

## In This Issue

2 Letter From the Executive Director

3 A Quick and Easy Event Idea from the Patient Services Department



4 An Overview of the New NTAf Web Site



5 NTAf Patient Tells His Story Through a Lens



## MS Patient Finds Relief with Stem Cells and NTAf:

*Preston Walker, of Texas, Shares His Positive Experience with Others*

A year and a half ago, Preston Walker was feeling depressed and fatigued, walking with an uneven gait, and experiencing cognitive dysfunction (He had difficulty putting sentences together).

Today, Preston is singing the praises of the alternative therapy that changed all that, and helping other patients – along his personal journey to better health, seek similar outcomes for themselves.

The recently turned 40-year-old Fort Worth Police sergeant was diagnosed with Relapse-Remitting Multiple Sclerosis (RRMS) in December 2001. RRMS is an early stage of MS, an autoimmune disease that affects the central nervous system (brain, spinal cord and optic nerves). Symptoms vary from patient to patient, but one thing is consistent – the disease is chronic, progressively worsening over time.

At this time, there is no cure for MS, but there are therapies to help manage MS symptoms and improve the quality of life for the individual.

For years, Preston tried conventional therapies (disease-modifying therapy

using medications), finding little relief or improvement. Preston, a police officer for nearly 17 years, worried he would lose the ability to perform his job. Preston, a husband, father and recent grandfather, decided to be his own health advocate,



continuing to ask questions about his disease and researching alternative therapies.

Preston learned about an experimental therapy being conducted by an American doctor at The Institute of Cellular Medicine (ICM) in San José, Costa Rica. The therapy involves using adult stem cells derived from a patient's own fat to treat autoimmune diseases, such as MS, and spinal cord injuries.

*[Disclaimer: NTAf does not endorse particular medical therapies, but provides fundraising assistance for those in medical and financial need who are considering alternative therapies.]*

*Continued on Page 5*

## Patients: Join NTAf's Peer-to-Peer Support Network Online

### FIND A FRIEND

In the new NTAf Patient Restricted Area of the NTAf Web site, patients can opt into NTAf's *Find a Friend* network. This new feature is intended to facilitate

communication between patients who have similar medical conditions and financial challenges.

Patients can search for peer support mentors by clicking the *Find a Friend* button in the restricted area. Search by injury or transplant type and/or by region code, to find a mentor most appropriate for you.

Consider becoming a peer support mentor today! Sign in to the NTAf Patient Restricted Area on the NTAf Web site. Click *Edit Profile* for details.

## From the Executive Director



Dear Friends,

During Thanksgiving, it is customary to offer one's gratitude. The NTAF family has much to be grateful for this year.

With the state of the economy forcing many Americans to live closer to the financial edge, NTAF patients and their families are increasingly grateful for the support they continued to receive this

year from selfless friends and neighbors.

Remarkably, NTAF helped patients raise nearly the same amount in their communities this year as we did last year – through more than 500 community-based fundraisers that were held on behalf of NTAF patients in Fiscal Year (FY) 2009.

### In FY 2009 (10/1/08-9/30/09), NTAF:

- Helped patients raise more than \*\$6.9 million for uninsured medical expenses;
- Disbursed more than \*\$6.1 million to pay for patients' out-of-pocket medical expenses.

*\*Unaudited amount*

The NTAF family is grateful, knowing that even though folks across the country have faced their own financial losses, they continue to dig deep to help neighbors, friends or family members who face the daunting uninsured expenses related to a transplant or catastrophic injury.

NTAF transplant patients and their families are grateful for the living and deceased donors who gave them a second

chance at life by giving the *gift of life*. **In FY 2009, 306 NTAF patients were transplanted.**

NTAF catastrophic injury patients and their families are grateful for the monetary gifts that helped to improve their quality of life. Because of contributions made to NTAF catastrophic injury patient campaigns in FY 2009:

- 11 vans were purchased for patients (\$244,476);
- 26 vans were modified to make them wheelchair accessible for patients (\$20,122);
- 46 home modifications were made to provide accessibility for patients (\$220,288); and
- 27 patients were able to pay for in-home health care (\$489,894).

