



Learn how you
can "Light a Life"
this holiday season!
Details on page 6.

NTAF Patients Raise Almost \$6 Million

Fiscal year 2006 sees 55% increase over FY 2005.

NTAF is pleased to announce that it has helped patients raise almost six million dollars in the fiscal year ending Sept. 30, 2006. This amount represents a 55% increase over the \$3.8 million that was raised in FY 2005.

"We are constantly amazed at the overwhelming generosity Americans show to their friends, family and neighbors," said Lynne Samson, NTAF Executive Director. "NTAF is pleased to be able to translate that generosity into life-saving assistance to pay for medications, hospital stays, medically-related relocation and transportation expenses, as well as the home and vehicle modifications and home healthcare required by spinal cord injury patients.

NTAF paid more than \$4.2 million for patient medical assistance during the same period, another "record" of sorts.

"Fundraising is more critical now than ever before," noted Samson.

New Yorkers Lend Their Legs to Charity

Fifteen cyclists set out on a five-day bicycle journey July 15 in Hartsdale, N.Y., with a destination of the Capitol and a determination to raise money and awareness for a friend and a cause.

Riders who made the 300-plus mile ride accomplished both goals: collecting more than \$40,000 for the NTAF New York Spinal Cord Injury Fund in honor of Lorraine Valentini, and meeting with lobbyists and executives regarding the importance of stem cell research.

Lorraine Valentini, a retired high school English Literature teacher, volunteer firefighter and an accomplished cyclist, severely injured her spinal cord in a bicycling accident on Memorial Day 2005. The accident left the formerly active Lorraine paralyzed from the neck down and unable to breathe on her own.

Good friend Colleen Kelly established Team Lorraine—a network of friends, family and fellow cyclists to help raise money for Lorraine's medical

needs and also to help raise awareness about stem cell research and spinal cord injuries.

Team Lorraine, along with Greenburgh, N.Y., Town Supervisor Paul Feiner, stopped at the Christopher and Dana Reeve Paralysis Foundation in Short Hills, N.J., and the Kennedy Krieger Institute in Baltimore to speak with executives about stem cell research before reaching the Capitol, the team's final stop.

"Visiting the Kennedy Krieger Institute was one of the most incredible experiences in my life," said Feiner, "It showed why funding for stem cell research is so important. Seeing disabled children and adults smile, observing their personal



Team Lorraine with Senator Hillary Rodham Clinton.

progress, watching them try to overcome the odds—is something I will never forget.

"It is important that we provide hope to people who have severe medical illnesses...important that we improve their quality of life.

"It's important that people who are friends of the patients get involved."

continued on page 4.



From the Executive Director

Dear NTAF supporters:

As our accounting staff tallied contributions in our last fiscal year, I was amazed to learn that we had raised close to six million dollars.

Our society may be becoming increasingly "high tech," busy and focused on individual pursuits, but it's clear that the urge to help a neighbor in a time of need is as strong as ever.

Patients and their support networks have worked hard to plan and execute the huge variety of fundraisers we witnessed last year. Events—a few of which are described in this newsletter—ranged from coin banks outside local supermarkets to weekend events that featured dinner dances and auctions...and everything in between!

Funds raised were translated into critical financial assistance for medical expenses. One hundred eighteen NTAF patients received their transplants during the last fiscal year. NTAF paid to renovate homes and modify vehicles and to provide rehabilitation and home health care for patients with catastrophic injury.

While speaking with professionals at a recent conference, it became clear that sometimes patients do not explore fundraising because they are simply too uncomfortable accepting "help" from their communities. That

hesitation is truly unfortunate, because here at NTAF, we see the ways in which community fundraising benefits all involved. Communities are energized and united by working together to help others.

My own family was introduced to NTAF six years ago when we were blessed to have our community begin a fundraising campaign in honor of my stepdaughter, paralyzed from the chest down in January 2000. Though incredibly humbling, I can now say, in retrospect, that allowing our community to show its support by organizing an annual fundraising Lacrosse festival has been a positive experience beyond anything we imagined, certainly for us, and also, from what we hear and see, for the community.

In this age, there seems to be little that binds us together. Fortunately, community-based fundraising for a person in crisis has always been a force that can unite even the most diverse groups of Americans.

