



## Lupus: Naperville Resident AnnMarie Glaviano Tells Her Story

By Anne Schwab

According to Native American folklore, the animal energy of the butterfly represents “Balance.” When an ecosystem is damaged, the butterfly is usually the first to leave. Symbolically, if a butterfly enters your life, there is a need for balance – fast.



AnnMarie with her son Vincent and family pet Medici (Medici also had lupus\*)

**Ironically, the butterfly that entered Naperville resident AnnMarie Glaviano’s life six years ago came in the form of lupus.**

For three years AnnMarie went from one specialist to another. Diagnoses included irritable bowel syndrome, possible brain tumor, premenopausal, possible non-Hodgkin’s disease, and food allergies. Then in the Spring of 2000, her chiropractor performed a simple non-invasive test in her ears that indicated an “energy” block in her kidneys. All the tests her family practitioner performed came back negative – except for one test that showed invisible protein cells in the urinalysis.

**To be on the safe side, she was referred to a kidney specialist.** After 60 more days of testing, the blunt message that AnnMarie received was that she was going into renal failure rapidly. Kidney biopsies showed that lupus had silently targeted both kidneys with rapid destruction. She was 46 at the time.

Despite enduring two years of chemotherapy and high dose steroids, both her kidneys have reduced ability. She experiences peripheral nephritis in her hands and feet making them feel numb. She has had two brain infarctions (strokes) which have affected her short-term memory and cognitive skills. At times her joint pains are so severe that she just wants to pull away.

**Like many lupus patients, AnnMarie became light sensitive and nauseated** when outside. Her joint pain has been horrible and she is out of breath just walking up stairs. Unable to keep up with her active children or to perform or enjoy the things she loved, she often felt like a total failure.

Probably one of the most frustrating aspects for AnnMarie is the public’s lack of understanding about lupus. “The public understands blindness but not lupus,” she says. “The public looks at a lupus patient

like myself and wonders why you can’t work full time. People doubt your ability to want to work. Unseen disabilities affect your memory, energy and cognitive skills, and you look like a slouch.”

**The chronic aspect of lupus coupled with continuously deteriorating physical**

**conditions** challenges the family as well – spouses who can’t cope and children growing up with a chronically ill mother. When AnnMarie was diagnosed in 2000, her son Vincent was 10 and her daughter Ariel was 7, and she had been married for 16 years. The chemotherapy and steroids caused her to gain 80 pounds. Her husband had wanted to place her in a nursing home and at one point commented to her that it would be easier if she would die. He is now her ex-husband and her son Vincent took over as her primary caregiver. (Vincent was a spokesperson for NBC’s *Young Caregivers*, an excerpt of which can be read at

<http://www.msnbc.msn.com/id/12188835>.)

And being a single mom unable to work added financial stress. As AnnMarie so candidly put it “I guess it looks as though it’s enjoyable to live alone with two children at poverty level, not being able to go or do what you want. Lupus is a mind game – you try to do more, but then fatigue, aches and flares take over, and things that need to get done end up sitting for a while. We look and feel like non-achievers.”

**But AnnMarie remains philosophical and positive** despite the challenges that lupus has created in her life. “It’s a hard lesson, but needed, if you are to move past this disability,” she says. “You must leave your life-before-lupus behind you. Much like the wake of a boat in the water, the wake is the trail that’s left behind. Staying in the past will not move you forward. To move forward, embrace your limitations. Lupus thrives when chaos is present so love yourself, and surround yourself with the people who love you. Admit to yourself that you are not picking up where you left off! You’re on a whole new course. Give yourself credit for having made it through the worst storm!”

Though unable to work, AnnMarie actively volunteers in many causes including the Lupus Foundation of

If you think that lupus is a rare disease, you will be surprised to learn that there are almost as many people living with lupus as are living with breast cancer. Like breast cancer, lupus predominantly affects women – accounting for 90% of lupus patients. But unlike breast cancer,

- what causes lupus is unknown, there is no cure and the only treatments available treat the symptoms, not the disease
- lupus is a disease of the immune system which can strike any of the body’s major organs including the kidneys, heart, lungs, blood, skin
- studies are showing that lupus patients are at higher risk of early onset of heart disease, loss of kidney function, potential for strokes, difficult pregnancies

America Illinois Chapter. She is co-chairing the Illinois Chapter’s first DuPage County Walk to be held on Sun., October 1st along Naperville’s scenic Riverwalk.

**Working in her wildflower garden is one of AnnMarie’s hobbies** – a garden designed to attract butterflies to remind her of the need for balance. The butterfly is also a symbol for lupus (many patients are diagnosed as a result of the distinctive butterfly shaped rash on the face, one of the few symptoms specific to lupus). It is a garden where butterflies can soar as well as feel safe to alight.

For patients and their families living with lupus, the Illinois Chapter of the Lupus Foundation of America is available to provide assistance, resources and support groups. More information about lupus can be found at [www.lupusil.org](http://www.lupusil.org) or call 312-542-0002.

With the prevalence of lupus as high as it is, you probably know someone who has lupus. You can make a difference in their life. Participate in or volunteer to help at the DuPage Walk – details on page 10. Walk proceeds are used to provide educational and support programs for lupus families, and towards research.

**Walk information is available at [www.lupuil.org](http://www.lupuil.org) or by calling 312-542-0002**

*Anne Schwab is the Chairman of the Board of the Illinois Chapter of the Lupus Foundation of America. She is also the National Council representative to the Board of Directors of the Lupus Foundation of America, and is co-chairing the DuPage Lupus Walk. She is also a CFP®, MBA and the publisher and owner of DuPage Woman Newspaper™.*

\*For more information on autoimmune diseases in dogs, go to <http://www.petsnpatients.com/medici.htm>.