

Summer 2008

Issue 31

Local Chamber of Commerce Names NTAF 'Nonprofit Business of the Year'



The Main Line Chamber of Commerce (MLCC) named NTAF (located on the Philadelphia Main Line) 'Nonprofit Business of the Year' at *A Celebration of Business Leadership* on June 17 at the Radnor Valley Country Club (Villanova, Pennsylvania.).

"NTAF is a model as a nonprofit agency," said R. Stanley Schuck, MLCC President and CEO,

"being active and positively engaged in the local business community. They currently participate in our *Nonprofit Roundtable* and our *Leadership Main Line Program*. In addition, NTAF was a sponsor for our *Network at Noon*, a highly powered monthly networking event. **Most local nonprofits could learn about engaging with the business community by watching the success of NTAF.**"

Also at the event, NTAF Executive Director Lynne Coughlin Samson, Esq., graduated with the Class of 2008 from the *Leadership Main Line Program*. Samson was selected from other area nonprofit leaders to participate in the program, an intensive six-month leadership development program. Samson was able to participate in the program thanks to an anonymous benefactor who paid for her tuition.

NTAF Catastrophic Injury Program Wins 'Award for Continuing Excellence'

NTAF will receive a **2008 Award for Continuing Excellence** for its Catastrophic Injury Program June 26 at a ceremony at **Inglis House**, a Philadelphia skilled nursing facility for adults with physical disabilities. The award was given by the Inglis Foundation, the parent corporation of Inglis House.

The Inglis Awards for Continuing Excellence recognize excellence, innovation and effectiveness, and honor the outstanding performance of nonprofit organizations in the Greater Philadelphia area that provide direct services, products and/or constructively influence public policy for people with physical disabilities, according to program

materials.

NTAF is one of five organizations to win a 2008 Award for Continuing Excellence. Winners receive a \$20,000 grant from Inglis Foundation.

"This award will help us serve more patients with enhanced services and begin outreach to returning severely wounded veterans," said Lynne Samson, NTAF Executive Director.

Inglis House services are designed to enable people with physical disabilities to enjoy life with the greatest amount of independence and mobility. For more information, visit the organization's website: www.inglis.org.

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5K Run & Walk Raises \$50,000 for NTAF SCI Patient

NTAF SCI Patient **Dave Denniston** to Compete for the U.S. Paralympic Swim Team at the 2008 Paralympic Games in Beijing this September!

See Page 5 for details.



From the Executive Director



October 2008 marks NTAF's 25th year of service to the transplant community. As we look back at what we have accomplished, we are proud.

With more than \$50 million raised for patients' uninsured medical expenses (and more than 1,500 patients transplanted), NTAF is the largest financial assistance organization in the United States

for transplant patients-- providing almost twice as much assistance in 2007 as the next largest service organization.

In 2000, we opened our doors to the catastrophic injury community -- extending our services to meet the needs of individuals living with spinal cord injury, brain trauma and burns. This program has soared to impressive heights! Now in just its eighth year, the NTAF Catastrophic Injury (CI) Program has helped CI patients raise more than \$6.2 million through "grassroots" fundraising. In Fiscal Year 2007, NTAF paid for 10 vans, home modifications to provide accessibility for 30 individuals, and more than \$1.1 million toward rehabilitation and home health care.

Together, NTAF, our patients, their families, friends and community members are changing lives! NTAF wants to take our 25th anniversary year to celebrate these individuals with NTAF Community Hero Awards. Please consider whether you can nominate someone or yourself for this special honor. *See Back Cover for details.*

We also want to take this special time to increase our education efforts-- a core component of our founding mission. See what we have done so far: *Read on Page 3* how NTAF, through education and awareness campaigning in our local community, registered more than 250 potential bone marrow donors to the National Marrow Donor Program Registry in just six months!

Finally, our 25th year is the perfect time to reflect back on our progress and plan for the future. With professional study of our impact and a survey of our patients and their caregivers, we aim to expand and improve our services even more. Many of you have been a part of this survey process already, and **we are grateful**. The results have been magnificent!

Here's what our patients and fund-raisers are saying about NTAF:

- *"I can't say enough good things about NTAF, just providing the opportunity is so important. Not feeling like you have any good options can be the most draining of situations in tough times. Human perseverance needs an outlet."*
- *"Having a nonprofit fundraising avenue eases the financial management and ensures trust for people who donate to my cause. Thank you for providing the NTAF option."*
- *"I was able to receive money very quickly to help continue to pay some bills that would show up last minute. NTAF gave me the financial security, knowing that I could send in my receipts and know that within two weeks I would have money. Thank you."*
- *"You have been a godsend."*

For those who have taken the time to give us your feedback, we are thankful. We look forward to hearing more about how we can improve for you as we continue this survey process. Here's to another great 25 years!

