



STEROIDS

Steroids are naturally occurring hormones. In brain tumor treatment, steroids are used to reduce the swelling, or edema, sometimes caused by the tumor or its treatment. The steroids given to brain tumor patients are “corticosteroids” – hormones produced by the small glands, called adrenal glands, near the kidneys. They are not the same as the “anabolic steroids” used by athletes to build muscle.

Dexamethasone (Decadron) and prednisone are corticosteroid drugs. These steroids can temporarily relieve brain tumor symptoms, improve neurological symptoms, promote a feeling of well-being, and increase your appetite. Because steroids are hormones, their long term use requires close monitoring.

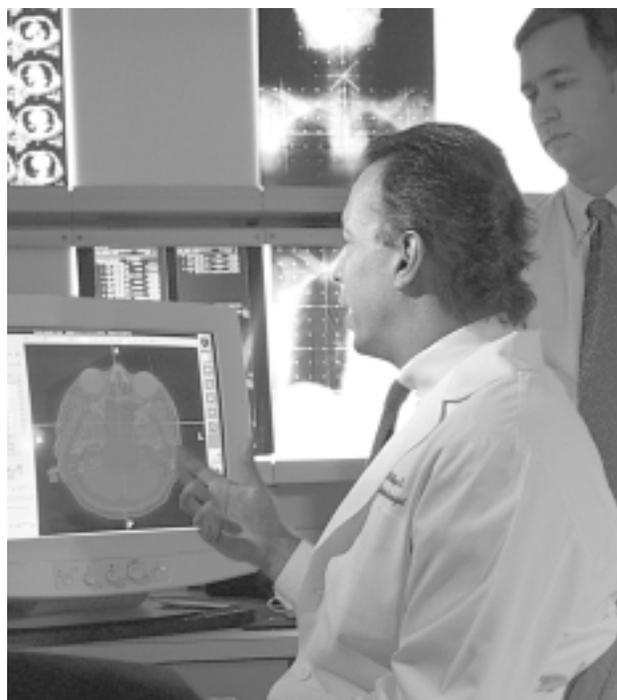
ABOUT EDEMA

Edema is the accumulation of fluids in the tissue around a tumor – it is a common occurrence in people who have a brain tumor. Edema happens when the blood brain barrier, an invisible protection around the brain, is disrupted by the tumor. Small blood vessels around the tumor can then leak fluids which collect in the surrounding tissue. Edema can also occur following surgery, radiation, or other treatment for a brain tumor.

Edema can lead to increased pressure within the brain which, in turn, can cause headaches and drowsiness. Sometimes the edema actually causes more symptoms than the tumor itself. Steroids are medications used to reduce edema.

HOW ARE STEROIDS TAKEN?

Although steroids can be started through an intravenous (IV) line or by injection into a muscle (IM), most people with a brain tumor take their steroids by mouth – also called “orally.” The pills come in doses that range from 0.25 mg to 6 mg tablets, taken between two and four times a day. Your doctor will determine the starting dose of steroid based on your MRI scan and your symptoms. It will take 24-48 hours before you



Inside *this Issue*

FEATURES

| | |
|--|---|
| Tough Questions to Ask Your Doctor | 3 |
| Steroids continued | 4 |
| Caregiving Resources | 6 |
| Join the Charge | 7 |
| Donate Online | 7 |
| Thank You, Frank | 7 |
| Congratulations To | 8 |
| Together in Hope | 9 |

DEPARTMENTS

| | |
|---------------------------------------|----|
| Mailbox | 2 |
| Shopper's Corner | 10 |
| Raising Funds & Raising Fun | 11 |
| ABTA Tributes | 18 |

Mailbox

MessageLine

VOLUME XXXI, NUMBER 1

Our Mission: The American Brain Tumor Association exists to eliminate brain tumors through research and to meet the needs of brain tumor patients and their families.

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Dear ABTA Doctors and Researchers:

Thank you for all the time you devote to brain tumor research. I am sure you all work harder than anyone gives you credit for. I hope for a cure, and pray for your success.

INDIANA

When I initially contacted your organization, just hearing the person answer the phone and say the simple phrase, "I understand," moved me. It moves me still. I know you REALLY DO understand the trauma of brain surgery, it's aftermath, the "beforemath" and so on... Thank you.

I did not have a tumor. I had a colloid cyst. Doesn't matter. What matters is that your personnel said the right thing at the right time and I appreciate you all more than I can ever express.

FLORIDA

I think your emails – *Sharing Knowledge, Sharing Hope E-News* and *Tips for Living and Coping (TLC Bulletin)* – are wonderful and I wanted to say Thank You to all who contribute to getting them published. It has been wonderful to receive all the helpful advice.

SENT VIA EMAIL

Editor's Comment: Our E-news announces treatment and support updates from within the brain tumor community. The TLC bulletin provides helpful tips for living with the diagnosis of a brain tumor. If you would like to receive these electronic communications, please send a message to us at info@abta.org.

Good joss to your organization. I suspect it may have a lot to do with why my friend is still alive, several years past the date he was first given. It's wonderful work that you do.

CANADA

I searched the net and found your site. It is brilliant. You have found a unique way of putting the large terms and acronyms into meaningful sense. Your site provides explanations, descriptions, and information to those of us who are a little overwhelmed by it all. Really well done...

AUSTRALIA

I just want to thank you very much for all the information you mailed to me. It helped me to learn and understand better what my mother is going through. At the beginning, when all this started it was like walking inside a very dark room, a big dark room, just letting everybody lead you. Bless you all for the work you do.

FLORIDA

During my wife's nine years of coping with a brain tumor, the *MessageLine* was a source of strength and encouragement. The more than \$1,000 worth of awareness pins which we purchased and distributed to friends was the best investment I ever made in building a community of support for my wife and myself during her struggle. Thank you for your excellent service to brain tumor survivors and their families.

