



# Inspirational Patient Award

Kathleen Arntsen

I have dedicated my life to improving healthcare, promoting patient-centric research and empowering individuals impacted by autoimmune diseases and will continue the battle until the day I die. I have tenaciously fought to ensure the next generation of lupus and autoimmune patients have better therapies and a better life. I am honored that there are now many more autoimmune warriors fighting by my side. I live in fear that I will become very ill again and not be able to be a strong advocate so take advantage of every opportunity.

People often ask me why I am an advocate. I was struck down in the prime of my life and forced to give up my hopes, dreams, and aspirations because of autoimmune diseases. I eventually won my disability, so becoming an advocate helped to fill a void left by disease; it has brought my life full circle, repeatedly bringing me back inside the beltway and various state capitals to influence public policy in an attempt to make a positive difference in the lives of others.

As an advocate I try to provide promise and hope to those impacted by lupus and other diseases of unmet need through the hotline, support and education meetings and one-on-one counseling. By sharing positive information as well as my own journey which although dismal at times has improved over the years. Providing encouragement by stressing research, improved awareness and being proactive in one's medical treatment are cornerstones in building a foundation to achieve a more positive prognosis. In dealing with the public misperception of lupus and autoimmunity for decades, many of us have fought tenaciously to let everyone know you can have a pretty good life if you become empowered and educated. It's easy to be a victim; it's difficult to take charge and fight. And it's ok to have bad days, we all do. Sometimes we even have bad years.

It has taken me decades to build a strong healthcare team and support system for myself and I am certainly blessed to be surrounded by resourceful, positive people who keep me and my quality of life as healthy as possible. And these relationships are reciprocal; I am thanked often by patients, loved ones and providers for sharing knowledge, positivity, hope and humor. Living with multiple autoimmune conditions and facing unexpected medical obstacles has certainly been dreadful at times and an unwelcome burden on numerous levels, but it has also brought many wonderful individuals into my circle of life. With each adversity we experience, we gain wisdom, strength and new opportunities to explore.

I am alive today because of the support of my parents, husband, and other advocates and because I became educated and empowered about my diseases. I am part of my healthcare team and play a major role in the decision making process, coordinating results between physicians. I also participated in clinical trials and as a visionary developed an interactive education program on the importance of clinical research trials in the development of therapies for diseases of unmet need and launched it in 2006 prior to other lupus trial programs. I remain hopeful that we will get better and safer drugs soon so all patients can have a better quality of life.

“The patient perspective is powerful, passionate, persistent, persuasive and non-proprietary.”

Thank you for all you do, Kathleen.

You truly are an inspiration!

The International Foundation for Autoimmune Arthritis & World Autoimmune Arthritis Day Committee

*Patient Inspiration Award*



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