

CURE REPORT

Winter 2003

The CURE Report is published quarterly to provide support for the families of children with cancer, as well as to educate the general public about these childhood diseases and CURE's programs.

Serving children with cancer and their families for more than 25 years.

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Spotlight on Emily Garner

by Jerri Garner

It is September 18, 2003...a beautiful sunny day. My daughter just called to share the news that she got the internship that she wanted. I started to cry as I remembered another September 18th, 22 years ago. It was a beautiful sunny day, too. This is where this story begins.

My husband, Wayne, and I were the parents of a rambunctious four-year-old son and a nine-month-old daughter. Wayne had been elected to the state senate the year before at the age of 28. Our life was idyllic. The legislature was in special session that September. Emily had a follow-up appointment with a pediatric ophthalmologist at Piedmont Hospital for a previously diagnosed vision problem. The children and I picked up Wayne at the capitol and off we went for the checkup and a fun afternoon in Atlanta. On that sunny day, little did we know that life as we knew it would never be the same.

The ophthalmologist examined Emily's eyes as Wayne struggled to hold her. He again confirmed that Emily would have to begin wearing glasses in a few months. He told us that he would examine her again in three months. As we were going out the waiting room door, his nurse stopped us and said that Dr. Pollard had decided to dilate Emily's eyes. Once her eyes were fully dilated, we took her back into the examining room. Wayne positioned her head between his knees and attempted to hold her while Dr. Pollard examined her again. As I watched, all color left the doctor's face. He said, "There is a growth in this eye that was not here four months ago." Young, innocent, believing that nothing bad ever happened to good people, I asked, "Could it be cancer?" His answer was, "Yes."

A few days later, Emily was diagnosed with retinoblastoma, a rare type of eye cancer. A new journey began. Disbelief, anger (how could God allow this to happen to our child?), and fear were now a part of our lives. While everyone around us seemed to be leading normal lives, we were now dealing with doctors, hospital visits, tests, blood work, spinal taps, bone marrow tests, cat scans, conflicting protocols, radiation, etc. No one seemed to have a definitive plan as to how to treat this type of cancer. This added to our fear, confusion, and frustration.

Columbia Presbyterian Hospital in New York City had a doctor who was doing cobalt implants successfully with retinoblastoma patients. We flew to New York, staying at the Reese House (in Spanish Harlem), while Emily was evaluated. It was decided that her tumor was too close to the optic nerve for this procedure. This group recommended that it would be worth trying external beam radiation to her eye as opposed to removing her eye.

Piedmont Hospital agreed to do her radiation through their outpatient clinic.

At Piedmont, we began a journey with a staff of angels in the outpatient clinic. They adopted Emily (and her family) with love and compassion. Emily was their first little person to become a regular patient in their clinic. After a few months, a rocking chair was purchased that they named after her. For more than five years, we



The Garner family from left to right: Emily, Griffin, Wayne, Jerri, and Molly

went every few months, for Emily to be put to sleep while her eyes were moved from their sockets to be examined thoroughly for satellite tumors that are common in her type of malignancy. During this time, we were also guided to another angel, Dr. "Billy" Ragab, head of pediatric oncology at Egleston. He did Emily's follow-up until a few years ago when he left Egleston to return to his family business in Egypt.

From the lifesaving radiation, Emily has endured many complications. Cataracts, facial growth anomalies, and severe sinus problems are just a few of the problems resulting from the radiation. She has had cataract surgery, sinus surgery, and two extensive facial reconstruction surgeries. Now that you've heard the bad stuff, let me share the rest of the story as it unfolds today.

Fast forward to October 29, 2003: Emily, a friend from Auburn and fellow counselor from Camp Sunshine and I attended

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CURE Childhood Cancer is a nonprofit organization dedicated to conquering childhood cancer through research, education, patient and family support. Our financial resources are devoted to supporting basic and clinical pediatric oncology research, but children fighting cancer need more than medical care. CURE also provides a broad range of support programs, resources and services designed to meet the needs of the entire family coping with childhood cancer, from diagnosis and beyond.

The *CURE Report* is a publication of CURE Childhood Cancer. We welcome and encourage contributions, comments and suggestions from patients, parents and staff members. If you would like to receive the *CURE Report* or have a change of address, please call the CURE office, 770-986-0035.