MAINE

Mailbox letters may be edited for clarity and space.

Sharing *Knowledge*

TOUGH QUESTIONS TO ASK YOUR DOCTOR

Asking questions is an essential part of understanding your diagnosis, symptoms, and treatment options. Regardless of whether this is your first experience with a brain tumor or you are a long term survivor, there are important questions you'll want answered as you participate in your healthcare. If you do not feel comfortable verbalizing your questions, practice at home. Consider writing the questions you need answered, putting the most important question on top. Make your questions short and to the point. Ask first the question that is most important to you.

Here is a sampling of questions patients need to be more comfortable asking their doctor:

1. Please write down the name of my tumor type.
2. What are your recommendations for treating my tumor?
3. What are the benefits of your treatment plan? What are the risks?
4. What other treatments are available for my tumor type - at this hospital and at other hospitals?
5. Tell me about clinical trials (research studies). Can my tumor be treated in a clinical trial?
6. How much of your practice is brain tumor patients?
There is not a correct "percent" response to this question. You're looking for an answer that tells you this doctor sees brain tumor patients on a regular basis. Neurologists and neurosurgeons can specialize in many disease areas, not all of which are brain tumors. We encourage you to look for a doctor who regularly treats people with brain tumors.
7. Does this hospital provide rehabilitative and support services for people with a brain tumor? If I need/want them, do I have access to nutritional services, physical/occupational/speech therapies, or supportive counseling?
8. If I decide I would like another opinion before making my decision, will you help me do that?
Don't be afraid of "offending" your doctor by talking about second opinions. You probably want a doctor who is open-minded and willing to help – this is the way to find out.
9. If I were your family member, where would you send me for another opinion?



STEROIDS Continued from *page 1*



begin to see the effects of the medication, but the change is often remarkable. The dose may need to be adjusted – either increased or decreased slightly – depending on how your body reacts to them.

To protect your stomach, take your steroids with food or milk. Your doctor may also prescribe an antacid to be taken daily.

If your doctor prescribes the long-term use of steroids, don't be disappointed if your steroid dose needs to be increased over time. The goal, of course, will be to find the lowest, most effective dose of medication that keeps your neurological symptoms to a minimum. With time, however, that “most effective dose” may need to be adjusted. The need to increase your medication does not automatically mean your tumor is growing, and it does not mean you've made errors in taking your medication.

When your doctor feels you no longer require steroids, you will be given instructions for slowly stopping the drug. **Do not abruptly stop taking your steroids.** The “tapering” process slowly decreases your steroid dose. Your body needs this period of time to again begin producing its own steroids, and to avoid an emergency medical crisis. Lowering steroid levels too quickly can also cause a “rebound” increase in swelling.

SIDE EFFECTS

Steroids can have several positive side effects. They can markedly decrease symptoms, give one an overall sense of well-being, temporarily increase thought and functioning abilities, and increase your appetite.

Steroids can also cause a wide range of effects that must be carefully monitored by your doctor. The most common side-effects are: weight gain; thinning of the skin; gastrointestinal upset; muscle weakness in your thighs, shoulders, and neck; susceptibility to infections; “masking” or hiding a fever; mood swings; insomnia; pneumonia; and increased blood sugar levels (especially if you have diabetes.) Steroids can interact with some seizure medications, either increasing or lowering their levels in your blood, which can alter their effectiveness. Other, more serious side-effects can occur, although they are less common.

The benefits of steroid use almost always outweigh their potential side effects. If you have any questions about balancing risks and benefits, please talk with your doctor.

MANAGING COMMON SIDE EFFECTS

Weight gain and increased blood sugar levels

After a few months of steroid use, you may begin to notice a significant weight gain. This is not the “fatty” weight of overeating – it is your body processing and storing food in a different way. You may notice your face looks puffy or moon-like, and you've developed a small hump on your back, just below the neck, called a “buffalo hump.” You may notice stretch marks across your abdomen as it increases in size, while your upper arms and legs seem to become thinner. These changes are due to your body storing more fat on the trunk of your body and less in your extremities. While this is an unavoidable effect of steroids, there are several things you can do to help manage this change in your body.

Firstly, steroid weight gain gradually increases. If you gain more than 5 pounds in one week, please call your doctor. A sudden, large weight increase can signal medical problems that should be reported to your healthcare team.

Secondly, ask your doctor for a referral to a licensed registered dietician experienced in treating people on steroids. This may be a dietician who regularly works with cancer patients, or a dietician experienced in treating people with pituitary disorders. Since nutritional needs vary from person to person, a professional is your best resource for this help.

Steroids may affect your blood sugar level, especially if you are diabetic. If your sugar levels increase, you may be referred to both an endocrinologist and a dietician.

Thirdly, it's important that your body maintain its ability to flush waste out of your system. Keep your kidneys and bowels in good shape – don't stop drinking water. It's a natural reaction to try to avoid adding liquids to your body right now, but that will only compound the problem.

Gastrointestinal problems

Steroids can cause an upset stomach. Be sure to take your medication with food, milk, or an antacid that your doctor prescribes for you. Call your doctor if you have stomach pains, run a temperature, are constipated, or notice any blood in your bowel movement.

Avoid the use of non-steroidal anti-inflammatory drugs (NSAIDs such as Advil, Motrin, Aleve) and aspirin unless directed by your doctor. While you are on steroids, it is especially important that you have regular bowel movements. If you become constipated, or experience diarrhea, call your healthcare team.

Insomnia

Sleep disturbances are a possible side effect of changing hormone levels. If you have difficulty sleeping, ask your doctor if your dosage can be adjusted so you take more medication in the morning and less after dinner. (Don't make this change on your own.) Healthful sleeping habits, such as avoiding bright light, caffeine and sugar as bedtime approaches, and a regular nighttime routine may be of help.