So, on behalf of NTAF and its board of directors, I would like to extend our deepest thanks to all who are involved in community fundraising -- patients, their support networks, professionals and contributors -- for their generosity and hard work.

We truly have much for which to be thankful.

Best Wishes,

Lynne Coughlin Samson, Esq.

Executive Director



Ronald W. Siggs

NTAF Board Member Named "Fundraising Executive of the Year"

NTAF is proud to share that Ronald W. Siggs, CFRE, has been named "Fundraising Executive of the Year" by The Greater Philadelphia Chapter of the Association of Fundraising Professionals (GPCAFP).

The award was presented on National Philanthropy Day, which is recognized around the country by AFP chapters in order to recognize the contributions of philanthropy and philanthropists.

Ron Siggs is vice president for development and public relations at Magee Rehabilitation Hospital, part of Jefferson University in Philadelphia.

Ron joined the NTAF Board of Directors in 2003. He chairs the Development Committee which is charged with exploring ways to increase funding for NTAF, a challenge for an organization that specializes in fundraising for others.

NTAF has benefitted immensely from his expertise in both fundraising and spinal cord injury.

"NTAF congratulates Ron for this well-deserved reward and considers itself fortunate to have him on our Board of Directors," commented Lynne Coughlin Samson, executive director.

~Patient Reminder~

Register on our website to be able to personalize your patient page.

You are able to upload a photo and change the text to tell your own story in your own words. You may also view your guestbook while online.

Coming soon: message boards for patients and their volunteer networks

**www.transplantfund.org
www.catastrophicfund.org**

Patient Guestbooks a Big Hit!

Every NTAF patient has a page on the NTAF website. Each of these pages now has a guestbook, which visitors can sign and leave messages of support for patients!

Be sure to check out the guestbooks, and encourage your friends and supporters to do the same!

For more information, call 800-642-8399.

Hi Joni:

**names have been changed*

...I also wanted you to know how much Tom and Joe and their families and friends are appreciating the guestbook on your website. While none of us anticipated it would be a way to communicate with the guys while they are in the hospital, it turns out that many family and friends are writing their wishes for both men on the site. And Tom's wife, Julie, is writing regular updates of their progress on the site. She's also printing out the comments regularly (from within the hospital) and reading them to the guys. We have spread the word that it's a great way to communicate. Both men are really enjoying and appreciating the support they are getting through the site. So, thank you so much. It's wonderful!...

Thanks so very much again,

Nancy

Limited Time Offer: Tax-free IRA Charitable Distributions

Americans have been accruing billions in pre-tax dollars in Individual Retirement Accounts (IRAs) since they were first introduced with the enactment of the Employee Retirement Income Security Act (ERISA) in 1974. Today, an estimated \$3.6 trillion is currently invested in IRAs and the amount will continue to grow.

In August 2006, President Bush signed the Pension Protection Act of 2006. He called the legislation "the most sweeping reform of America's pension laws in over 30 years." Provisions of the new law enable older Americans to share their retirement wealth by giving directly to charities tax-free. Under prior law such distributions were included in one's gross income and therefore subject to income tax.

The new provision allows individuals age 70 ½ and older the opportunity to make tax-free, qualified charitable distributions of up to \$100,000 each year. All charitable distributions of this kind will be counted toward the minimum distribution requirement. Because distributions of this kind will not be included in taxable income, contributors will not be able to claim such contributions as a tax deduction.

Tax-free distributions from IRAs to charity will only be effective for tax years 2006 and 2007 unless Congress deems otherwise.

Qualified charities under this law are public charities which include: designated nonprofit funds, scholarship funds, field of interest funds and unrestricted endowment funds.

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NTAF Hits the Road!

NTAF staff members took their work on the road this fall, attending several transplant and spinal cord injury conferences across the United States.

Judy MacGregor, patient services representative, joined more than 30 liver transplant professionals at the 19th annual North American Liver Transplant Social Workers Association conference in Seattle, Wash. Some of the largest and most active liver transplant programs in the country sent social workers to represent them.

Judy Walker, director of communications, attended the Transplant Financial Coordinators workshop held in Redondo Beach, Calif. This 2nd annual meeting was an opportunity to speak with the transplant professionals whose



chief concern is the patient's ability to pay for services. NTAF participated in a panel which discussed Medicare Part D and assistance in meeting drug costs. NTAF has always paid for drug insurance coverage and co-pays; Since the implementation of Medicare Part D, NTAF staff has observed larger numbers of patients who indicate a need for assistance in payment of drugs costs as patients seem to fall into the cracks between government coverage and drug companies' medications programs.

