piece of the skull and placed a plastic grid to record various parts of the brain during seizures. In the second stage, Weiner removed the most active area that corresponded with one of the benign tumors in the right frontal lobe. After recording more seizures, Weiner removed another significant mass and the adjacent epilepsy tissue in the right temporal lobe.

### **End of the affair**

"Tommy has recovered phenomenally well," Devinsky reports. "Our goal was to reduce the seizures by 80% — that would have been fantastic. So far he has been seizure-free for four months. He's on two antiepileptic medications but less than before. Our plan will be to watch him and hopefully reduce the medications."

Tommy's parents are ecstatic at his improvement.

"We saw a change immediately after surgery," Peggy says. "For instance with

speaking, Tommy was non-verbal – he could only say a few words but right afterwards in the hospital, he was trying to repeat words. He was actually trying to communicate with us. And his attention span also dramatically improved."

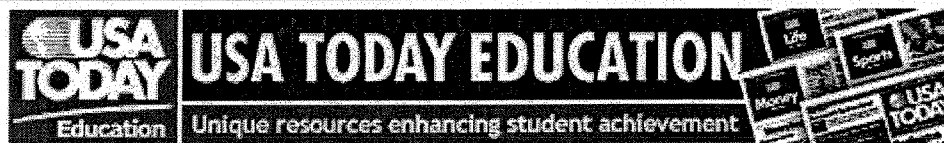
Beyond helping their son continue to improve, there is much work to be done to help others.

"We need to promote more awareness, and we need funding to find a cure," Peggy explains. "I don't want people to go through what we did with a doctor giving us terrible news when he had no idea what he was talking about. Each case of TSC is so different, and it's not a death sentence. And there are other parents like us who have been through this that people can turn to for support and to ease the pain because there is a lot of hope."

Devinsky agrees. "Although it is an uncommon disorder, by doing TSC research we will learn how to better treat epilepsy which affects almost 2.5 millions Americans," the NYU physician notes. Researchers can "learn more about treating tumors by understanding the function of the tumor suppressing genes. This means learning about TSC could conceivably be the answer to some cancers."

A chance encounter with a man pushing a stroller with his son has produced great dividends.

"We just need to get the ball rolling and start people thinking about this disease so we can help more kids like Tommy," Moore concludes. "It's a start, and I'm thrilled to be able to help."



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