Depression/mood changes

While taking steroids, you might experience depression, mood swings, irritability, or agitation. These symptoms are due to the steroid's effect on the natural hormone balance in your body, and can be treated. Let your doctor know how you are feeling. Medications may relieve some of these symptoms and can be particularly helpful if you remain on steroids for a long period of time. It is also helpful to discuss these effects with your family so they know what to expect and can be supportive.

Muscle weakness

Steroids sometimes cause weakness in the muscles of the legs, arms, neck and chest. Leg weakness may be most noticeable when you get up from a sitting position and try to use the large muscles in your thighs. If leg weakness is a problem, ask for assistance when using the bathroom or getting up from a chair. Walk with another person who can get help should you stumble, or try an assistive device – such as a cane or walker. If the chest muscles are affected, you may experience difficulty breathing or pain when taking deep breaths – especially if you have a history of asthma, emphysema, or smoking. Please be sure your doctor is aware of your past medical history. Ask your doctor about exercises that may help strengthen your muscles, or for a referral for physical therapy.



JEFFREY RAIZER, MD

Infections

Steroids have a tricky way of “masking,” or hiding the beginning of an infection in your body. Be alert to anything that just doesn't seem right. An increase in temperature may be the first – or only – sign something is amiss. Because of that, some people on steroids take their temperature at the same time every day, regardless of how they feel. This is an easy way to keep a baseline check on your good health.

Additionally, look at your tongue each time you brush your teeth - people on steroids are especially prone to yeast infections, or “thrush,” in their mouth. If you notice a thick white coating on your tongue, make your nurse or doctor aware.

Some people are prone to developing a certain type of pneumonia after they have been on steroids for awhile. Your doctor may start you on an antibiotic to prevent this from happening.

While you are on steroids, follow the health precautions used by people at higher risk for infection. Wash all fresh fruits and vegetables carefully. Wear gloves when using a kitchen knife. Cook meat and poultry until well done. Use gardening gloves when working outside. Avoid crowds and, in general, avoid sick people.

CALL YOUR DOCTOR IF...

- You are running a temperature – even if you feel well otherwise.
- You see any blood in your bowel movements.
- You have stomach pain.
- You gain more than 5 pounds in one week.
- You develop a rash.
- You are drinking and urinating a lot.
- You are falling.
- **Chest pains or difficulty breathing may signal a medical emergency. Call for emergency help.**

This article is an excerpt of our new publication, Steroids, written with the assistance of Jeffrey Raizer, MD, Director of Medical Neuro-Oncology, Northwestern Memorial Hospital and Assistant Professor of Neurology, Northwestern University/Feinberg School of Medicine, Chicago, Illinois. Healthcare professionals: please contact us for a sample and quantity ordering instructions.

Sharing *Resources*

CAREGIVING RESOURCES

Caregivers face immense challenges as they try to juggle care for their loved one along with other family responsibilities, and in some cases, work outside the home. But whatever your personal situation might be as a caregiver, it is important not to lose sight of ways in which you can care for yourself, as well as for your loved one.

We have compiled a variety of resources that might be useful to you as a caregiver. Please contact us by phone at 800-886-2282 or by e-mail (info@abta.org) to request our extensive Caregiver Resource Listing. Below is a description of the various types of resources we have available for you.

FACE-TO-FACE SUPPORT GROUPS

We offer listings of support groups for both patients and caregivers. Please contact our office if you would like to receive the listing for your state. In addition, many caregiver organizations can help you locate support groups in your area that are specifically for caregivers. Other possible sources for information on caregiver groups include your physician, local hospital or brain tumor treatment center, and your Area Agency on Aging, which is listed in your local phone directory.

ONLINE SUPPORT GROUPS AND WEBSITES FOR CAREGIVERS

There are a variety of Internet-based resources. They include online support groups, listservs, chat rooms, message boards and other Internet communities of interest, through which caregivers can share information and support each other. There are also websites focused on the needs of caregivers. These Internet-based forums offer an alternative for those who do not have access to a face-to-face support group, or who prefer to communicate and seek information via the Internet. Access is easy regardless of the weather, time, or location. Most online forums require that you "subscribe" or "register" prior to sending messages. After subscribing as directed, you'll receive a confirmation as well as a welcome letter. Each forum has its own "netiquette" rules and procedures. Save those guidelines; they will also tell you how to unsubscribe should you so choose.

STRESS MANAGEMENT AND SELF-CARE

We offer a listing of resources for stress management and self-care. These resources include a variety of videos, cassettes, CDs, software and books to promote relaxation, wellness and healing. Products include resources on guided imagery, meditation and self-care.

Also, many hospitals now offer programs that utilize the connection between mind, body and spirit to promote relaxation, anxiety management and wellness. You can contact your hospital's Social Work department, the center for Integrative Medicine at your local hospital or medical center, or inquire at your doctor's office about programs and classes available in your community.

CAREGIVER ORGANIZATIONS AND PROGRAMS

There are numerous organizations offering programs dedicated to helping caregivers overcome challenges. These programs offer everything from practical information, coping tips and emotional support to teaching caregivers the skills needed to care for a loved one.

Our Caregiver Resource Listing also includes a comprehensive bibliography ranging from the "hands on," day-to-day aspects of caregiving and developing a care plan for your loved one, to the joys and trials of caregiving, to dealing with financial and insurance issues, to meditations and affirmations on topics specific to caregivers, to the healing benefits of laughter in coping with the stresses of caregiving.

* * * *

ABTA offers Social Work consultations Monday through Friday from 8:30 am to 5:00 pm CST. If you are interested in learning more about caregiving, please give us a call at 800-886-2282 and ask for Social Work. We would be happy to explore this topic with you and put you in touch with a variety of resources.

This article was made possible by a generous Social Work Grant from the Tim & Tom Gullikson Foundation.

