By the time Thea Johnson was born, she had already faced more challenges than most babies will ever know. Her mother, Paula, had been diagnosed with advanced breast cancer the same day she learned she was pregnant. When Paula went into labor nearly two months early, Thea entered the world medically fragile, needing oxygen and a heart monitor, and fighting multiple infections. As if she knew the road ahead would be rough, “she screamed nonstop,” says her aunt, Erika Frake. “You couldn’t soothe her.”

That road turned out to be rougher than anyone anticipated. For the past 16 years, while Paula battled breast cancer, a fight she recently lost, Thea struggled with multiple health issues, developmental delays, and learning disabilities. “Thea had many sensory issues,” Erika recalls. “Paula was told Thea would probably be deaf and blind. But Paula was a total advocate for her from the beginning. ‘I know she hears me. I know she sees,’ she would say. Her mission was to help Thea succeed. Paula lived and breathed Thea. She really fought.”

That advocacy took many forms. Born with a genetic autoimmune disorder and many allergies, Thea was medically complicated. “A lot of times we didn’t know...”

Fighting for Thea continued on page 2
whether Thea would live or die," Erika says, noting that her niece would be in the hospital for months at a time.

School was a struggle, too. Frequent hospitalizations meant a lot of missed classes, and Thea was just expected to catch up on the work she’d missed. In addition, Thea has ADHD and dysgraphia, a learning disability that affects handwriting and the ability to express thoughts in written form. She couldn’t copy images, so learning to write was tedious. “She had trouble learning concepts, such as telling time. She doesn’t learn in a traditional format,” Erika says. “Teachers didn’t know what to do, and they didn’t have time to work with her.

“Paula was in tears many days,” she recalls. “She’d say, ‘I just want her to be able to learn. No one’s working with her.’ The family was in desperate need,” Erika says, as they faced mounting medical bills, constant stress, and education barriers.

Then, when Thea was 10, someone suggested that Paula call PACER Center. “I still remember when she called me in tears telling me about PACER and the wonderful people there,” Erika says. “She said, ‘Can you believe it? They do everything to make sure Thea will have what she needs in school. I don’t have to face this alone anymore! We’re implementing an Individualized Education Program (IEP).’ PACER told me things no one else had told me about. And they helped us sort out the insurance issues and find personal care assistants so we can have respite care.”

It was a turning point. Instead of moving from crisis to crisis, they had a plan and support. The IEP addressed many issues and ensured that Thea would receive tutoring during her long hospitalizations. In addition to help from PACER’s Health Information and Advocacy Center and parent advocates, Paula strengthened her own advocacy skills by attending numerous workshops on everything from the special education process and ADHD to assistive technology. Thea, meanwhile delved into PACER’s technology workshops, Creation Station art activities, and the popular EX.I.T.E. technology and science camp for middle-school girls with disabilities.

“She is actually doing very well now,” Erika says. “She’s a typical teen. You would never guess in talking with her that she has learning disabilities. Her main issues are still with writing and math.”

Throughout this journey, Paula was in and out of remission, coping with her own health issues while raising Thea and three other children with her husband. Eventually, her cancer spread to her bones and treatments stopped working. Knowing that her time was limited, Paula began to worry about who would advocate for Thea as she grew older and faced transition issues. Concerned that the time after her death would be very hard for her husband and other loved ones, she worried about whether they would have the strength to advocate for Thea alone during this time.

“She wanted to have a plan of action that was set to go and would continue so Thea would not fall through the cracks,” Erika says. Paula again turned to PACER. “The parent advocates jumped up to the plate,” Erika says, noting that a plan was put into place that would protect Thea’s educational rights in the future.

In January 2009, Paula lost her 16-year battle with cancer. In the grief that has followed, there has been one island of comfort, Erika says. “She told me a few months ago, ‘I know Thea will be okay because even though I can’t be her advocate anymore, PACER is still there and will help her.’”
Passion for a cause often leads people to new, uncharted territory. Take PACER volunteer Jessica Broyles, who describes herself as more comfortable working behind the scenes. Why, then, is she often up front delivering a Count Me In® puppet show to rooms full of children and teachers?