CURE REPORT

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From the Desk of Jill George, Executive Director

Dear Friends and Families,

Winter is traditionally a time of reflection, of looking back at the year gone by and anticipating the new one. At CURE, we are remembering and celebrating some of the gifts received and given in 2003. Several outstanding fundraisers and significant donations allowed CURE to support important pediatric cancer research and the families of children with cancer.

The fundraisers were innovative and traditional, fun and hard work and involved many people and companies. Here are some highlights:

- ❖ Using donated materials and services, *Lowell Pratt Residential, LLC*, built a house in Chandler Crossing, a new Gwinnett County community, dedicated to the memory of young *Emily Biggerstaff*. When "Emily's House" was sold, *Lowell Pratt Residential* donated \$61,000 to CURE.
- ❖ For the twentieth time, the *Atlanta Alumnae Chapter of Tri Delta* held a dinner/dance/auction to benefit CURE. CURE accepted the chapter's incredible gift of \$108,000, bringing the total to more than \$1 million this group has donated over the years.
- ❖ Summer concertgoers who made a \$5 tax-deductible donation to CURE entered a drawing for a Nuclear Red Triumph Speed Triple motorcycle donated by *Triumph Motorcycles Limited*. Thanks to *Marcie Cardwell*, *Mad Booking*, and CURE's association with the *2003 On the Bricks Concert Series*, CURE received more than \$7500.
- ❖ *Radio station Z-93's* on-air auction was music to our ears. A "priceless prize

package" donated by *Atlanta Motor Speedway* included a pair of tickets and pre-race pit passes to two major races and a meet and greet with NASCAR driver, Dale Jarrett. The high-speed bidding brought in funds for CURE as well as created awareness among listeners. Additionally, the *Speedway Children's Charities Foundation* gave \$11,300.00 from its annual fundraisers.

- ❖ Members of the *Snellville Theta Sigma Chapter of Beta Sigma Phi* are tireless in their efforts for CURE, hosting two events in 2003. Their 15th Annual Valentine Dinner/Dance for CURE raised more than \$47,000. The chapter then put together the CURE Childhood Cancer 2003 Golf Classic Sponsored by *BellSouth*. The sold out tournament drew over 250 golfers to The Oaks Course in Covington, netting \$90,000 for CURE. Special thanks to presenting sponsors *BB&T/Stephens & Company*, *Volume Transportation and CS Truck & Trailer Repair* as well as to tournament sponsor *BellSouth*. *BellSouth* has generously agreed to sponsor again in 2004.
- ❖ As of October 31st, 2094 vehicles have been donated to CURE and processed which raised \$124,387.95 in 2003.
- ❖ I was honored to be invited to the *62nd Annual Convention of the National Federation of Grandmother Clubs of America*, where I accepted a gift of \$25,000 from Grandmother Clubs nationwide. The *Designing Grandmothers Club of Snellville*, with 32 members, contributed \$4020 to the campaign. Even a small group can make a big impact.

Through these remarkable efforts and other gifts from many other individuals

and companies, CURE continued to fulfill its mission of funding pediatric research and helping families of children with cancer. Here are some of the ways CURE helped in 2003:

- ❖ CURE's *Open Arms* dinner and fellowship programs are offered every Thursday night at both the Egleston and Scottish Rite campuses of Children's Healthcare of Atlanta for families of children on treatment. Monthly food donors include *Papa John's Pizza*, *Moe's Southwest Grill*, *Publix Supermarkets*, *KFC Atlanta Region Catering*, *Folk's*, *Ingles Supermarkets* and *Savage Pizza*.
- ❖ Almost \$500,000 will go to *Children's Healthcare of Atlanta/Emory University School of Medicine* in 2003-2004. Funds are used for Whole Health Services, Professional Development, and Family Emergency Services at both hospital campuses; by Harry Findley and his team of medical researchers working on ways to combat drug resistance in acute lymphocytic leukemia and neuroblastoma; and by the Fellowship Training Program at the AFLAC Cancer Center and Blood Disorders Service.
- ❖ Along with *Ronald McDonald House Charities of North Carolina*, CURE sponsored the now annual *Red Carpet Day* for 50-60 teens from across the southeast. Seventeen year old *Savannah Solomon*, founder of *Red Carpet Day*, wanted to find a way to connect with other teens



Jill George

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\$90,000.00 for CURE Childhood Cancer!!!