Mission *Fulfilling*

JOIN THE CHARGE!

Looking for an easy way to support the American Brain Tumor Association? Consider the Charge! Against Brain Tumors. Through this unique program, we will automatically charge your credit card for an agreed upon amount on a monthly basis.

The Charge! is a great way to make affordable donations to support brain tumor research or services for

patients and family members. Your donations will bring us a step closer to a cure and help us continue to provide free educational and resource information to those affected by brain tumors.

To join the Charge! Against Brain Tumors, call our office at 847-827-9910 and ask for Janice. Thank you for supporting the American Brain Tumor Association.

DONATE ONLINE

Making a donation to the American Brain Tumor Association has never been easier – just go to our website, www.abta.org, and make your donation online through our secure donation page. Donations in honor or in memory of a loved one may also be

made online. Just complete the form, tell us where to send the card, and provide your name and address. Your receipt will be sent to you. Regardless of how you make your donation, please know that we appreciate your support.

THANK YOU, FRANK



Behind the scenes, the American Brain Tumor Association relies heavily on volunteers who make our events happen and our programs effective. One person certainly stands out in the group.

Frank is so much a part of the day-to-day operations in the ABTA office that we think of him as family. For the past several years Frank has made sure patients and family members receive the materials they need in a timely fashion. He coordinates the information pieces in our library, collates material in response to patient requests, and oversees delivery of our extensive inventory.

Frank has touched the lives of thousands of people through his generous weekly donation of time. From all of us at ABTA, thank you, Frank, for the smiles, inquisitiveness, and re-grounding you've brought to our lives.

American Brain Tumor Association

www.abta.org

Sharing *Knowledge*

CONGRATULATIONS TO ...

...Susan L. Weiner, PhD, founder and president of The Children's Cause, on her selection as recipient of the 2003 Tim Gullikson Spirit Award.

The award is a program of the Tim & Tom Gullikson Foundation (TTGF). Given to brain-tumor patients, caregivers, individuals or corporations, recipients are chosen based on their ability to give hope to others with the same fighting spirit and positive attitude that TTGF co-founder Tim Gullikson exhibited during his battle. Dr. Weiner's energies are focused on children with disabilities and their families, and like many activists, motivated by personal challenge. She served

as executive director of the Children's Brain Tumor Foundation, then as Washington liaison for the North American Brain Tumor Coalition. Dr. Weiner has testified before Congress and the President's Cancer Panel; served on many National Cancer Institute and Food and Drug Administration advisory panels; and participated in many national cancer policy forums. Our heartfelt congratulations to Dr. Weiner on this most deserved recognition.

AND TO ...

...the Brain Tumor Resource Center at Moffitt Cancer Center in Tampa Florida, on receiving the TEAM Award.

Each year, Moffitt recognizes outstanding programs and services that were a success due in large part to team work. Brain Tumor Talks, a series of presentations offered through the Brain Tumor Resource Center at Moffitt, won the TEAM award for the Reaching Out to Community section. The program was recognized by Moffitt's CEO, William Dalton, MD, PhD, and awarded \$1,000 to be spent on program development.

The Brain Tumor Resource Center at Moffitt is supported by a grant from the American Brain Tumor Association. We send our special thanks to Marguerite Obadia, AHT (left in the photo) and Lauren Bush LCSW, for their unwavering efforts on behalf of the Center as well as their creativity in initiating the Tumor Talks series.



Sharing *Knowledge*

TOGETHER IN HOPE

In January, the American Brain Tumor Association and the Florida Brain Tumor Association co-sponsored *Together in Hope* in Tampa. At this meeting for survivors/patients and family members, participants learned about treatment options, managing medications and side effects, clinical trials, what the future holds and other important topics.

Together in Hope was made possible through the generosity of our sponsors:

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NeoPharm, Inc.

We appreciate their assistance in our continuing efforts to provide education and support to the brain tumor community.



A similar meeting, co-sponsored by the American Brain Tumor Association and the Childhood Brain Tumor Foundation, will be held in Washington DC on March 26-27. Call 800-886-2282 for more information.

Shopper's *Corner*

AWARENESS PINS



Help raise brain tumor awareness by wearing a Brain Tumor Awareness pin. These 1" lacquered pins are a soft shade of grey, symbolizing the gray matter of the brain. Pins are \$5 each.

ABTA NOTECARDS

Soothingly pretty, the ABTA notecards are the perfect way to share your appreciation, send a greeting, or tie on a package. The scenes are soft photos printed in hues of purple-blue; the inside top panel of the card shares the ABTA vision. The inside facing panel is blank for your special message. A set of 5 notecards is \$25.



ABTA SHIRT

A rich purple with the ABTA logo on the pocket, these short-sleeved polo-style knit shirts are the perfect gift for holidays, birthdays, or just to say "Thinking of You." The shirts are 50% cotton/50% polyester and run true to size. In response to your requests, there are no sponsors or events on this shirt. Shirts are \$15.00 each.



TO ORDER

I would like to order:

| Quantity | Description | Each | Total | |
|------------------|-------------------------------------|-------------------|-------------------|----|
| | Notecards | \$25 set of 5 | \$ | |
| | Pin(s) | \$5 each | \$ | |
| | No Postage/Handling charge for pins | | | |
| | Shirt(s) | \$15 each | \$ | |
| | CIRCLE SIZE | S M L XL XXL XXXL | | |
| Postage/Handling | 1 to 2 Items, \$2 | 3 to 6 Items, \$3 | each add'l, \$.25 | \$ |
| | Total | | \$ | |

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(Please fill in should we need to contact you regarding your order.)

