



Kelly Young, second from right, with (from left) Becky Roder, Roxanne Williamson, Jay Sprinkel, Nancy Murphy, and Katie Beth Young.

## A Voice for Patients

*An RA Warrior creates an advocacy and support organization for patients.*

BY DIANA PRICE

When Kelly Young was diagnosed with rheumatoid arthritis (RA) after the birth of her fifth child in 2006, she didn't know anyone else with the disease. Desperate for information, she struggled to shed light on the diagnosis that, overnight, transformed her from an active 40-year-old to someone incapable of performing basic, everyday tasks. Determined to be proactive, Kelly sought out research and community, reaching out to other patients and the medical community.

In 2009, realizing the critical benefit to patients provided by shared resources and experiences, Kelly started a website and blog, Rheumatoid Arthritis Warrior (*rawarrior.com*), to support those battling the disease. For the past four years, Kelly has provided invaluable information to patients who find themselves facing a diagnosis that, though incredibly common, is not well understood and is often not acknowledged for the debilitating impact it can have on patients' lives.

As Kelly worked with other patients and rheumatology professionals to build the online RA Warrior community, she found that patients were seeking a way to make their voices heard: "We were connected with a lot of patients, and they were asking—via e-mails and blog posts—'Isn't there an RA foundation?' and telling us, 'The RA foundation should do X.'" But there was no such foundation that represented pa-

tients, and after several years of hearing patients continue to clamor for an outlet to raise awareness and advocate for research, Kelly, along with a group of equally committed patients and with input from two other leaders in the RA nonprofit community, took the leap and created the Rheumatoid Patient Foundation (RPF).

With a mission to improve the lives of patients with rheumatoid diseases such as rheumatoid arthritis and juvenile arthritis through a variety of means—including research, public awareness, patient education, and patient-led advocacy—RPF is now in its second year of striving to make a difference in the lives of patients. The organization's website (*rheum4us.org*) provides information about RA, answers to common questions, and links to other RA sites and resources. In addition to the information provided online, RPF has created print brochures and posters about RA and has made them available to doctors and nurses to distribute to newly diagnosed patients, with the goal of educating patients upfront about the disease and available support.

In addition to the resources and information, Kelly says that RPF is dedicated to serving as the voice of patients through advocacy efforts that raise public awareness of patients' needs among rheumatology professionals, policymakers, and the public. The organization has presented at the Ameri-

can College of Rheumatology annual meeting, the Arthritis Introspective annual gathering, and on Capitol Hill, sharing information and highlighting patients' experiences and needs.

It's critical, Kelly says, to be sure that patients' voices are heard by industry professionals who, up until now, may know about RA only from the outside. "If the only message a provider or industry professional has ever heard is a commercial, which is selling a product, they don't have the full picture. The patient perspective is key to present to industry." The organization is also working to ensure that patients are represented in research; to this end RPF is currently collaborating with the Mayo Clinic on a survey about patient care.

Moving forward, Kelly hopes RPF will continue to increase awareness of RA, add patient input to research studies and policy that influences patient care, and help improve diagnosis for patients, many of whom have symptoms for years before they are accurately diagnosed. "The best hope we have for remission, from what we've seen from science, is early, aggressive treatment," Kelly says, "so the public and the medical community need to be more aware of the disease."

As she works with the RPF Board of Directors to further the organization's mission while waging her own private battle with RA, Kelly remains fiercely committed to improving the lives of other patients. "I often work

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been done, but you can slow the damage and you can stop the progression of new damage in these women”—a breakthrough that could significantly improve the well-being of women with MS. It's hoped that research along these same lines can have a positive impact on other diseases.

### It's All About Awareness

Awareness, it appears, is the key to understanding and managing AI disease in women. From diagnosis to research to long-term management, increased attentiveness to these conditions, their symptoms, and their impact on women in particular will help in accurate diagnosis and care that's personalized for women's needs.

Patients like Nancy are also doing their part to raise awareness. “I have become an advocate to raise awareness about the disease [lupus] through education,” she says of her own efforts. “I now take every opportunity to communicate with my friends and family and provide them with information about the various aspects of lupus so that they understand what I am going through.” She also reaches out to a larger audience using social media.

Becoming “your own best advocate” with such efforts, Nancy says, is the best advice she can give to others affected by AI disease: “Learn as much as you can about your disease and take an active role in your medical care.” She also encourages others to create a support system, particularly by finding “someone you trust to help you through the hard times.” ❀

#### REFERENCE

1. Autoimmune Disease in Women. American Autoimmune Related Diseases Association website. Available at: [http://www.aarda.org/women\\_and\\_autoimmunity.php](http://www.aarda.org/women_and_autoimmunity.php). Accessed October 16, 2012.

Nutrition and headache prevention may be about more than avoiding suspected triggers; observing a balanced eating plan may also help prevent headaches. Aim to eat regular meals, as the low blood sugar levels that can result from missed meals can be a trigger. Meals should be balanced, providing protein, carbohydrates, and vitamins and minerals. You can further keep blood sugar levels stable by avoiding excess sugar and by consuming caffeine and alcohol only in moderation (if at all), as excess amounts of either substance may trigger a headache.

### MEDICATION

There are several different options for preventing and treating headaches and migraines with medication. Ask your doctor about drugs—both prescription and over-the-counter—that may be appropriate for you. When choosing medication options, your doctor will consider such factors as the nature of your symptoms, your overall health, any other medications you are taking, and the type of headaches you experience.

Some people find that over-the-counter pain relievers such as aspirin, ibuprofen, and Tylenol® (acetaminophen) help control headache pain. The US Food and Drug Administration has also approved some over-the-counter medications formulated specifically to treat migraines; these include Excedrin® Migraine (acetaminophen, aspirin, and caffeine) and Advil® Migraine (ibuprofen).

Migraine headaches may also be treated with prescription medications; one of the most common such drugs is Imitrex® (sumatripan succinate), which targets migraine symptoms. Other prescription medications used to treat migraines include drugs to counteract blood vessel constriction (used for prevention) and drugs intended to reduce the frequency and the severity of migraines. Antidepressants and anticonvulsants may also be used.

For women whose migraine attacks appear to be related to their menstrual cycle (changing hormone levels), hormone therapy or birth control pills may offer some relief.

### LIVING WITH MIGRAINES

With a combination of lifestyle measures and medication to prevent migraines and treat their symptoms, it's possible to control the frequency and the severity of attacks. Some people affected by migraines find that alternative therapies like acupuncture, acupressure, and yoga help control the frequency of attacks and symptoms and contribute to an improved quality of life. Biofeedback is also used to help people manage migraine attacks; this self-help treatment involves the monitoring of breathing, pulse, heart rate, temperature, muscle tension, and brain activity—all involuntary physical responses to stimuli like stress (a potential migraine trigger). By learning how to identify and control these responses, individuals can learn to control their body's response to stress and thus prevent some migraines. ❀

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60 to 80 hours a week—much of it from my couch or soft chair—using my laptop and talking on the phone to connect with patients and review research,” Kelly says, describing her daily work on behalf of RPF and RA Warrior. And though the work is intense, she does not anticipate slowing down anytime soon. “Every single time I think *This is too hard* or *It's too much*, I read messages from patients that keep me going—messages that say, ‘What you're doing is giving me hope,’ or ‘What you're doing has saved me,’” she says. “That's why we're doing this, why we're driven to do this; we believe we are helping people and that this is necessary work.” ❀

For more information about the Rheumatoid Patient Foundation, visit [rheum4us.org](http://rheum4us.org) and [rawarrior.com](http://rawarrior.com).