by Jeana Coleman

Isn't it a wonderful thing when children's cancer research can benefit from 250 golfers enjoying a great day of golf? Well that's pretty much the formula of the CURE Childhood Cancer Golf Classic that is held each year at the beautiful Oaks Course in Covington. This event has been hosted by the members of Snellville Theta Sigma Chapter of Beta Sigma Phi for 10 years and was sponsored this year by BellSouth. Along with Bellsouth's generosity, BB&T/Stephens & Company and Volume Transportation/CS Truck & Trailer Repair were presenting sponsors. The sorority members, CURE board members, staff and sponsors spend many days reaching out to their contacts and community to sponsor and/or play in this special tournament. Playing in the Classic has become such a tradition for many that the spots fill up by the first of August.

Friday, September 26th, turned out to be a perfect day of blue skies and bright sunshine for this year's tournament. With such gorgeous weather, it was only appropriate that Channel 46 came out to broadcast their noon weather report from the Golf Classic! After collecting the registration fees, sponsorships, raffle and contest fees, the day profited \$90,000.00 for CURE Childhood Cancer! Many, many thanks go out to all of the volunteers who organize and work on this tournament. Also, many thanks to the gen-



From left to right: Bob Thomas, BellSouth Senior Attorney; Lloyd Nault, BellSouth Entertainment General Counsel; Mo Andriate, BellSouth Regulatory & External Affairs Manager; Charles Ginn, Director, BellSouth Security

erosity of the sponsors, especially our tournament sponsor BellSouth.

Please join us next year on Friday, September 24, 2004, for the CURE Childhood Cancer Golf Classic Sponsored by BellSouth. For the complete list of sponsors and winners of the 2003 Golf Classic, log on to www.curechildhoodcancer.org.

COMING TOGETHER FOR OUR CHILDREN

CURE Childhood Cancer and Bradley's Fund come together once again to unite families who have lost a child to cancer.

The festivities will be held at Lake Oconee on **Saturday, June 12, 2004** from 11:00 a.m. until 4:00 p.m.

It will be a day of fellowship, fun, food, boat rides and activities for the entire family. Save the date on your calendar and look forward with us to a great time!!

Continued From the Desk of Jill George...

with cancer. This amazing three day fun-filled event was summed up this way by a participant: "I felt so special...I never felt comfortable with my cancer until I came here...thank you so much for making it possible."

Incredible things happened at CURE in 2003 thanks to those named here and those of you who gave in other ways. Our work for children with cancer and their families would not be possible without the support of friends like you.

Here's to 2004!

Jill George

P.S. 2003 was a special year for me as well as for CURE. In May, I married my best friend and super CURE volunteer, Art George. Good things happen at CURE!

Continued from Spotlight on Emily Garner...

a funeral for a six year old young man named Collin who lost his battle with leukemia. We listened to his grandmother as she shared about her grandson with humor and great bravery. She's a part of the club that we belong to that none of us ask to join. Emily, today, is a senior at Auburn University. She has enjoyed being a War Eagle, a sorority girl, a campus recruiter, a student government cabinet member, and most of all, a dear friend to many people in Auburn, young and old. Emily is old beyond her years and is fortunate that she has learned early in life that life is precious and is never to be taken for granted.

Life for us before September 18, 1981, was idyllic. Life after that date has been so much sweeter. In our late twenties, Wayne and I were blessed to learn what it takes some people a lifetime to learn. Bad things do happen to good people. Sometimes God does not choose to prevent these bad things from happening, but He is always there to see us through each step. He has been there with us as we have enjoyed watching our son, Griffin, Emily, and later another daughter, Molly, grow up. There have been tears; but, oh there's been so much laughter!

To end this story today, I must share with you the news Emily shared with me on September 18, 2003. After her graduation in early May, Emily will be joining the CURE Childhood Cancer staff as an intern beginning May 17, 2004. Please get to know her; you will be blessed by her presence.

CURE WISH LIST

NEW LASER PRINTERS • NEW COMPUTERS •
NEW COPIER • PAPER CUTTER • STEP STOOL •
COMPUTER WIZ VOLUNTEER • GIFT CERTIFICATES TO:
WAL-MART & PAPA JOHN'S PIZZA

Three Who Survived



Ansley and Paul are tenth graders and Lucy is a seventh grader at Paideia. Lucy and Paul were treated for Wilms' Tumor while Ansley was treated for Acute Myelomonocytic Leukemia. All live in Atlanta and are seen at Children's Healthcare of Atlanta at Egleston.