“I’m not an in-front-of-people kind of person, but the puppets are different,” says Jessica, a former analyst in the actuary field. “It’s my favorite thing to do for PACER.”

Even though she admits to a bit of stage fright before each puppet show, the joy of being a PACER puppeteer quickly overrides any uncomfortable feeling.

“I love doing the shows,” Jessica says. “The PACER staff train you really well. The coordinators are great and provide all the support you need. I’ve talked with people who work at other nonprofits, and I think the support volunteers receive from PACER staff is unusual.”

Educating children about disabilities through the Count Me In® shows has a special meaning for Jessica. While teaching young children about disabilities, she believes she is also preparing a more accepting environment for her son, Sam, who has Down syndrome.

“I pretty much got involved with PACER because of Sam,” she says. “PACER was one of the first places we called after Sam was born.”

Jessica is happy to report that Sam recently turned five and is thriving in an inclusive preschool. “This year he’s really improved in his receptive and expressive language, and I think it’s because of the inclusive environment. Just watching the other kids helps him learn. He’s having a wonderful year.”

After Sam’s birth in February 2004, Jessica and her husband, Rowan, didn’t waste any time taking advantage of PACER’s resources, and Jessica was also quick to lend a helping hand. She began volunteering for PACER in the fall of 2004. In addition to being a puppeteer, she brings her enthusiasm and infectious smile to the PACER board and the Benefit Committee, where she has served as co-chair for the past three years.

“When you walk into PACER, it feels good,” she says. “The staff have that compassion; they can relate to you and you don’t find that in everyday life, so it’s nice.”

“I’ve learned so much at PACER,” Jessica adds, promptly listing several ways that PACER has benefited her family in the past and the present. Workshops on IDEA, the Simon Technology Center, a presentation on public policy to her Special Education Advisory Council, and articles in PACER’s newsletters have all been helpful.

“PACER’s work makes it easy to be an advocate,” she says, even if you’re not outspoken, and even if you find yourself up front, on stage.

“PACER does such wonderful work,” she says. “It’s a privilege to be part of PACER. It really makes a difference.” That difference is greatly magnified when volunteers like Jessica put themselves on the front line for children with disabilities.
When Frankie Valli & the Four Seasons take the stage at the Minneapolis Convention Center May 2, you can expect an energetic, full production performance that will have you dancing in your seat—or even in the aisles. The inspiration for the smash Broadway hit “Jersey Boys,” they played to sold-out crowds for two performances in Minneapolis last fall and received rave reviews from PACER friends who saw the show. With chart-topping hits such as “Sherry” and “Big Girls Don’t Cry,” the group has sold more than 100 million records worldwide and was inducted into the Rock and Roll Hall of Fame in 1990.

Before the performance, you’ll have the opportunity to support PACER by bidding on delightful Silent and Live Auction items you’ll want for your own. Add some intrigue to your evening by donating $100 for one of the “extravaganza mystery treasure bags” from JB Hudson. Every one of the bags contains a gift generously donated by Extravaganza Sponsor JB Hudson along with a $25 gift card. Many of the bags contain a special treasure, and one of the bags is out of this world! Your $100 donation will go directly to PACER programs, and in exchange you will receive a delightful surprise. Embark on your evening of intrigue and mystery by looking for our young volunteers with JB Hudson bags on their arms.

Offering everything from getaways to sports memorabilia to jewelry, the Silent Auction begins at 6 p.m., in Exhibit Hall A, a new, more spacious location on the lower level. The Extra Special category features items we wouldn’t want anyone to miss. Here is a sampling of what you can expect:

Vikings Fans – Chance of a Lifetime! Two lower-level tickets and VIP pregame field passes to the 2009 Minnesota Vikings/Chicago Bears game. See and hear the intensity of the NFL and the Minnesota Vikings on the field for the team’s pregame warm-ups, and then cheer them on from your lower-level seats.