Lynne Coughlin Samson, executive director, and Joni Henderson, patient services representative, represented

NTAF at the 21st annual Society for Transplant Social Workers Conference in Austin, Texas. NTAF was the Elite Tote Bag sponsor, the second lead sponsor at the conference, thanks to a generous grant given by Wyeth Pharmaceuticals. Lynne was able to give a short presentation about NTAF services.



Lynne and Judy Diner, director of development, attended the 2nd annual Summit of the National Spinal Cord Injury Association held in Bethesda, MD. The theme was "Action through Collaboration," and brought together about 250 members of the spinal cord injury community – including researchers, rehabilitation professionals and advocates. The conference gave NTAF staff a unique opportunity to meet members of the spinal cord injury community who did not know about NTAF Catastrophic Injury Program and to strengthen relationships with partners at rehabilitation facilities including Craig Hospital, the Shepherd Center and the Henry H. Kessler Foundation.

"We are inspired, having met so many people who work with patients facing serious illness and injury," said Lynne. "We hope to be able to further partner with transplant and SCI professionals to provide the best possible services for patients."



ORGANIZATIONAL SPOTLIGHT

National Spinal Cord Injury Association (NSCIA)

The National Spinal Cord Injury Association is a national nonprofit organization and is the nation's oldest and largest civilian organization dedicated to improving the quality of life for hundreds of thousands of Americans living with the results of spinal cord injury and disease (SCI/D) and their families.

NSCIA provides education, peer support and advocacy on issues affecting people with spinal cord injuries and diseases.

NSCIA just joined with the Teddy Pendergrass Foundation to try to urge Medicare and Medicaid to postpone changes that would limit coverage for power mobility devices.

For more information, or to read about NSCIA advocacy efforts on behalf of patients, visit their website: www.spinalcord.org

Legs to Charity, cont'd from page 1.

One of the reasons this event was so successful was because Lorraine has so many close friends who sincerely want to help her."

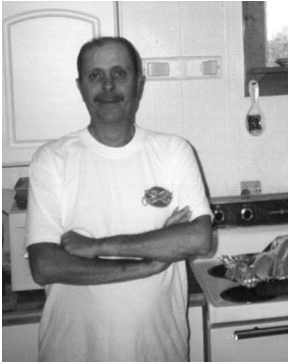
Team Lorraine was recognized for its efforts at its last stop on the steps of the Capitol. Riders met with Congresswoman Nita Lowey (D-N.Y.) and Senators Charles E. Schumer (D-N.Y.) and Hillary Rodham Clinton (D-N.Y.). Lowey presented Lorraine's husband, Chris Reyling, with a Congressional Record Citation.

Team Lorraine has raised more than \$130,000 for Lorraine's NTAF fund since it began fundraising in 2005, but this is not the end of the road for the team.

Feiner said that he hopes to organize another bike ride in Lorraine's honor, this time from Westchester to Albany, ending up at the New York State Legislature. The hope is that Albany lawmakers will hold hearings on the difficulties families have dealing with insurance companies, medical institutions and the vast bureaucracy they encounter.

Grassroots Determination

“Thank you for getting a cake ready for me,” wrote seven-year-old Danielle Odells in her handmade, heart and floral decorated letter to David Peardon. “I would like to have strawberry for my flavor. I am very thankful for you find this cake. Thank you!”



Dave Peardon in his kitchen.

Little Danielle cannot have dairy products in her diet, so David made her a special cake of her very own for his Spaghetti Dinner fundraiser.

“Danielle had a fit over that cake I made her,” said David. “Had a smile ear to ear when I said she could take the whole thing home with her.”

David understands the need for dietary restrictions as he has had to adopt a salt-free, low sodium diet since he became sick. For the former semi-professional cook, the adjustment hasn’t been that difficult.

He has created alternatives to his food favorites that are both healthy and tasty, like his tangy low-sodium barbecue sauce for pulled pork sandwiches, which Dave said, is much tastier than the store bought alternatives. And Dave respectfully does the same for others who attend his fundraising events; making Alfredo sauce for attendees who cannot eat tomatoes, as well as diabetic chocolate cake and Australian sponge cake.