Mail your order today with a check payable to:
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OR

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Charge card minimum of \$25. Charge my order to:

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Account # _____ Expiration Date _____

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Raising *Funds* & Raising Fun

Thank you! Thank you! Thank you! is barely adequate to express our gratitude and awe to the dozens of organizers and committees and the thousands of participants who gave the most generous gift of all – they gave of themselves – to heighten awareness of brain tumors and to raise funds for the American Brain Tumor Association (ABTA) programs of research and patient education. You inspire us and give us the resources to carry on our work so that a cure for all brain tumors will be found. Thank you for choosing ABTA to pay tribute to your loved ones.

If you would like to honor or memorialize your loved one with a special event, call 800-886-1281. We will be happy to assist you in planning your very own special tribute event.

ILLINOIS



Mark Linder (far left) accompanied by his mom, lead the walkers during the 5K Walk for the Mind.

Mark Linder is a brain tumor survivor who felt isolated in Central Illinois when he was diagnosed. For that reason he decided to host A Walk for the Mind to raise awareness about brain tumors. Mark was completely overwhelmed when 250+ brain tumor patients, family members and friends showed up to support him and his efforts. We extend grateful thanks to Mark and his committee for raising funds and raising awareness, and for showing that you never need to walk alone.

FLORIDA

Tom and Kris McAlvanah were courageous people. Even though they were bravely battling Tom's brain tumor, they cared about everyone else's battles, too, and devoted their energies to raising funds for the H. Lee Moffitt Cancer Center and ABTA. This successful event marked Year 2 of their Swing-N-A-Cure Golf Tournament to honor Tom. The afternoon of golf was followed by dinner, an auction, and prizes for the most winning golfers. Did anyone win that hole-in-one automobile? Sadly, three short months after this successful event, Tom succumbed to complications from his disease. Our thoughts are with you, Kris.

NORTH CAROLINA

Thirteen-year-old brain tumor survivor, Amanda Worley attended the NC Legislators' School for Youth Leadership Development, a program aimed at developing young leaders. They urged the young attendees to work on a community service event. Amanda said she "wanted to help an organization that helps people with what I've been through." She decided to use her favorite hobby of scrapbooking and stamping to raise funds for ABTA. She organized a Crop & Shop with seven local craft stores that provided materials and the opportunity for fellow scrapbookers to learn new techniques. Thank you for your outstanding efforts on our behalf, Amanda and keep making those scrapbooking memories!

Raising *Funds* & Raising Fun

MISSOURI

Schaffner's Farm was the site for Tracy Goodall and her family to host their 3rd Annual Dick Schaffner Fall Festival, in memory of Tracy's father. Tracy says, "It's been the best so far." In addition to a BBQ dinner, there were hayrides, live music, live auction, fireworks and a bonfire. And if that wasn't enough, they even raffled off Dick Schaffner's 1994 Lincoln Town Car! Tracy said what's in our hearts. "Our family hopes that one day we won't need to send money for research." Tracy, thank you for helping us work towards our mutual goal.

NORTH CAROLINA

Ten years! This was the tenth year that Stephen and Kim Ammons hosted the Strokes for Progress Golf Tournament to memorialize their son, Forrest. All those golf strokes by all those golfers during a 10-year period have surely helped research work progress – your dedication is making a difference. Even though this was the first time in 10 years that it rained, friends and family of the Ammons' were there to show their support as a tribute to Forrest. And ABTA extends our grateful thanks to Stephen and Kim for continuing to support our research programs.

VIRGINIA

For six years now, Sandy Carr has honored the memory of her firefighter husband, John C. Carr, Jr. by hosting John's Jamboree to Help Extinguish Brain Tumors. This good time evening features live music and dancing, together with prizes for some lucky folks. Sandy, thank you for all you do on our behalf and thanks to the Leesburg Volunteer Firehouse for lending their facility and to NOVEC, the Northern Virginia Electric Cooperative for their sponsorship.

CONNECTICUT

Cheryl Lyon recently had surgery to remove a brain tumor. While she was recovering she often looked to the ABTA website for information and encouragement. She said: "I was comforted by other patients' stories, impressed by the support your organization offers them, and optimistic about the research you fund." Her life-changing experience moved her to participate in the 5K race of the Greater Hartford Marathon. She asked family and friends to sponsor her effort to raise funds for ABTA and to memorialize her father, Jerry Petrarca. Cheryl, thank you for sharing your success story with us and thank you for supporting our research programs.

MISSOURI

In memory of her sister Terri Yarbrough, Jeanne Savel chaired the enormously successful 6th Annual Fall Festival together with the help of Melinda Marquart, in memory of her husband, Keith. Their party with a purpose attracted 300+ adults and children to this wonderful family event. "The Snapperhedz" volunteered their musical talents in memory of their beloved friend and fellow band member, Keith Marquart. David Bailey, guitar-playing songwriter and brain tumor survivor, lent his inspirational songs of faith, hope, and love. Jeanne says it best: "Our past fundraisers have lead to continued medical advances and promising new research and your compassion and generosity lets patients know they are not battling this disease alone." Jeanne and Melinda are already planning next year's Fall Festival in order to "step up the pace of research." Thank you one and all for your efforts and your heartfelt message.



Before the Fall Festival officially gets underway, Melinda Marquart (left) and ABTA Associate Director Jeanne Savel pause to pose. In memory of their husband and sister respectively, these two women organize an amazing family event.

MARYLAND

The sun shone for the first time in a week for the 1st Annual Mary Carole Pilarski Golf Event. Mary's husband and five children organized this wonderful day and evening of golf, dinner, silent auction, and golfer prizes to memorialize their wife and mother. Everyone came together to remember this wonderful woman who always took care of everyone else. Thank you all for paying tribute to Mary by raising funds for ABTA's programs.