Kitchen Makeover of Your Dreams! Enhance your kitchen with 50 square feet of Cold Spring Granite
counter tops and appliances, including a refrigerator, an electric or gas self-cleaning range, and a dishwasher, from ApplianceSmart.

A Summer Evening of Chopin’s Piano Works, Fine Food, and Wine on Echo Lake in Mahtomedi, Minn. Dr. Reid Smith will perform a special series of three classic Chopin piano concerts, each of which will be paired with food and wine from a specific period of Chopin’s life.

Tickets to the Elton John/Billy Joel concert on May 5, 2009. Don’t miss this much sought-after ticket! Two legends come together for an unforgettable performance at the Xcel Energy Center in St. Paul, Minn.

WCCO TV news anchors Amelia Santaniello and Frank Vascellaro will emcee and join auctioneer Karen Sorbo in leading a fast-paced and spirited Live Auction. Attendees will be able to bid on a **two-year lease of a 2009 Mercedes-Benz SLK300** donated by Sears Imported Autos; a **four-night, five-day stay in a multimillion-dollar home in Los Cabos**, donated by Exclusive Resorts; and an **original work of art by Anthony Whelihan**. That’s just a sampling of the exciting opportunities awaiting you May 2.

The Benefit is made possible only with the help of volunteers, corporate sponsors, Silent and Live Auction donors, the Extravaganza Sponsor, and many other individuals and businesses that provide in-kind support. Thank you to every person and business that has contributed to this year’s event. PACER’s Annual Benefit provides a significant portion of the budget each year. Its success is vital in keeping PACER’s excellent services available to families of children with disabilities. Purchase tickets now to experience an incredible evening and to help families throughout Minnesota!

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**feeling lucky?**

donate $100 to receive one of the mystery treasure bags

(and you just may hit the jackpot!)

every one of the bags contains a gift generously donated by jb hudson.
every one of the bags contains a $25 jb hudson gift card.
much of the bags contain special treasures.
one of the bags is out of this world!

PACER Center’s 27th Annual Benefit, Saturday, May 2, 2009

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**Thank You!**

PACER thanks the Benefit Committee co-chairs Patrice Alkire, Jessica Broyles, Colleen McGough-Wood, Danna Mirviss, and Judy Schumeister, along with Corporate Sponsor Committee co-chairs Don Davidson and Jim Oricchio. PACER appreciates the wonderful Benefit committee members, generous sponsors, dedicated volunteers, and loyal attendees who are all Champions for Children with Disabilities.
Aspiring young artists with disabilities gathered at a February workshop to compete in PACER’s fourth annual Creative Kids Contest. The coveted prize? The winning design will be made into the 2009 PACER greeting card, which will be sold online throughout the year and at the PACER Benefit.

Paints, pencils, and paper of all colors flashed and shimmered during the two-hour workshop where artists let their imaginations meet the materials. Celebrated artist Anthony Whelihan was on hand to provide inspiration and direction to the artists at the Bloomington Art Center. Children with disabilities from ages 3 to 17 were eligible to enter the contest.

The talented artists now anxiously await the decision of the judges. The winner will be revealed to a large crowd at PACER’s 27th Annual Benefit at the Minneapolis Convention Center on May 2.

The original artwork of the top 10 designs will be framed and sold at the Benefit Silent Auction as well. Don’t miss this opportunity to acquire the early works of up-and-coming artists!

Creative Kids Contest Winner to be Announced at PACER’s 27th Annual Benefit
PACER’s Fourth Annual Family Fun Day Draws Kids and Kudos

More than 275 children, parents, and volunteers were all smiles when they gathered for PACER’s fourth annual Family Fun Day in February. Led by Captain PACER (Michael Keller, chief brand officer of Dairy Queen, Inc.), 12 teams of children with and without disabilities and their families giggled their way through a maze of accessible games and activities, including snowball bowling, parachutes, and the ever-popular sock throw. Sporting colorful bandanas, each team cheered its members on. At the close of the games, families marched enthusiastically in an Olympic-style parade and every child received a winning medal as well as a special treat from Dairy Queen.