Lucy Cleland, Ansley Riedel and Paul Yates are students at The Paideia School in Atlanta. But this trio shares more than the same school: they share the story of a diagnosis of cancer as children. More important, they share recovery. Lucy's mom, Sydney Cleland, sat down with these remarkable students for an intimate conversation for this issue of the *CURE Report*.

Sydney: *As you know, we are talking for an article to appear in the CURE Report. CURE does many wonderful things for kids and their families, but also supports cancer research. Do you think childhood cancer can be cured?*

Paul: There are so many different kinds [that] it's hard to say.

Ansley: Hasn't their been big progress on some [kinds of cancer]?

Lucy: Yes. I learned about [the development of] bone marrow transplants for sickle cell anemia just yesterday in my science class. But with some cancers there is only treatment, not cures.

Ansley: That's true.

Paul: There are no sure-fire cures.

Sydney: *Do any of you have an interest in pursuing a career in medicine as a result of your experience? If not, what are you interested in?*

Ansley: I do want to be a doctor, a pediatric oncologist/hematologist. I am interested in medicine and not scared of blood. Also, the nurses influenced me so much, they were so fun and cool and nice, that I might be a nurse or maybe a counselor.

Paul: I want to act and sing.

Lucy: I want to be an artist or maybe an architect.

Sydney: *You've all probably seen or heard of the television show "Survivor". How do you feel about that term "survivor" being applied to you? What does it mean to be a cancer "survivor"?*

Lucy: I don't really feel like it applies. We just got treated [for the cancer]. Sometimes it seems like an honor, something people want to be, a kind of rank.

Ansley: I've known many kids who have struggled and relapsed. I relapsed when I was little, so I don't really remember. I have friends who have died or are now on therapy because they have relapsed, so I do think of it as surviving.

Paul: I also know lots of people who have died. We actually survived the cancer but with lots of help.

Ansley: That makes me feel proud. Everyone says, "Ansley is healthy, doing great." But some of my friends were "doing great" too [and then relapsed] so there is a voice in my head asking "What if?" Are you ever really cured? [Also] on the "Survivor" show, people don't care about others; they are only out for themselves. With cancer, we all work together. Everyone is very supportive. You can't survive on your own without a community

of doctors, nurses, medicines, family and friends. You do have to be determined and strong but [you are] not alone.

Paul: I am a really religious person, so God had a role.

Sydney: *Do you find that people treat you differently once they find out that you have had cancer?*

Lucy: [Either] people treat me awkwardly or it doesn't matter.

Ansley: Most of my friends already know; they hear me talking about doctors, Camp and all. New people get emotional all of a sudden, especially adults. [They say], "Oh my God, you're so beautiful!" They look at me like they can't relate but want to be supportive.

Lucy: Yeah, suddenly they want to give you all these compliments. Adults want to help you. Friends accept you for you and not for your cancer. I liked Camp [Sunshine] because of the fun things. It was not about our experience of cancer.

Ansley: I meet people at checkups who think if I survived their kid will too. [They think], "Normal! Has hair! Not sick!"

Paul: It doesn't faze my friends and teachers. I don't tell many people. I don't meet some-

one and say, "Hello, I had cancer."

Ansley: I like to share about it to show it may not seem like cancer can affect you but it could [happen to you]. I don't dwell on it.

Sydney: *Besides your parents, were there others in your life who helped you during or since your diagnosis and treatment?*

Ansley: My grandmother lived with our family and really helped a lot. She even stayed in the hospital with me sometimes and was like a grandmother to the other patients. I am also still friends with the doctors and nurses [who treated me].

Paul: I am an only child. My parents' best friends, Mark and Karen Scott, have three daughters who are like my sisters. They treated me like a baby [brother], gave me what I needed. I also had my grandparents and other friends [who helped].

Lucy: My dog Rosie was the best help. She would just sit and listen [to me].

Sydney: *What was the best thing that happened to you while on treatment? For example, did you have a "wish" granted? Have you been to any of CURE's Off Therapy Celebrations?*

Ansley: I wished to re-do my room. I was three years old and no one could believe that was what I wanted. But I knew what I wanted. And I still have all that stuff. The CURE Off Therapy Celebration was always a big family outing for us. I liked it, going up on stage and hanging with my friends.