INDIANA

The 2nd Annual Gary's Gallop/Gary Freidenberg Memorial Run/Walk had a new twist this year. Organizer, Todd Reinhart, added a 5K Dog Walk to the People Walk/Runs. Todd's mission is to provide an event which fosters fun, happiness and hope. He obviously succeeded on

all fronts. This event is meant to remember Dr. Gary Freidenberg and to continue his work of helping others. Todd, thank you for helping others through ABTA, and keep having fun doing it.



ILLINOIS

Lou and Celeste Cagnina decided they wanted to "give back to the brain tumor community, which has taken such good care of us" during their battle against Lou's brain tumor. Together with their family and friends, Celeste spearheaded a successful luncheon fundraiser, "Lou Cagnina: Bringing Home the Cure at the Home Run Inn." The lovely afternoon featured live entertainment, raffle prizes galore, and an opportunity to celebrate Lou's life with their "lifelong" family and friends – as well as their new friends in the brain tumor community. Thank you for including the ABTA research programs in your heartwarming celebration.



Lou Cagnina (background) proudly looks on as his wife Celeste (far right) presents plaque to Home Run Inn CEO Joe Perrino and co-owners (foreground) Marilyn Carlson, Lucretia Costello and Loretta Perrino.

NEW JERSEY



Ten-year-old Matthew Passarella spends a moment with his own thoughts during the Matthew's Miles Walk for a Cure.

To celebrate Matthew's 10th birthday, his family organized the 1st Annual Matthew's Miles – A Walk for a Brain Tumor Cure. His mom, Andrea Passarella says, "I felt like we needed to do something to celebrate his life and help others. I'm going to do all I can to see that no parent has to hear that their child has a brain tumor." Thank you Andrea for helping us get closer to this goal. The successful 2-mile Walk was followed by an auction of sports memorabilia, including items donated by the Philadelphia Flyers and Phillies and the New Jersey Devils. Thank you to all who helped Matthew celebrate his birthday in such a meaningful way.

Raising *Funds* & Raising Fun

WASHINGTON, DC

Brain tumor survivor, Danielle O'Brien, has true grit! To celebrate her survivorship and to raise awareness and research funds, in 2001 she completed the Washington DC Marine Corps 26-Mile Marathon. The following year she had tumor re-growth and her father, Don Duffy, passed away unexpectedly. None of this was to keep Danielle from running again in 2003 with her twin sister Deanna. Danielle asked family and friends to support their efforts "to make my run a victory run for brain tumor survivors" and to memorialize her father who gave her guidance, endless love, and support to have the strength to be a survivor and who continuously celebrated the joy and adventure of life. Our most sincere gratitude is extended to both Danielle and Deanna for their ongoing support.



Danielle (aka Yellie) and her twin sister Deanna (aka Anna) appear to be running effortlessly in the 26.2 Mile Marine Corps Marathon.

ILLINOIS

The end of year holidays are a special time filled with special traditions for most, but especially so for Paul and Jill Taylor. Each year, Paul and Jill went to a musical theatre event, *The Christmas Schooner*. Its message resonated for them, and even more so after Paul was diagnosed with a brain tumor: Remember the good times when the times aren't so good. As a most meaningful tribute, Jill annually hosts The Christmas Schooner benefit for their family and friends to memorialize Paul and to carry on their tradition. Jill, thank you for making ABTA a part of your holiday tradition now.



A man and his surfboard riding the waves at the 4th Annual Surf for a Cure. Isn't life grand?

NEW JERSEY

It doesn't matter how good or bad you are at surfing. When you become part of the Marie A. Becker Memorial Longboard Contest, you become part of something that is making a contribution to brain tumor research and awareness. Organizer, Erich Becker, tells us that each year they get more and more beginners and more and more veterans. After surfing, there's more fun on the bay with fantastic views and delicious food. "A bad day of surfing is better than a good day at work" - a great motto for a great cause. Grateful thanks to everyone who participated in this 4th Annual Surf-for-a-Cure. Surf's up!

ILLINOIS

Craig Dooley ran in the Chicago Marathon to remember his mother. "For me, the marathon represents a race to find more effective treatments for brain tumors. Finishing this race can demonstrate that my mom's strength and spirit are alive and well in those who loved her so dearly." Ann Marie Mulhern, a brain tumor survivor, ran the marathon "so more research can be funded and more people will be able to resume their lives and their passions." Both of these winning individuals crossed the 26.2 mile finish line in their race for a cure. Thank you for making a difference for us all. Well done!!



Brain tumor survivor Anne Marie Mulhern observes runners after she completed the Marathon.

ILLINOIS

This year the Monty Rachell Memorial Golf Tournament was held to pay tribute to their lost friend and to honor another friend, brain tumor survivor Dave Moormann. Organizer, Dennis Phillips invited their family and friends to come for a fun-filled day of golfing and to applaud Dave's courage while battling a brain tumor. Thank you to everyone for supporting Dave and the programs of ABTA.

WISCONSIN

Started in 1988 by Marcy Weinsheim in memory of her husband, Harold, Strain for the Brain is one of the more popular Run/Walks in the Milwaukee area. Mary Doyle Lehman and her eight siblings adopted "Strain" nine years ago to memorialize their Mother, Patricia J. Doyle. This 15th anniversary of "Strain" showed no sign of fading. The Doyle kids and their families are as exuberant as ever in the planning and successful execution of this event. Special thanks to Bonnie Blair for being the official race starter each year and thanks to all who support this event year after year. The ABTA family is fortunate to have the Doyle family dedicated to our mutual cause. We sincerely appreciate your ongoing efforts and dedication.



Craig Dooley displays his happiness and pride upon completing the Chicago Marathon.