Workplace Giving

Every fall, workplace giving campaigns gear up to encourage charitable contributions from employees. NTAF welcomes gifts through the CFC (Combined Federal Campaign) and state campaigns.

For CFC campaigns, NTAF is listed as a member of the Health and Medical Research Charities of America. We are listed as National Transplant Assistance Fund (NTAF). Our CFC designation number is 12095. Contributions through the CFC campaign will be designated for general

support. NTAF can also be designated as your charity of choice for United Way contributions.

If you wish to make a contribution to a patient campaign through the CFC or United Way, please call NTAF for instructions, 800-642-8399. Thank you for your support!



NTAF Celebrates National Donate Life Month and its 25th Anniversary at a Special Transplant Donor Awareness Luncheon



More than 200 guests joined NTAF Friday, April 25, 2008, at our 3rd Annual Transplant Donor Awareness Community Luncheon and (this year) Bone Marrow Donor Registration Drive.

NTAF hosts a free luncheon (open to the public) each April at our headquarters in Radnor, Pennsylvania, to celebrate National Donate Life Month. The event raises awareness about the importance of organ, tissue and marrow donation, and celebrates individuals-- both life-saving donors and professionals-- for their selfless contributions to the transplant community.

Guests enjoyed hors d'oeuvres and had a chance to survey NTAF services and transplant donor awareness displays, as well as our archives display-- 25 years of newspaper articles from across the nation about NTAF patient fundraisers and NTAF accolades.

Later, guests ate a buffet lunch while NTAF Executive Director Lynne Samson presented this year's Community Hero Awards.

2008 NTAF Community Heroes

Dr. Jack and Patricia Kolff, B.S.N., NTAF co-founders, were presented with an anniversary gift by Tim Haahs, former NTAF heart transplant patient, and NTAF Executive Director Lynne Samson, for their long-time contributions to the transplant community. Dr. Jack Kolff founded the first heart transplant program in the Delaware Valley in 1983 at Temple Medical Hospital, one of only 12 in the country at the time.



From left: Patricia and Jack giving their remarks after being presented with their anniversary gift.

Together Jack and Patricia launched NTAF (originally named the National Heart Assist and Transplant Fund [NHATF]) in 1983 in suburban Philadelphia. Patricia served as executive director of NTAF from 1983 to 2003.

Dave Huddleston, Emmy award-winning journalist and Fox29 (Philadelphia) weekday news co-anchor, was recognized for his selfless gift (twice given) of bone marrow to a 17-year-old leukemia patient, and his ongoing

participation in educating the public about the need for organ, tissue and marrow donation. Dave actively reports on issues pertaining to organ, tissue and marrow donation during the month of April on Fox29. He is a registered National Marrow Donor Program (NMDP) donor and an NMDP Board Member.

The Rev. Robert (Bob) Rogers, formerly interim pastor at Paoli Presbyterian Church of Paoli, Pennsylvania, was honored for his selfless decision to be a living-kidney donor to the Rev. Jim Churchill, also formerly of Paoli Presbyterian.



From left: the Rev. Churchill, the Rev. Rogers, Dave Huddleston and NMDP's Yvette Torres at the luncheon.

This year, to commemorate NTAF's 25th year of service, we hosted a bone marrow donor registration drive in a wing adjacent to the luncheon. NTAF was able to register an impressive 72 potential donors to the National Marrow Donor Program Registry during the two-hour event!



The April 25th drive was NTAF's fourth local marrow donor drive since the launch of our *Save a Life Initiative* in October 2007 -- a year-long commitment to educate and register

250 potential bone marrow donors to the NMDP Registry.

The drive helped NTAF surpass its goal of 250 registrants. Total potential donors registered to date: 253 -- in just six months!

NTAF will host a drive this fall on the Philadelphia Main Line in partnership with the Main Line Chamber of Commerce.



A Bargain for her Buck

E-mail interview with Annamarie Ausnes and Sandie Andersen. Edited and adapted by Shannon McMonagle, New Start News Editor.

Each morning for more than three years, five days a week, Annamarie Ausnes, 55, stopped in at the North 26th and Proctor Starbucks in Tacoma, Washington, en route to her work at the University of Puget Sound in Tacoma.

