

## Daughter gives hope to her father, all those living with ALS

Tina Forshey, whose father, Tom Milianti, has fought ALS in Chicagoland for five years, recently entered the fight herself when, as a consumer reviewer, she helped evaluate research applications submitted to the Amyotrophic Lateral Sclerosis Research Program (ALSRP) sponsored by the Department of Defense (DOD).

As a consumer reviewer, she was a full voting member, along with prominent scientists, at meetings to determine how Congress' FY10 appropriation of \$7.5 million will be spent on future ALS research. Consumer reviewers represent people living with ALS and family members, and persons at risk for the disorder, when they prepare comments on the impact of the research in supporting preclinical assessment of therapeutics for amyotrophic lateral sclerosis. Tina was one of four consumer advocates who participated in the September 2010 peer review meetings and provided comments and scores for research applications.

"The part of this role that I take most seriously is representing those who have ALS, those who would participate if they could but can't travel or are a sole caregiver to a loved one and don't have the time to required to participate," says Tina, who lives in Virginia but traveled home to walk with her family at the 2010 Walk to Defeat ALS. "For some of the board panelists, the work they do to fight ALS is fueled by a passion for science; my passion is fueled by fear, love and a need for hope."

Her goal was to make sure the review process was a well-rounded one, and that patients were held as the most important part of the process.

After The ALS Association nominated her for the review board, Tina went through an interview process before being selected as a consumer reviewer. She says that it "felt like the biggest interview of my life."

"I was very nervous and excited when I spoke with the DOD representative for my interview," she says. "I still recall very clearly the phone call when I got the news I was selected — a few tears streamed down my cheek and I called my dad to celebrate."

Consumer advocates and scientists have worked together to evaluate the scientific merit of ALS research applications since 2007. To date, five consumer reviewers and 35 scientist reviewers have served on ALS panels. More than 60 ALS research applications will be reviewed for FY10 funds. Scientists applying propose to conduct innovative ALS research aimed at developing effective therapeutics for the treatment of ALS.

"My passion is driven by my love for my father, his strength and grace with which he has fought this disease for five years," Tina adds. "He would tell you, 'if you can be lucky

with ALS, I am,' but he also once told me a smart man/woman makes their own luck."

Tina Forshey, who recently served as a consumer reviewer for the Department of Defense.



### Our newest sponsor: NOVA

The ALS Association Greater Chicago Chapter is thrilled to announce NOVA as a new corporate sponsor. One of the nation's leading retail medical equipment manufacturers, NOVA will work with both the Patient Services and Development departments.

Scott Deis, Vice President of Eastern Operations and Sales, will spearhead the partnership. "Ultimately our goal is to help ALS patients live as active a life as they can by providing daily living aids," Scott says. "Our products allow people to be mobile, functional and stylish which gives each patient the ability to express themselves individually."

Sue Chen, President/CEO of NOVA, was the driving force behind the company's involvement. NOVA, which is headquartered in the Los Angeles area and has been involved with the ALS community there, wanted to expand their involvement. "After exposure to the ALS community, we felt compelled to help," Scott explains. "We believe this is such a worthy organization. Our industry is an industry where you can get instant results of impacting other people's lives and that is what we want to do for the ALS Association Greater Chicago Chapter. I am really looking forward to seeing this relationship grow throughout the years."

Not only will NOVA assist our Chapter with daily living aids, but Scott has promised that he will also get his employee base involved by attending the 2011 Walk to Defeat ALS at Cantigny Park. "I believe it is important to educate my employees about this disease," he says. "I'm looking forward to the walk because I think everyone benefits."