Lucy: I wished to go to "Pooh-land" and my family and I got to go to Disney World. I've been to the Off Therapy Celebrations at Six Flags. I liked going in the park.

Paul: I've been to the CURE celebrations several times, at Lake Lanier and Six Flags. I only went on the stage once.

Sydney: *What advice would you give to someone who has recently been diagnosed with cancer?*

Paul: Hang in there. Don't give up hope. Live life to the fullest. Everyone has the same 24 hours in a day. Do what you want even if you are not sure you will live. Believe God will help you through the doctors, nurses, and your parents.

Lucy: Yes, press forward.

Ansley: Be strong. Be confident. Stay positive. Believe you can do it. Don't give up even if you are really tired. Even when you have bad days you have something positive to look forward to [like Camp] so don't dwell on being sick.

Dear Families

CURE is fortunate to have Child/Adolescent psychologist, Marla Shapiro, who has worked in schools and hospitals, volunteer to write a Q & A column for our newsletter. She can address topics ranging from school re-entry, post-treatment learning issues, social/emotional functioning of patients and siblings to student and family legal rights in the school system. You can forward questions for the column to eva@curechildhoodcancer.org, but please keep in mind that she will not be able to answer all questions submitted.

Most of the questions that have been submitted thus far touch on school-related issues. In my last column, I wrote a bit about "late effects" and briefly mentioned educational and neuropsychological testing. In this month's column, I will explain what these kinds of evaluations are usually like.

What is psychoeducational and neuropsychological testing?

Individual testing administered by school psychologists within the public schools is usually referred to as *psychoeducational* or *psychological* testing. Such evaluations usually consist of tests of academic achievement (reading, writing, math), copying/writing skills, global measures of intellectual functioning ("IQ tests"), and measures of social-emotional and behavioral functioning. Observations of classroom behavior and a review of the student's educational, developmental, and medical histories may also be included. Although these types of evaluations are often sufficient for students with developmental learning disabilities or attention disorders, they are usually ineffective in detecting the sometimes subtle effects, or atypical patterns of strengths/weakness, that are the result of treatment for childhood cancer or leukemia. Consequently, most tests of intellectual and academic functioning are much better measures of *previous* learning than of learning *potential*.

Neuropsychological evaluations, however, are much more comprehensive evaluations of an individual's functioning in many areas. In addition to tests of academic, intellectual, and emotional/behavioral functioning, measures of language, perceptual, motor, attentional, memory, problem-solving, planning, and organizational functioning are also administered. Formal and informal measures of functioning in all areas, as well as input from home and school, and detailed reviews of the medical, developmental, social, family, and educational history are all considered in providing a comprehensive profile of a student's strengths and weaknesses. Specific recommendations for home and school are linked directly to evaluation results.

Who can provide these evaluation services?

Within the public schools, instructional support teachers (IST) or special education personnel may administer some basic screening measures of academic functioning, whereas school psychologists administer more comprehensive psychological or psychoeducational evaluations. A neuropsychological evaluation can only be completed by a licensed doctoral-level psychologist who has had specialized training in brain-behavior relationships and neuropsychological assessment. Very few school systems employ neuropsychologists. However, sometimes neuropsychologists who usually work in hospitals or private-practice settings provide contractual services for schools.

What is the usual outcome of testing?

That depends on the reason for the evaluation and the presenting concerns. Results are often used to confirm or clarify a diagnosis; determine eligibility for specialized educational assistance or accommodations; provide a profile of strengths and weaknesses to facilitate educational planning; and to assist individuals, families, educators, and specialists in understanding the difficulties that led to the referral for evaluation, and in determining appropriate services.

Next issue: Educational laws and regulations, and how to obtain services in the schools.

Dr. Marla Shapiro is a Licensed Psychologist and Camp Sunshine volunteer. She works at the Regents Center for Learning Disorders at GSU and maintains a private practice in Marietta providing psychological and neuropsychological evaluations and educational consultation.

CURE now proudly accepts The American Express Card for donations, merchandise purchases and event entry fees.

Young Medical Miracles Celebrate at the "Off Therapy Celebration 2003"

Pediatric Cancer Patients Commemorate Their Survival

A medical miracle took place on Sunday, October 19, when a record number of former patients and guests attended the 20th Annual Off Therapy Celebration at Six Flags Over Georgia. Nearly 1900 people gathered to celebrate the survival of area children who are beating cancer.