She placed the same order each time -- a short drip, double-cupped coffee for \$1.52.

Tacoma Starbucks barista Sandie Andersen, 52, often had Annamarie's order poured before she even reached the counter. Sandie took notice of the frequent customer because of her 'upbeat' personality and unusual method of payment.

"I always counted out my change of \$1.52," wrote Annamarie. "It was my routine to take it off my husband's dresser, where he would leave his loose change that became my morning coffee money."

Annamarie's daily routine of counting coins bought the two women extra time to exchange conversation over the counter. They had much in common-- grandchildren and a taste for travel to sunny spots-- away from Washington's rain.

Though the two women exchanged words nearly every day for years, they did not even know one another's name until last November. Today, the two women's names go hand-in-hand, popping up in countless newspaper articles and TV programs nationwide.

In March, Sandie was a living-kidney donor for Annamarie-- saving a life, developing a life-long friendship, and sparking a nationwide media buzz about the charitable Starbucks barista from Tacoma.

Annamarie discovered that she had polycystic kidney disease (PKD), a genetic kidney disease, after an automobile accident in 1990. By 2007, her kidneys were failing.

One morning in late November 2007, Sandie noticed that Annamarie was not her usual self when she arrived for her morning coffee. The friendly barista inquired what was



From left: Annamarie and Sandie at the Proctor Starbucks.

wrong. Though at first hesitant to share, Annamarie told her barista that she needed a kidney transplant, and with no family match, doctors had placed her on the National Kidney Transplant List for a donor (a wait time of up to 5 years).

"She threw her hands up in the air at that moment and said, 'I am going to test for you', wrote Annamarie. "Yes,

it was that instantaneous."

"My only thought," wrote Sandie, "was that I could relate to this woman. I, too, have grandkids and a family that count on me. I can help!"

"I told her I had been praying for an Angel," wrote Annamarie, "and she said, 'Maybe I am your angel.'"

The following week, Sandie found out she was a match. After talking it over with family members, Sandie decided to share the good news with her customer.

"There was a line all the way to the door and here comes Annamarie," wrote Sandie. "Talk about time stopping! I grabbed her hand and said, 'I'm a match'. We both started to cry."

The two Tacoma women underwent surgery on March 11, 2008, at Virginia Mason Hospital in Seattle. Both have recovered well and are glad to have shared the experience.

"I haven't had this much energy in the last five years" wrote Annamarie. "People who know me even say they can hear the energy back in my voice."

Though Annamarie was the lucky benefactor of Sandie's life-saving kidney, both women say they have gained a "new life" from this experience.

"I'm the one that received so much more than I gave. You can't know that until you experience it. I have gained the most gracious and loving friend. If I could say one thing to Annamarie it would be thank you. You have taken me on a journey that changed my life for the better forever. It's humanity at its finest and I got to be part of it."

NTAF SCI Patient To Compete in the 2008 Paralympic Games in Beijing, China!

E-mail interview with Terri Denniston, mother of NTAF SCI patient Dave Denniston. Interview conducted on June 11, 2008, by Shannon McMonagle, New Start News Editor.

NTAF SCI patient Dave Denniston, 29, was selected for a spot on the U.S. Paralympic Swim Team, after fareing well at the U.S. Paralympic Swim Trials in April at the University of Minnesota in Minneapolis.

On September 5, Dave will represent the United States in the 100-meter breaststroke, 50-meter backstroke and 50-meter butterfly at the 2008 Paralympic Games in Beijing (following the 2008 Olympic Games).

"When his name was announced, a great cheer went up from all who were there," wrote Terri Denniston, Dave's mom. "Tears started flowing immediately -- from his family, from some of his former coaches who were there, and from Dave."

The Denniston family had been to the University of Minnesota before – back in 2000 when Dave (then an able-bodied swimmer) competed in the NCCAs for the University of Auburn. (In 1999, Dave led the University of Auburn Swim Team to an NCAA Championship title.)

"Coming back was poignant for me," wrote Terri. "This was our first paralympic swim event to attend."

Friends and family of Dave contacted NTAF in May 2005, after the 16-time All-American swimmer suffered a spinal cord injury in a sledding accident. Dave's injury left him paralyzed from the waist down.

Just a few months prior, the world record-setting swimmer had come just shy of qualifying for the 2004 Olympic Games -- a lifelong dream of Dave.

Now, Dave is making waves in the paralympic swim world -- a sport that he became involved in at the encouragement of former coach and friend, Jimi Flowers.