When diagnosed with cirrhosis in 2004, David learned that he would need a life-saving liver transplant, and though his insurance would cover the cost of surgery he would need to raise money to cover the high cost of post-transplant medications estimated to run approximately \$3,100 per month for the duration of his life.

David is the definitive example of a “grassroots” fundraiser. From his rural town in Georgia, David has managed to raise nearly \$7,000 through his small, but numerous, fundraising events. From raffles to bake sales to coin banks and spaghetti dinners, David has done it all.

“I’ve done pretty good,” said David. “Anytime you can make \$200 to \$300 you gotta take it.” David plans to keep plugging away at his goal until his spot on the transplant list gets him a transplant. He also hopes to continue fundraising after transplantation.

“I would like to start helping some families around here—focus my time on other peoples,” said David. “I’ve got a second chance at something... I look at it like I’m not supposed to be here so I’m gonna give it all that I can.”

What a Pair!

When Troy Kahklen met Ray Vidic 20 years ago, Troy had no reason to believe that Ray held within him the key to his future. The pair were not even close friends.

“You know Ray and I—the way we met— was through our wives who worked closely together at the same bank,” said Troy.

“I’ve been struggling with Lupus since I met Ray. He kept tabs on me all the time... always concerned with how I was doing.”

Diagnosed with the autoimmune disease in 1984, Troy received a kidney transplant in 1991, which allowed him to live healthily for several years, but his kidney eventually failed in 1994. Since then, Troy has been receiving dialysis three times a week for six hours each day and waiting on a list for a life-saving transplant.

“I’ve been waiting for a cadaver kidney for 10 years. One day Ray approached me; invited me to lunch and said he’d be willing to be my donor.”

Ray was also willing to fundraise to help meet Troy’s uninsured expenses. Ray recently coordinated a walk-a-thon that raised close to \$20,000 in Troy’s honor. They received many contributions from those who couldn’t walk

	<p>Saturday, October 7, 2006 11 am Walk to begin at Valley Chapel, 9741 Mendenhall Loop Road Contact Joe Kahklen 586-4118 for information on pledging or if you want to be a team leader or if you would rather solicit for individual donations.</p>
<h1>Troy Kahklen's Walk for Life</h1>	
	<p>to benefit the NTAF Northwest Kidney Transplant Fund in Honor of Troy Kahklen</p> <p>Please bring a Pot Luck Dish to share after the event.</p> <p><small>Contributions are tax deductible to the extent allowed by law. This campaign is administered by the National Transplant Association Fund, a 501 (c)(3) nonprofit providing fundraising assistance to transplant and catastrophic injury patients. Information: 800-642-8399</small></p>

Ray and Troy made a PDF of their flyer and put a link to it on their NTAF patient page, so that any visitor could download it. To learn more, call NTAF at 800-642-8399.

or attend, thanks to media attention they garnered on AOL, local TV, radio and newspapers.

Unfortunately, Ray was not a matching blood type. So Ray did some research and came across Paired Exchange Donation. “What’s going to happen is Ray’s actually going to give his kidney to someone else; Someone I don’t know will donate their kidney to me.”

The procedure will be performed at Johns Hopkins Medical Center in Baltimore, one of five hospitals in the country that practice Paired Exchange.



Looking for a meaningful gift alternative this holiday season?

You can "Light a Life" by going to the NTAF website www.transplantfund.org and clicking the "Light a Life" link. You can print out the tribute forms and add the name of the person you'd like to honor.

Simply send the forms to NTAF along with your check or credit card info.

NTAF will take care of the rest, sending a prompt gift acknowledgement to your honoree.

Your "Light a Life" gift can truly make a difference:

- \$50 pays for parking at the hospital for one week.
- \$100 pays for one week of immunosuppressant drugs.
- \$250 pays for one week of lodging for a family.
- \$500 pays for one week of home health care

Make an impact in the lives of NTAF patients this holiday season!

All "Light a Life" gifts will benefit the NTAF Emergency Grant Program.

For more information, call 800-642-8399.

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National Transplant Assistance Fund and
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150 N. Radnor Chester Road, Suite F-120
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800-642-8399