As more and more children are winning their battle with cancer, the number of young survivors attending this special event grows. Only 70 children came to CURE's first off therapy celebration back in 1980 when it was held in a small hotel ballroom. Children just off treatment celebrated alongside former patients who have now reached adulthood, married and begun families of their own. Seeing so many happy, healthy families in one place is what reinforces CURE's commitment to research and patient and family support.



Kyle McCormick enjoying himself at CURE's Off Therapy Celebration. Photo by Joaquin Lara.

Alex Richman was the former patient off treatment for the shortest time, 1 day. The longest time was Shalonda Bain, off therapy for 28 years!

Thanks to all of the families and volunteers including event MC, Mickle the Pickle, The Seed & Feed Marching Abominables band and Friends in Harmony for making this such a great event. A special thanks goes to Speedway Children's Charities, Publix Super Markets Charities and the Atlanta Foundation for their financial support of this celebration.

The 2004 Off Therapy Celebration is Sunday, October 17th.

A Very Special Kind of Birthday Gift ...



Adrianna Arce asked that her friends bring a donation for CURE Childhood Cancer in honor of Carter Martin, who is being treated for Ewing's Sarcoma, instead of giving her presents for her birthday. This is what she had to say about the experience:

I sent this money because of my friend Carter who had cancer and other children. I hope it works. I'm going to do it again next year. I can't wait! Carter is a lot better now. He is even walking! Bethany who is my best friend is so happy that I did this and I am too!

Adrianna Arce, 8 years old



The Health Insurance Portability and Accountability Act (HIPAA)

Developed by the Department of Health and Human Services (HHS), **these new standards provide patients with access to their medical records and more control over how their personal health information is used and disclosed.** If your organization deals with Protected Health Information (individually identifiable health information), you're probably already familiar with the regulations set forth by HIPAA.

For those of you unfamiliar with the law, HIPAA establishes national standards regarding the privacy of personal health information and sets forth rules about how "covered entities" (healthcare plans, healthcare clearinghouses, or healthcare providers) can use a client's/patient's health information. Under HIPAA, entities must first obtain an individual's specific authorization before disclosing their healthcare information for marketing and fundraising purposes. At the same time, the rule permits doctors and other covered entities to communicate freely with patients about treatment options and other health-related information, including disease-management programs.

The primary implication for nonprofits is that, without explicit authorization from a patient, fundraisers can only use the demographic portion of medical records (name, contact information, age and gender), but not any information about the patient's illness or treatment. Use of information on diagnosis, treatment and nature of services can be used only with a patient's consent.

Other provisions in the law establish guidelines for privacy notices, opt-out clauses and other uses of protected information. The U.S. Department of Health and Human Services maintains the authoritative site on HIPAA regulations. The Association for Healthcare Philanthropy has an informative white paper on what fundraising organizations need to do to conform to HIPAA.

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"Blackbaud provides nonprofit fundraising and accounting software."

"Fun" Raiser Card



Glenridge Pointe
860 Johnson Ferry Rd.
Suite 200
Atlanta, GA 30342
PH 404.303.0081
FX 404.303.0084



Along with donating food once a month for Open Arms at Scottish Rite, Moe's Southwest Grill at Glenridge Pointe is supporting CURE Childhood Cancer through its "Fun" Raiser Card program.

For each \$5 purchase at the Glenridge Pointe location at 860 Johnson Ferry Road, Moe's will donate \$1 to CURE when the "fun" raiser card is turned in at checkout. If you would like to receive "fun" raiser cards, please contact Eva Walston at 770-986-0035. Fundraising has never been this fun and tasty!

WAYS YOU CAN DONATE TO CURE

CURE Childhood Cancer always appreciates cash donations to help support our many wonderful programs. **Contributions are tax deductible** and can be made in honor or memory of someone special. Please think of CURE the next time a special occasion comes along.

There are other ways you can give to CURE Childhood Cancer. **Donate your car, truck, boat, motorcycle or RV.** Your donation is fully tax-deductible and free towing is available. For more information, please **call 1-800-513-6560.**

Have you cleaned out your closet and want to donate some used clothing? For information regarding a pick up of all types of donated *clothing and household items* in Atlanta and surrounding areas, **call 678-298-2073.**

Please remember, Clothing Pick-Up Service (CPUS) is an independent organization that collects used merchandise and contributes to CURE Childhood Cancer. CURE is neither an agent nor principal of CPUS, and we are not responsible or liable for any acts or omissions of ownership, operation or activities of the organization.