"To my knowledge," wrote Terri, "Dave is the first able-bodied champion swimmer that has crossed over to disabled."

Dave is currently training at the U.S. Olympic Training Center in Colorado Springs, Colorado, until August 20.

NTAF extends its congratulations to Dave and the Denniston family. Best of luck to Dave in Beijing this September! We'll be watching on-line here in Radnor!



Lynne Visits NTAF SCI Patient at Nutech Mediworld in Delhi, India: A Letter from the Executive Director

"During a recent family trip to India (my brother is Director of Operations at Boeing in India), I visited the Nutech Mediworld facility. There, several of our patients are "medical tourists"-- as the term is becoming known-- receiving experimental, cutting-edge stem cell treatments (not available in the United States) to increase their function after significant spinal cord injury.

NTAF does not endorse or suggest any particular treatments or facilities, feeling that each patient and their provider must decide what is best for them. NTAF provides a list of questions to ask when considering any experimental treatment, whether in the United States or outside.

During my visit I had the opportunity to visit with NTAF SCI patient Kasie Burtard. I was impressed to see the optimistic "positive energy" attitude of Kasie in view of the equally impressive challenges to getting treatment in what is admittedly still a third world country in so many ways.

I commend all of our patients' courage, perseverance and strength, and I am eternally grateful for all the contributors who have made access to these treatments possible.



NTAF Meets Extensive Charity Evaluators' Standards



NTAF recently earned the highest possible rating from three charity evaluators, for its high standards of public accountability and program effectiveness.



Charity Navigator (the nation's largest independent evaluator of charities, according to its website) awarded NTAF four stars (out of a possible four) for the fifth consecutive year.

From the Charity Navigator letter of award:

“Only 3% of the charities we’ve rated have received at least 5 consecutive 4-star evaluations, indicating that National Transplant Assistance Fund outperforms most charities in America in its efforts to operate in the most fiscally responsible way possible. This “exceptional” designation from Charity Navigator differentiates National Transplant Assistance Fund from its peers and demonstrates to the public it is worthy of their trust.”

BBB WiseGiving Alliance has found that NTAF meets all 20 of the Alliance's Standards of Accountability. The standards were developed to promote ethical conduct by charitable organizations.

NTAF has also received the Seal of Excellence from Independent Charities of America, awarded only to organizations meeting the “highest standards of public accountability and program effectiveness” (www.independentcharity.org). Charity Navigator, BBB WiseGiving Alliance and Independent Charities of America all evaluated NTAF's governance, financial stewardship, fiscal accountability, program effectiveness and cost-effectiveness, among other practices.



Websites: www.charitynavigator.org; www.give.org; www.independentcharities.org.

Planned Giving: Consider NTAF

A Letter from the Executive Director

Last month, we were incredibly fortunate to receive an \$80,000 distribution from the estate of a woman who remembered NTAF in her will. This month, we have received paperwork indicating that another generous soul left NTAF \$250.

Large or small, “planned gifts” – those thoughtful gifts that are part of someone’s will or estate planning – provide NTAF with critical funds to create and sustain its future.

Planned giving can also create tax advantages for your family. We previously announced that those who give in this way become, at the time of the pledge, part of our Enduring Hope Fund. Won't you think of joining?

We have entered into a partnership with The Philadelphia Foundation to manage our planned giving program. Through The Philadelphia Foundation, interested individuals can set up annuities and other financial vehicles that provide both favorable tax benefits and income to the donor and beneficiaries, as well as future benefits to NTAF. In the current investment environment, many people are looking to annuities as part of their investment strategy due to their dependable favorable returns in this turbulent market.

If you would like to explore a planned gift, please contact me at 1-800-642-8399.

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Fundraising Spotlight

A Doubly Important Race to Recovery

The 3rd annual *Race to Recovery* to benefit the NTAF Great Lakes Spinal Cord Injury Fund in honor of Bret Neylon will kick off at 8:40 a.m. Saturday, July 26 at Brownsburg East Middle School, in Brownsburg, Indiana. Proceeds of this year's race will also benefit NTAF newcomer John Wassen (referred to NTAF by Bret), another spinal cord injury patient from Brownsburg.



Bret post-injury on the Brownsburg track.

The annual benefit 5K run & walk was started in 2006 by concerned citizens of the Brownsburg community shortly after Bret-- a long-time Brownsburg teacher and varsity track and cross country coach, suffered a severe spinal cord injury in a bicycle race.