Like our patients and their families, the NTAF staff is grateful for the support we continued to receive through company and foundation grants this year, allowing us to increase our services for patients. At the end of FY 2009, NTAF was able to launch a new Web site (See *Page 4* for details); begin hosting monthly educational Webinars for interested patients, and health care professionals; and increase staff to meet the growing demand of our services.

I am additionally grateful for the NTAF staff who demonstrate incredible loyalty, flexibility and teamwork day-in and day-out to meet the needs of our patients and their families.

NTAF wishes you and your loved ones a happy and healthy holiday, and thanks you for being a part of the NTAF family, whatever your connection may be.

## NTAF Legacy Circle of Families

NTAF is starting a new program called **The Legacy Circle of Families**. The Legacy Circle of Families is a network of families who, after the death of an NTAF patient, perpetuate the memory of their loved one with a contribution to NTAF, by way of a direct monetary gift or donated proceeds from a fundraising event.

Contributions will be used to help other NTAF families overcome the financial challenges they face because of the uninsured medical expenses related to their health care. **Give the gift of a second chance to another family in need.** If you are interested in hearing more about this program, please feel free to contact Lynne at 1.800.642.8399.

## From the NTAF Patient Services Department

### *Consider a ‘Percentage of Sales’ Event at Your Local Restaurant*

Many chain restaurants will donate 10 to 20 percent of a day’s or evening’s proceeds from a group of people to an NTAF fund in honor of a patient. All you need to do is invite friends and family and enjoy a great meal! Follow these steps to ensure a successful fundraiser:

1. **Identify and visit the restaurant** – Visit your local chain restaurant (for example: Applebee’s®, Friendly’s®, Outback Steakhouse®, California Pizza Kitchen®) or your favorite local independent restaurant, and ask the manager if they have a program to assist nonprofits in raising money. Tell the manager about the patient for whom you are raising money, and that you are working with NTAF – a nonprofit dedicated to helping transplant and catastrophic injury patients. Remember to bring your Tribute Gift Form and State Authorization Letter as proof of your relationship with NTAF.
2. **Establish the terms of your agreement and a mutually convenient date** – Find out the restaurant’s rules regarding fundraisers (For example: What percentage of the proceeds will they donate? How will they keep track of guests who are participating?). Select a date. Also ask if you can set up a table with organ donor or catastrophic injury awareness materials, or if you can include activities at the restaurant like face

painting, or a clown with balloons for children attending.

3. **Review the plan with your NTAF Patient Services Coordinator** – Based on the details of your agreement with the restaurant, she will help create an event flyer and coupons. The coupons are often used by participating restaurants as a way to track the percentage of proceeds to be contributed to the patient’s NTAF fund.
4. **Advertise your fundraiser** – This step is critical. Several weeks before the event, begin distributing the flyers and coupons to as many friends, family members and neighbors as possible. One week before the event remind them about the event.
5. **Be prepared for the event** – Get to the restaurant early to help the restaurant manager greet your supporters. Make sure the manager has the NTAF fund name and our address, so they know where to forward the proceeds. Finally, remember to thank the manager for his or her time.



Thanks,  
Rebecca Carr, Joni Henderson, Judy MacGregor, Susann Reiher and Amy Faigenbaum



**A special thanks to Astellas Pharma US, Inc.  
for generously underwriting this issue of  
New Start News.**

**Visit the Transplant Services section of the  
new NTAF Web site for details on  
Astellas’s Reimbursement Services  
for transplant patients.**

**Click on the Astellas banner ad for details.**

### Consider Planned Giving

We hope that you will remember NTAF– and thousands of transplant and catastrophic injury patients nationwide who cannot afford the cost of their medical care– in your Will and other long-term financial plans.

There are a variety of planned gifts that provide tax advantages and income to the contributor, while benefiting NTAF in the future.