CANCER SURVIVORS NEEDED

Cancer survivors who were diagnosed and/or treated between the ages of 12-17 are needed for a research project. Completion of a brief pencil and paper survey is all that is required to participate. If you are interested, please call or e-mail Coralea Dingley at 336-229-5360, cdingley@elon.edu

CURE Joins State Cancer Network

Recognizing the power of many voices to accomplish what one voice may not be able to, CURE has joined 16 other state cancer survivor organizations to form **The Cancer Survivor Leadership Council of Georgia**.

The Council's member groups serve as a loosely woven coalition that will educate and advocate for cancer patients, families and survivors. The Council also plans to work with the Georgia Cancer Coalition (GCC) when it's appropriate to share knowledge and concerns with key policy makers and the general public.

As advocates for all the state's cancer patients and their families, the Council's focus is building community, business and government support for cancer patient and survivor issues. Through its member groups, the Council also will monitor and address cancer policy developments, especially in the state legislature and in the Department of Human Resources where Medicaid, PeachCare for Kids and state employees' healthcare insurance plans are housed.

CURE Board member, **Jane Bick**, and the Brain Tumor Foundation for Children's Executive Director, **Mary Campbell**, represent the pediatric cancer community in the new organization.

CURE 2004 Valentine Dance Sponsored by Barron's Fine Jewelry

The 16th Annual CURE Valentine Dinner/Dance will be held Saturday, February 14, 2004, at Atlanta Marriott Gwinnett Place. This event, hosted by the Snellville Theta Sigma Chapter of Beta Sigma Phi, includes a popular silent auction sponsored by Barron's Fine Jewelry from Snellville. Reservations are \$75/per person and all proceeds go to CURE. Please contact the CURE office or Dance Chairman, Linda Davies at linda.mckay@tycohealthcare.com if you would like to receive an invitation. *Article submitted by Jeana Coleman*



CURE 2004 Spring Symposium

CURE Childhood Cancer's 2004 Spring Symposium will address **cancer survivorship issues and late term effects of treatment**. This year's program will feature **keynote speaker Kathy Ruccione, RN, MPH, FAAN**. Ms. Ruccione is the Nursing Administrator in the Children's Center for Cancer and Blood Diseases at Children's Hospital Los Angeles. Her particular interests are in three areas: preparing patients and families to be informed participants in their care; the long-term follow-up of childhood cancer survivors; and the epidemiology and genetics of childhood cancer. She has published extensively and is frequently invited to speak on these topics. Kathy has lived in Southern California most of her life. She has one child, Daniel, a 17-year-old who is profoundly deaf. Living with Daniel has brought many new challenges and opened new worlds. Her experience as a mother of a child with a disability has enriched her perspective and deepened her commitment to finding ways to help children and their families survive and transcend the experience with cancer.

The symposium will be at **The Westin Atlanta North at Perimeter** on **Thursday, April 22nd**. Registration and hors d'oeuvres begin at 6:30 p.m. with the program to follow at 7:30 p.m.

CURE Bereavement Workshop

January 24-25, 2004

CURE Childhood Cancer and a group of caring professionals are planning a special weekend for parents who have lost their children to cancer. This year's Bereavement Workshop is scheduled for **January 24-25 at the Hilton Atlanta Northeast Hotel in Norcross, GA**. The weekend gives bereaved parents the opportunity to deal with their loss and grief among people who both understand and care.

There is no cost for the workshop and attendees are encouraged to bring along a spouse, friend, or significant other. Professionals can help you cope with problems and difficult feelings as well as make suggestions on how to make this year a little less painful.

Do something for yourself by attending this wonderful weekend of sharing, caring and fun, too. Space is limited, so please call 770-986-0035 to make a reservation. We hope to see you January 24th!