Bret was injured in the final stretch of the 2006 Summer Solstice Race in Wilmington, Ohio, while riding for 'Team' *Heroes Foundation*-- a

nonprofit cycling team whose mission is to serve the cancer community by raising money for patient programs, community education and research.

Bret fractured his C4 vertebra-- leaving him paralyzed from the neck down.

The annual *Race to Recovery* has raised nearly \$50,000 toward Bret's rehabilitation and continuing medical costs.

John, a carpenter, business owner and beloved

member of the Brownsburg community, recently sustained a C5 spinal cord injury at work, after falling from the second story of a house in August 2007.

"People in the community reached out to us, asking questions about how we went about fundraising for Bret," said Heather Dawes, a member of the *Race to Recovery* fundraising committee for which husband, Brent, is a co-chair.

"This year we will also give to John," said Dawes.

Bret returned to both teaching and coaching, switching to Brownsburg High School, because it is more wheelchair accessible than the middle school, where he previously taught. John is working hard on outpatient rehabilitation with the support of wife and caregiver, Tamie, his two daughters and the Brownsburg community.

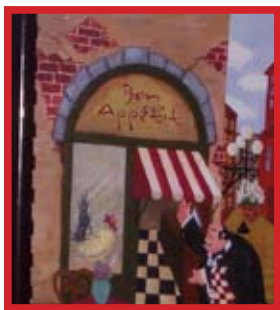
For information on the annual *Race to Recovery*, please visit www.RaceToRecovery.org.

For information on the *Heroes Foundation*, visit <http://www.heroesfoundation.org/>.



John with wife, Tamie, at a Silent Auction fundraiser in March 2008.

A Cookbook in Loving Memory of Former NTAF Patient Greg Matthews -- Proceeds to Benefit NTAF!



A prelude to the cookbook by Greg's wife, Rolanda Matthews:

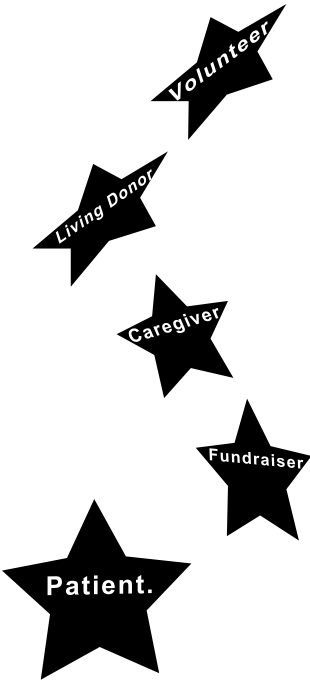
I began this cookbook with my husband, Greg, to raise money for his operation. ... Unfortunately, we never got to finish the cookbook. (Greg passed away in February 2007, three months after his second liver transplant.)

Several months after he passed away, I talked to his children, Daryl and Neely, and we decided to continue with the cookbook in Greg's memory, and donate the profits to patients registered with NTAF. ... Greg would do anything for anyone, and we want to continue that legacy. ... Your support is critical to the success of someone's fight for life!

To order a cookbook, please email Rolanda at rgmatt952@yahoo.com.

Barbecue Ribs Marinade

- 1 lb. beef or pork ribs*
- 2/3 bottle barbecue sauce*
- 1 stick butter*
- 1/2 can honey*
- 1/4 bottle apple cider vinegar*
- 1/2 bag brown sugar*
- 1/2 lemon*
- 1/4 large sweet onion*
- 4 cloves garlic*
- 1/2 bottle Sangria wine*
- 1/2 bottle honey Dijon mustard*



NTAF Wants to Know: Who's Your Community Hero?

Each year, at our annual transplant donor awareness community luncheon, NTAF honors local community members who have saved or improved the lives of transplant patients with NTAF Community Hero Awards. This 25th anniversary year, NTAF wants to hear who your NTAF Community Hero is.

Please consider nominating someone or yourself for this special honor. Visit our Web sites www.transplantfund.org and www.catastrophicfund.org to download an NTAF Community Hero Nomination Form.

To submit a nomination: please fill out the form (be as detailed as possible); save to your computer; and send as an e-mail attachment to smcmonagle@transplantfund.org. Assuming that all information is relevant and complete, NTAF will honor nominees in our e-news, newsletter and on our Web sites. Nominees will also be awarded an NTAF Community Hero certificate and t-shirt in recognition of their accomplishments.

Please consider nominating an NTAF Community Hero.



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