**Leave a legacy of helping others.**

For more information on planned giving, please contact NTAF Executive Director, Lynne Coughlin Samson, Esq.,

**1.800.642.8399.**

# NTAF Launches a New Web Site for Patients and Professionals

## *An Overview of the New Sections and Tools*

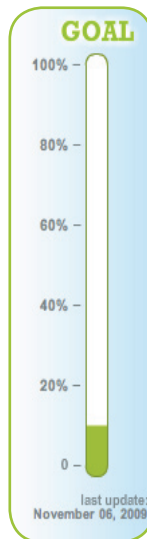
In September 2009, NTAF launched its new and improved Web site with more tools for patients, increased capabilities for contributors, and a new look and feel for all.

### What's New for Patients

Active fundraising patients now have an expanded personalized Web page on the NTAF Web site to highlight their NTAF fundraising campaign, receive online contributions and share news with family, friends and supporters.

Patients (and/or a designated volunteer) can manage their personal Web page in the new NTAF Patient Restricted Area. In this password-protected area, patients can choose from a variety of new features to display on their NTAF Web page:

- A funds raised thermometer to display fundraising progress;
- Photo galleries to showcase fundraising event photos;
- A News section to share information about fundraising events, provide health updates, and link to media coverage of your fundraising campaign and more;
- Icons that link to your favorite social networking sites (Facebook, MySpace and/or Twitter) to further increase the exposure of your fundraising campaign.



Patient Web pages are usually created within one business day from the time a patient campaign receives its first contribution and becomes 'active.'



The patient (or in many cases, their support person) receives a temporary user ID and password by e-mail. This information allows the e-mail recipient to access the NTAF Patient Restricted Area. Once logged in, the user ID and password can be changed in the *Edit Profile* section.

In this section, an additional user can be given 'Full' or 'Limited' access to the restricted area to help manage the Web page. Limited access prohibits the user from viewing the *Edit Profile* section (where a patient's personal user

information, funds raised thermometer and Find a Friend option are located) and the *Contributors List* section (where a list of campaign contributors' names and contact information are displayed).

In the restricted area, registered users also have access to the NTAF Flyer Library, Fund Request Form, as well as NTAF brochures and other downloadable materials.

If you have an NTAF Patient Web Page but you are not currently registered, please call NTAF at 1.800.642.8399 or use the *Contact Us* page on the NTAF Web site to request access.

### New For Contributors

Scroll no more! Now contributing to a patient campaign or an NTAF program or fund is easier than ever before. You can even set up recurring contributions online. The new Web site also allows contributors to manage their own personal contribution profile to track their donation history and store their billing information. Please note that recurring contributions set up through NTAF prior to the launch of the new site (on 9/23/2009) are not available online.

### New for Professionals

Transplant and catastrophic injury professionals also have a new section on the NTAF Web site. Professionals can request access to the NTAF Professional Restricted Area, by clicking on the Professionals tab. Once registered, professionals can log in to download NTAF brochures/handouts for patients, training materials for professionals, and learn about the NTAF Emergency Grant Program – a limited program to assist patients in emergency medical situations where fundraising is not an option.

Details about NTAF's free educational Webinars are also available in this area under *Training*. Power Point presentations from NTAF Webinars are posted under *Downloads*. While you are there, download the new NTAF Fundraising Follow Up Form to use with your patients to help get fundraising started.

*A tutorial of the NTAF Patient Restricted Area can be viewed under Resources & News on the NTAF Web site.*

*A printable overview is also available under Downloads.*



## NTAF Patient Tells His Story Through a Lens: *Patient Auctions His Photos at a Benefit Dinner in His Honor*

Curtis Almeter, of Neosho, Missouri, has been fighting to stay healthy his whole life. Born with the inherited disease Cystic Fibrosis (CF), Curtis endured daily breathing treatments and repeated rounds of IV antibiotics for 26

years, just to live. Recently, after obtaining his Associate's degree, Curtis's lung function rapidly began to decline – a day Curtis knew would one day come.

