



NEW YORK STATE SENATOR

Catharine Young

WELLSVILLE WOMAN WITH ALS HONORED FOR ADVOCACY

CATHARINE YOUNG July 15, 2011



OLEAN – Debra Quinn of Wellsville proves everyday that Amyotrophic Lateral Sclerosis, or ALS, doesn't have to affect the mind, the spirit or the determination to make the most of one's talents in helping others who also have this disease.

Ms. Quinn, who was diagnosed with ALS in 2009, has become a tireless advocate in raising public awareness about ALS – earning the respect of many ALS advocacy groups for her work across the state and the country.

Senator Catharine Young (R,I,C – Olean) was so impressed by Ms. Quinn's courage and commitment in fighting ALS that she recently presented Ms. Quinn with the New York State Senate Liberty Medal – one of the highest civilian honors that a New Yorker can receive.

“Deb never dwells on what she can't do because of this disease but focuses her energies on her new calling - communicating about her illness and bringing awareness and greater attention to it. She has

helped so many with ALS and continues to fight for a cure. She is a true heroine,” Senator Young said.

Created in 2000, the New York State Senate Liberty Medal, similar to the national Congressional Gold Medal, is given to individuals who have merited special commendation for exceptional, heroic, or humanitarian acts and achievements on behalf of their fellow New Yorkers.

"I'm really honored to be receiving this award. This is for all of the people who have supported me and joined me in the fight against ALS. I'd also like to thank Senator Young for her support of the ALS community. I am proud to be raising awareness of this disease and be the voice for others. I will never, ever give up," said Ms. Quinn.

ALS, commonly known as Lou Gehrig's disease, weakens muscles, leads to complete paralysis and is often fatal within a few years of diagnosis. Ms. Quinn was diagnosed with familial ALS which is a form of the disease affecting 5-10% of ALS patients.

Ms. Quinn grew up watching an aunt and grandmother suffer from ALS and later discovered that more than 20 of her father's ancestors had ALS, dating back to the early 17th Century.

When she lost her younger sister Rhonda to the disease in 2007, Ms. Quinn decided that she didn't want others to have the same experiences with ALS that her sister had and began working with the ALS Association's Upstate New York Chapter in alerting others about ALS.

Kathy Lahey, Executive Director of the ALS Association, Upstate NY Chapter, said, "Despite her diagnosis of familial ALS and the obstacles it has created, Deb Quinn has fought this disease with her heart, body and soul. She persistently searches for opportunities to make life easier for other PALS (Person with ALS), and their caretakers without concern for the situation she herself faces. Deb has been an ardent supporter of The ALS Association Upstate New York Chapter, and we believe if anyone can make a difference in the search for a cure for ALS, it is Deb Quinn. She deserves this prestigious award, and we are very proud to know her."

In 2010, she participated in the Walk to Defeat ALS in Rochester. The Walk, which is the chapter's biggest annual event, raises funds to sustain patient care and support cutting-edge research to find treatments and a cure for the disease. Ms. Quinn's team raised almost \$12,000 for this event.

Earlier this year, Ms. Quinn participated in the ALS Association's National ALS Advocacy Day and Public Policy Conference in Washington, D.C. She was asked to be a presenter for a breakout session about familial ALS during the conference.

Ms. Quinn is actively involved with a new non-profit foundation called "Hearts for ALS NY" - an all volunteer organization dedicated to making the lives of ALS patients as comfortable and useful as possible. The group, started by caregivers of ALS patients, or "CALs," provide useful information and resources to ALS patients.

"The younger a patient is, the harder it is to get help," says Ms. Quinn. "CALs will help to ensure patients with ALS don't fall through the cracks of what can be a very complex and intimidating health care system and that they get the needed help, either for equipment or financial assistance."

Ms. Quinn also continues to actively work with local, state and federal legislators to help them understand the financial impact of ALS and to try to influence policy to help patients and caregivers access services.

Senator Young said to learn more about ALS and what you can do to help, log onto the ALS Association's website at: www.alsa.org. More information for "Hearts for ALS NY" can be found at the foundation's website at: www.heartsforalsny.org.