American Brain Tumor Association

800-886-1281

Raising *Funds* & Raising Fun

PENNSYLVANIA

Those who knew him say that Frank Colden III probably would have been embarrassed to know people were making such a big fuss over him. His brother Chad said “Frank was always one to give of himself but not expect anything in return.” There is no doubt though he would be proud of what his memory has inspired as 300+ people participated in the 2nd Annual Francis Colden III 5K Run/1-Mile Walk to raise funds for ABTA programs and to fund a scholarship for a senior on the track team at Spring-Ford High School. A star athlete, Frank was a member of two track teams, one at Spring-Ford, where he still holds two records and the other at college. Judy and Frank Colden, Frank’s parents, hope to double the attendance at this successful event every year. Thank you to everyone who contributed to its most recent success.



Frank Colden II (far left) and Chad Colden (far right) don't want to ruffle any feathers at the Francis Colden III Memorial Run/Walk.

OHIO

The 2nd Annual Daniel Martinelli: Night on the Towne is an extravaganza that is hosted by Sandy Martinelli in memory of her husband and to support brain tumor research. This hugely successful evening features a dinner buffet, silent auction, live auction, two-act Broadway Variety Show: Manhattan Melodies, and a raffle! Couple all these activities with family and friends and you have the formula for spending a lovely evening and raising research funds. Thank you to Sandy and her extraordinary committee members for bringing together this creative, fun-filled event.

TEXAS

The 7th Annual Dallas Stars Bonnie Blair Golf Classic was a spectacular weekend of fun and camaraderie. The three-day event kicked off with a beautiful banquet followed by a spirited celebrity draft auction. This was a chance to bid on a celebrity – Dallas Star player or Olympian – to join one’s golf foursome for the tournament. Picture perfect weather greeted golfers the following day on the golf course, followed by the post-tournament awards dinner. The following evening, the Dallas Stars exchanged their golf irons for hockey sticks and a preseason hockey game. Our special thanks are given to Bonnie Blair for always including ABTA as a beneficiary of this successful event and thanks to the Dallas Stars staff for their southern hospitality. It was a great time for a great cause!

ILLINOIS



Santa with the Palya family (left to right) Randy, Dean, Dean, Jr. Nancy and Dayna.

Chicago Bears defensive linebacker Brian Urlacher played Santa Claus for the American Brain Tumor Association’s Fifth Annual Holiday Party for pediatric brain tumor patients hosted by the Hilton Northbrook. Judging by the smiles on the children’s faces, Brian was a perfect Santa. The kids took their turns sitting with Santa, receiving a gift and autograph from Santa Bear while having their picture taken with him. Thank you to everyone who helped make this a wonderful afternoon for all those who attended.

OHIO

You may remember Howard Pinsky. He rode his bike 100 miles in a single day last year in honor of his wife, Michelle, who was diagnosed with a brain tumor at the age of 16. Well, he decided to take on the challenge again this year, not only for Michelle but also to memorialize his friend, Stan Greenberg. Howard had some company this time on his bike ride. Two friends rode along side him; he also had the encouragement of Stan's wife, Sandy. In addition, Howard and Michelle were expecting their first child any day. "Last year was very emotional because due to your research I was marrying Michelle. This year is just as emotional because now she is going to give birth to our first child." Thank you for remembering ABTA during your life cycles, Howard. We are sincerely honored to be part of your life. Now, send pictures of the baby!



Sandy Greenberg (far right) greets (from left to right) Howard Pinsky and Bob and Gary Speary after their 100-mile journey.

NEW JERSEY

For the second consecutive year, in the spirit of the holiday season, Satsang Yoga Studio sponsored a Thanksgiving Yoga Class to benefit the ABTA. The students came together with an "attitude of gratitude" and a heartfelt desire to remember their loved ones who fought "the good fight." Celia Konigsberg and Helen Chierchio were an inspiration to their families. This annual event to raise awareness, as well as funds, honored these women in the spirit of the yoga tradition. Satsang's owners: Ellen Kaplow, Connie Schaffer and Barbara Baranyay say they "continue to be inspired by our students." And so are we at ABTA. Thank you!



A class is in session at the Satsang Yoga Studio where students with an "attitude of gratitude" perform their exercises.

American Brain Tumor Association

www.abta.org

ABTA *Tributes*

Anniversary Wishes

ABTA, 30th
Mr. & Mrs. Robert Brown, 25th
Dr. & Mrs. Burns, 50th
Rev. & Mrs. C. Buterbaugh, 50th
Mr. & Mrs. Gilbert Goldberg,
50th
Melvin R. Greear, Jr,
6th Year Survivor
Jim Horn, 9th
Bill & Sue Kolitz
Bob & Sandy Kolitz
Mr. & Mrs. Manuel (Manny)
S. Kramer, 40th
Mr. & Mrs. Henry Samuels, 60th
Mr. & Mrs. Dan Schlanger, 45th
Rabbi & Mrs. Shlomo Shuster,
50th
Edward & Hannah Truth, 55th

Birthday Wishes

Jennifer Anderson
Ashley Bokhart
Jack Capsuto, 80th
Chick Chaikin, 80th
Mrs. Ralph Cople
Arthur Coren, 70th
Judy Coren
Dr. Ron Goodman
Norman Gordon, 90th
Sidney Grossman, 85th
Julian Hayum, 60th
Bob & Sandy Kolitz
Harriet Nathan
Dottie Palay
Mr. & Mrs. Douglas Petroni
Hattie Rubin, 90th
Cory Rzasa, 16th
Nate Rzasa, 15th
Daniel Scheib
Donald Segal, 65th
Alex Weisz
Mr. & Mrs. Martin Witkin,
80th & 85th
Burt Zis, 60th

Congratulations

Rachel Cogut, Bat Mitzvah
Ezra Glenn, Bar Mitzvah
Frannie Goldberg,
Chicago Marathon Run
Jack Houston, 5year survivor
Mark J. Jensen, 7 Years
Cancer Free
Mr. & Mrs. Bret Maxwell's Son,
Bar Mitzvah