CF is a chronic disease that affects the lungs and the digestive system. A cell defect causes a thick mucus to build up in the lungs, blocking the airways. The buildup of mucus attracts bacteria to grow, which can cause serious lung infections. Eventually, the lungs fail.

Curtis now requires 24/7 oxygen as he awaits a double lung transplant. Curtis is fundraising to help cover his transplant-related expenses, which will include: temporary relocation (to St. Louis where he will wait for and recover from a double lung transplant); lodging and food; and costly immunosuppressant medications that Curtis will

need to take daily for the rest of his life.

Curtis admits that he was hesitant at first about fundraising, but he realized that it was 'absolutely necessary,' he said, in order to raise the money needed to improve the quality of his life.

Curtis is using his passion for photography as a way to help raise money for his cause.

The amateur portraitist and photo editor had his landscape photos, called *Life Through a Lens*, displayed at a benefit dinner/silent auction at a local church. Other auction items included: furniture, event tickets and other donated items. Proceeds will benefit the NTAF fund in his honor.

Some of Curtis's portraits and other photos are displayed under *Photos* on his NTAF Web page. Visit [www.transplantfund.org](http://www.transplantfund.org) to view. Search for Curtis's Web page using the blue Find a Patient box on the NTAF home page.



**You can also view Curtis's photos on the NTAF Facebook Fan Page. Become a fan today!**

### *Preston Walker's Story continued from Cover*

Stem cells are removed from the patient's fat, purified and assessed for quality, then reintroduced intravenously into the body. The idea is that the patient's (immune) stem cells will regenerate a new, functioning immune system.

In May 2008, Walker and a friend who also has MS, traveled to Costa Rica to take part in the therapy. [Note: This therapy is not recognized by the U.S. FDA].

Preston's stay included: five intrathecal (spinal canal) injections; five physical therapy sessions; a mini-liposuction to remove his stem cells; and an intravenous injection of his cultured stem cells into his body. The cost: \$20,000 for therapy, plus travel and food expenses— which Preston was able to pay for thanks to the contributors who supported his NTAF fundraising campaign.

Today, Preston rarely experiences MS symptoms – Reporting only one 'bad day' since seeking stem cell

therapy. He credits his improved quality of life to stem cell transplantation. Though Preston no longer relies on conventional MS therapies, he does not believe stem cell therapy means an end to all diseases, including MS.

"It's important that your body is in the right environment to heal itself," said Preston, who takes testosterone, T3 and T4 (for his thyroid) and the antioxidant glutathione (to boost his immune system), in addition to continued 'tune ups' (stem cell therapy).

Preston has referred dozens of patients to ICM and NTAF for fundraising. To date, 16 NTAF fundraising campaigns have been initiated because of his referrals, and all but one are seeking the experimental stem cell therapy at ICM.

Preston's therapy sparked a lot of media attention.

"Just Google® me," said Preston with a laugh. Watch a video of Preston before and after therapy on NTAF's YouTube page (Search 'NTAF83' on [www.YouTube.com](http://www.YouTube.com)).



## Looking for a meaningful gift alternative this holiday season?

You can **Light a Life** this holiday season by visiting the NTAF Web site at [www.transplantfund.org](http://www.transplantfund.org) or [www.catastrophicfund.org](http://www.catastrophicfund.org). Click on the *Light a Life* logo; print out tribute forms(s) directly from the Web site; and add the name(s) of the individual(s) you would like to honor with your gift. Send the form(s) to NTAF, along with your check or credit card information. NTAF will take care of the rest, sending a prompt gift acknowledgment to your honoree. All size gifts can make a difference.

### Your *Light a Life* gift can truly make a difference:

- \$25** pays for co-pays for five medications
- \$50** pays for parking at the hospital for one week
- \$75** pays for a night of hospital housing
- \$100** pays for one week of immunosuppressant drugs
- \$500** pays for one week of home health care

This holiday season, make an impact in the lives of patients in need!

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

Visit the NTAF Web site or call NTAF at 1.800.642.8399.