Family Fun Day provides an inclusive environment where parents can have fun and relax regardless of their child’s disability or behaviors and connect with other families who may be facing similar challenges. The event also encourages children of all abilities to make new friends and support each other in a fun and active setting.

Family Fun Day took place at the Lindbergh Center in Hopkins. It was made possible by the generosity of presenting sponsor Learning Rx, Art Station sponsor All About Children Pediatrics, and the following activity sponsors: Coborn’s Delivers, Dairy Queen, E.O.P. Friends & Family, the Mahony family, the Tom and Kathy Miller Family Foundation, and the Sheehan family.
PACER’s National Center for Bullying Prevention is creating a new puppet program to help children in first through third grade learn how to recognize and respond to bullying. The only obstacle to launching the program is money, and you can help eliminate that barrier.

Being developed at the request of parents and teachers, the new puppet program builds on the strength of two popular and effective PACER projects: The PACERkidsAgainstBullying.org Web site and the Count Me In® puppet program. For more than 25 years, Count Me In® has used child-size puppets to promote inclusion of children with disabilities.

Producing a new puppet show is an expensive proposition. Two new hand-and-rod puppets must be designed and built. A professional writer must create scripts for a show, and the scripts must be reviewed by professionals. The shows must be piloted in classrooms to gauge the children’s reactions. Finally, volunteers must be trained to perform this new puppet show.

The total cost: $17,500. Fundraising is off to a good start, thanks to several foundations and companies that have donated $10,800. Now, PACER needs your help to reach the goal and get this new show on the road.

The project is important. Every day, more than 160,000 children nationwide stay home from school because they are bullied. Early intervention can help bring that number down. You can be the one to make it happen. Thank you for contributing to PACER’s Bullying Prevention Puppet Program.
Happy Hour “Friendraiser” Increases Awareness of PACER

More than 100 new supporters and volunteers learned about PACER’s activities and programs while enjoying food, drink, and games at PACER’s first Happy Hour event. Held last November at the chic new Hotel Minneapolis, the gathering was sponsored by the Friends of PACER Advisory Board (FOPAB).

FOPAB members shared PACER’s mission and built new relationships with young parents and professionals through fun activities. Guests loved the PACER table crawl, where the correct answer to a PACER trivia question was rewarded with a drink coupon. A giant slide show highlighted PACER’s many programs and events.

The Hotel Minneapolis generously provided gourmet appetizers, and Frog Prince Floral supplied beautiful centerpieces. Prizes were donated by numerous local sponsors, including Chipotle, Brian Graham Salon, Kieran’s Irish Pub, and The Madison Center.
As a former Board member and long-time supporter, Eleanor Swanson has been giving to PACER since the organization began in 1978. She now is giving to the future by naming PACER in her will.

“PACER serves children with all disabilities, which is important to me. I believe in the integrity of this outstanding organization, and I know it will be around for a long time. My family is pleased that I have made the commitment to do my part,” Swanson says.

It’s not surprising that her family would be so encouraging. In fact, several relatives are PACER supporters as well. Eleanor’s niece Karen Reynolds is a member of PACER’s Board of Directors and Investment Committee. Her grandniece Elizabeth Reynolds volunteers for PACER events. Niece Sarah Meek is carrying on the family tradition, serving as a Board member and as a Silent Auction co-chair for PACER’s 27th Annual Benefit and Silent Auction, to be held May 2, 2009.

At 83, Eleanor understands the joy of leading a full life. A retired speech pathologist, she attends university classes, goes to Minnesota History Center lectures, and enjoys St. Paul Chamber Orchestra concerts. She is a charter member of an investment club that is celebrating its 40th anniversary this year, and she still finds time to play bridge with friends. Knowing that PACER helps people with disabilities live equally full lives, she lends her support to make sure the future will be as strong as the past.