Tracy Lynn Maytas, 10 Years
and Going Strong!
Fr. Stephen Potter, 25 years
of Ordination
Rob & Sheryl Rosenberg's Son,
Bar Mitzvah
Sam Rosenblum, Bar Mitzvah
Jordan Scott Rumeld, Bar Mitzvah
Eli Schoenberg, Bar Mitzvah
Raymond C. Ward, 7 Years
Cancer Free
Scott & Dana, Engagement

GetWell Wishes

Steve Conway
Dale S. DeFrancis
Ronnie Freeman
Ira Izenstark
Helen Samuels
Briana Santiago
Sara Mae Schaeffer
Richard Sobleman
Henry Zipperman

Holiday Wishes

Mr. & Mrs. Charles R. Beauregard
Mr. & Mrs. Jim Boon
Dr. Fernando Diaz
Christina DiFrancesco
Dr. Maher Fakhouri
Larry Graybill
Mr. & Mrs. William Guyton
Ruth A. Jasper
Joe Kallas
Robert Manchester
Mr. & Mrs. A. Andrew Miller
Mr. & Mrs. Richard Morgan
Charles Passerman
Mr. & Mrs. Robert W. Petrus
Mr. & Mrs. Jack Rearick
Kathy Taslitz
Dr. Craig Watson
Mr. & Mrs. Tom Whealon

On the Birth of

Madison Jay Glick
Zachary Shanks' 7th Grandson
Dr. & Mrs. Lokesh Tantuwaya's
Devon

ThankYou

Rabbi & Mrs. Dov Kentof,
Officiating at Marriage Renewal
Keshin Family
Steven Weiner, MD, Grey
Matters Presentation

Thinking of You

Ann B. Bates
Mr. & Mrs. Christopher A. Bates
Blair Dean
Thomas Eddy II

Wedding Wishes

Donna J. Brandt &
Mark Brokowski
Michael Freeman Daughter's
Marriage
Daniel Guttman & Patty Peirce
Mr. & Mrs. Hooper Jones
Monte F. Mar & Heather Harris
Chris Peck & Leigh Kahle
Mr. & Mrs. Jerry Ringer
Eric Silverman
Mr. & Mrs. Ira Weinstein

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J. Steve Addington
Christian Shawn Allen
Bruce Amlaw
Douglas Anderson
Joanne Anderson
Harold Artz
Brad Beldon
Gilbert Berry
Lee Blackmon
Joe Blaustein
Paul Bloomdahl
Carol Bloomfield
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David Moormann
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Connie Muse
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Eloise Nathan
Adam Navarro
Laevata Nelson, RN
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Donald A. Nichols
Mr. & Mrs. Osmond E. Nickerson
Jeffrey K. Norman's Grampa Toto
Edward Nugent
Katie Pedersen
Catherine Pepper
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Franklin K. Scheib
Franklin R. Scheib's Darlene

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Dale Williamson
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**To set up a Memorial Fund,
call the ABTA office at
800-886-2282.**

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Nellie Brugger
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Linda Bueti
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Clarita Castillo Nenne Pfeffer
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Richard Riesterer
Virginia Rife
Michael W. Roache
Brenda Ann Schweigert

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Ronald G. Seeley
William Nicholas Shepesh
Betty Broaddus Show
Richard Leroy Sizemore
Brenda L. Spedale
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Nancy Carolyn Schroeder
Tarczy
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Sue Cline Walker
Joseph A. Walsh
Marie E. Webster
Michael E. Whelan
Donald Wilson
Lois Wright
Ann Yokich

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Victor F. Acocella's Wife
Toni Adelung
Ira Adler's Father
Godwin O. Akhibi
Joanne Brodell Alpern
Joseph L. Alvarez
Forrest Ammons
David B. Anderson
Gertrude Anderson
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Saul Leo Antecol
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Harriett Boyer Arnold
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Bradley Bacon
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Virginia Ruth West Baisden
Nancie J. Baker

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William A. Barbe
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Dean Paul Baron
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Jessica Jennifer Cohen
Milton A. Cohen
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E. Barry Combs
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Linda S. Favoriti Coons
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Jenny Dolins' Grandmother Frieda
Sandra Domina
Kevin P. Dooley
Marsha Dooley
Emily Ann Dorfman
Mark Dorfman

ABOUT ABTA SPECIAL OCCASION DONATIONS

Thinking about someone on their special occasion? Looking for a creative gift idea? Consider making an "In Honor of..." donation to ABTA.

Mail your check to:
American Brain Tumor Association
2720 River Road
Des Plaines, IL 60018-4117

Include a note informing us of the occasion, and give us the name/mailling address of the person to whom you wish a card sent. We will send a card to the person you specify, signed with your name, and send you a receipt for your donation.

Donations can be made by calling 847-827-9910 or at our web site, www.abta.org, using a MasterCard, Visa, or Discover card.

The Special Occasion donations listed were made between July 1 and December 31, 2003.

ABOUT ABTA MEMORIAL FUNDS

An ABTA Memorial Fund provides a special way to remember a loved one at the time of their death. Once a memorial fund is arranged by calling the ABTA office at 800-886-2282, family and friends can make donations to the individual's Fund using a check or credit card. There is no charge to open an ABTA Fund. If you would like to learn more, please call us.

The Memorial Funds listed were opened between July 1 and December 31, 2003.

| | | | |
|-----------------------------|------------------------------|-----------------------------------|----------------------------|
| Leonard J. Downey | Harry J. Geddings | Sarah A. Harsh | Sally B. Johnson |
| Tim Doyle | Lisa M. Bachman George | Harry Hartel | Archibald W. Johnston |
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| Dyer Family's Father | Janet M. Gifford's Friend | Deana Beardsley Hauser | Eugene E. Kalinec |
| Monica Eckert | John McIver Gillespie, Jr. | Eugene Haworth | Eugene J. Kalinec |
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