The CURE Help Desk Been There, Done That! Helpful Hints

*From Andrea Fine, mother of Marshall Fine, age 5,
medulloblastoma, Scottish Rite*

- For hospital and clinic visits, take favorite videos, books, small toys (particularly those that are comfort objects), a calling card for long-distance calls, and favorite snacks or other food.
- For hospital stays, take socks with non-skid bottoms to keep feet warm without having to use slippers and socks. Use the hospital gowns so that you don't have to launder clothing when possible. If your child wants to wear his/her own clothes, bring things that either zip or button down the front so that changing is easier.
- If your child isn't eating in the hospital, ask your social worker for meal vouchers for the cafeteria. This will give the child a choice of other food.
- Use Coke to mask the taste of liquid medicines. Use chewables when possible.
- Try to schedule everything on the same day, instead of making multiple trips.
- Be sensitive to other families. Remember that the comfortable chairs are for the patients. If there are extra seats, then you can get comfortable too.
- Do special things with your healthy kids. They need your time. While a trip to the zoo with grandma may be a nice treat, they feel rejected. Give them the option to sit around the house or hospital with you.
- Be relentless in getting help from the school system. Continually make the school aware of the late effects of treatment so that they can watch for signs. Follow up regularly with teachers directly as well as those who may be less involved with your child's day-to-day activity. Make them aware of changes in treatment, side effects, etc.

The CURE Help Desk is a regular feature of the CURE Report. If you have tips you'd like to share, please e-mail them to: eva@curechildhoodcancer.org, fax them to (770) 986-0038, or mail them to: 1835 Savoy Drive, Suite 317, Atlanta, GA 30341-1000.



CURE'S SUPPORT REPORT

Whatever the occasion, a great way to make the moment is with a tribute. When you send a donation to CURE, the honoree is honored twice, once by mail and again in the next issue of the CURE Report. Remember tribute gifts for graduations, anniversaries, weddings, birthdays, memorials, special thank yous, or for any occasion. These gifts will help support the dream of a world free from childhood cancer.

CURE gratefully acknowledges all of our contributors. All gifts are listed for the previous quarter. Our sincerest thanks to the following companies or individuals for their support. CURE's work could not exist without them!

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In Memory of Meli Arant

Sylvia Arant

Car Program

Due to the overwhelming success
of our car program, we are unable

to list individual donors.

However, CURE would like
to thank everyone who has
participated in this program.

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Alvarado's 60th Birthday**
Suzan D. Tibor

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Family**
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In Honor of Brandon Connor
*Due to the overwhelming
response, we are unable to list the
individual donors who generously
gave in honor of Brandon Connor.
However, CURE would like to
thank everyone for their support
of the Connor Family.*

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Tom & Kim Doolittle

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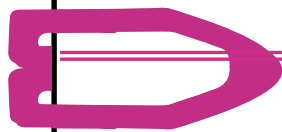
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CURE Childhood Cancer

2004 Calendar of Events



- | | | | |
|----------------------|--|--------------------|--|
| January 24 | Heart of GA Square Dance Federation Annual Dance | June 1-4 | Red Carpet Day at Emerald Pointe Resort at Lake Lanier Islands |
| January 24-25 | Bereavement Workshop at the Hilton Atlanta Northeast • Contact: CURE 770-986-0035, or print registration form online at www.curechildhoodcancer.org | June 12 | “Coming Together for Our Children” Bereavement Day at Lake Oconee. Contact: Denise Deford 770-943-1911 |
| February 14 | Theta Sigma Valentine Dinner/Dance to benefit CURE at the Atlanta Marriott Gwinnett Place • Contact: Linda McKay, linda.mckay@tycohealthcare.com | July 17 | CURE Family Picnic at T.W. Briscoe Park in Snellville |
| March 27 | Tri Delta Atlanta Alumnae Chapter hosts the Care Affair Gala at The Atlanta Athletic Club, Duluth. For ticket information, contact Maggie Feeney, feeneym@earthlink.net | TBD | 8th Annual HSMAI Chinese Auction “The Year of the Monkey”
Contact: Allison Farinas, 770-433-0340 or Allison@theassociationgroup.com |
| April 22 | “Lessons Learned: What Patients and Families Have Taught Me About Survivorship.”
Keynote speaker: Kathy Ruccione
6:30 p.m. Registration begins at the Westin Atlanta North at Perimeter • Contact: CURE 770-986-0035 or print registration form online at www.curechildhoodcancer.org | Sept. 24 | CURE Golf Classic Sponsored by BellSouth at The Oaks Course in Covington
Contact: Joe Coleman 770-482-1400 ext. 203 |
| | | October 17 | Off Therapy Celebration at Six Flags |
| | | TBD | Fall Parent Workshop (location TBD) |
| | | November 25 | Thanksgiving Dinner at Egleston & Scottish Rite campuses |
| | | December 25 | Christmas Dinner at Egleston & Scottish Rite campuses |



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