“There will be many needs in the future we aren’t even aware of today,” she says. “I hope I can motivate others to remember PACER when they are doing their estate planning so PACER can meet those future needs.”

A simple statement in a will or living trust is all it takes to make a powerful gift. Whether made in cash, securities, real estate, or tangible personal property, gifts by bequest may be fully deductible in determining estate taxes. Any provision should state PACER’s legal name: **PACER Center, Inc., a 501 (c) (3) nonprofit corporation in Minnesota**. If you have questions or would like additional information, please contact Mary Schrock, PACER’s chief operating and development officer, at 952-838-9000.

If you wish to make a bequest, please notify PACER Center so you can be acknowledged and thanked. Doing so also helps PACER plan for the future. Friends of PACER who make their planned gifts known become members of the **PACESETTER Circle**.

“Thank you to those who have already provided for PACER in their planning. You serve as beacons of hope and role models in providing for children with disabilities in the future,” says Paula Goldberg, PACER’s executive director. “We encourage others to consider naming PACER Center in their will.”
Thank You!

It takes time, energy, and resources for PACER to provide all its services and programs—and it couldn’t be done without the amazing support of hundreds of volunteers, board and advisory board members, donors, and corporate and foundation sponsors. You each play a vital role in helping families of children with disabilities. Your efforts have far-reaching impact and are deeply appreciated. Thank you so much!

EX.I.T.E. Camp for Girls, Aug. 10 – 20

Middle-school girls with disabilities have until May 1 to apply for this fantastic science and technology camp, held at PACER. Creative, energetic volunteers are also needed. Visit PACER.org and click on the Simon Technology Center link for more information about applying or volunteering.

Campers at the 2008 EX.I.T.E. Camp

SPRING 2009

PACER’s 27th Annual Benefit, May 2

Don’t miss the premier event of the spring, featuring Frankie Valli and the Four Seasons. Exciting Live and Silent Auction items are pouring in as this newsletter goes to print. See pages 4–5 for details on what intrigues and treasures the night holds, then order your tickets at PACER.org.

SUMMER 2009

The Ted and Roberta Mann Foundation National Symposium about Children’s Mental Health and Learning Disabilities, Aug. 12

The fourth annual Symposium will be held at the Sheraton Bloomington Hotel. Teachers, administrators, and parents will gain insights and strategies to help them work with children who have learning disabilities and mental health issues. More information on the Symposium will be available May 5 at PACER.org. PACER thanks the Ted and Roberta Mann Foundation for providing this important full-day conference.

PACER VOLUNTEER OPPORTUNITIES

Help Children Learn about Inclusion

PACER’s COUNT Me In® puppet program relies on volunteers to go into the schools as trained puppeteers. Become a volunteer and bring the important message of inclusion into early elementary classrooms.

Lend a Hand

PACER’s front office can always use volunteers to help with many tasks, particularly when preparing for events and conferences.

We welcome your ideas, energy, and participation. To be involved in these or other opportunities at PACER, call Rianne Leaf at 952-838-9000. Thank you!
When you receive your United Way pledge card from your workplace giving campaign, please consider writing in “PACER Center” under the “Other” category. Doing so provides funding that helps PACER continue to respond to the 43,000 requests for assistance received each year.

PACER is not a United Way agency organization and therefore does not receive support from its general funds. PACER does, however, benefit from the donor choice programs of the Greater Twin Cities United Way, Tri-State United Way, and others.

“Identifying PACER as your choice organization provides important funds to PACER while still contributing to your overall workplace campaign,” says Mary Schrock, PACER’s chief operating and development officer. “Your donation helps PACER open doors for children with any disability. Thank you for being a Champion for Children with Disabilities.”

Write in PACER on Your United Way Pledge