Dr Janis McCaffrey

“Doctor Mom”
Living with Lupus

ACE has met many amazing mothers who live with arthritis. This year at the Canadian Rheumatology Association’s Annual Meeting, ACE spoke with Dr. Janis McCaffrey, a general practitioner and mother living with lupus who shared her journey.

Q. What has been your experience living with lupus?
A. I was diagnosed with Lupus at 50 with acute renal failure due to nephritis. I was critically ill and my mother came out to help (it’s supposed to be the other way around!). I could not work. Lupus ‘retired’ me and forced me to give away my practice with more than 2000 patients. After I got off the ‘big’ meds, I had a giant identity crisis and became depressed. How could I suddenly NOT be a doctor? I needed counseling and, thankfully, took and remain on an antidepressant.

To manage my lupus I began a treatment pathway that includes getting deliberate and regular exercise (yoga and tennis for me, but I started with walking!), and having quiet time to consciously set goals. If I can, I read, play chess and many word and number games for my brain. I paint and draw and garden for my psyche. I also have my own book with questions, test results and current medications list to ensure I am prescribed the right medications and maintain good communication with my doctors.

Q. How can caregivers, family, and friends support women living with arthritis?
A. Throw down your calling cards. You’d do it for any of your family and friends, right? My book group and other friends and neighbours rotated a meal to our family as they saw we needed. Extra help with childcare, driving, shopping, ironing, yard work, and handyman chores were appreciated. A friend’s ear is still the best therapy in the world.

Teach your kids to be independent in age appropriate ways: to clean their rooms, do their laundry, take the bus, make their lunches, share household chores. Thank, play with, and treat them regularly.

Partners need to be intimately honest (relationship-wise, sexually, emotionally) and figure out together what to do and what will work. Be brave, and get some help if you need it.

Q. Do you consider yourself a role model?
A. Physicians I learned from were role models whether they wanted to be or not. I think a position of influence always presents an opportunity of being a role model. We act accordingly: professional, inherently teaching to whoever is listening, often the patient, their family, staff, colleagues, and we are always learning from others if we have our eyes and ears open!
What special projects are you leading?

My research team is developing a patient decision aid called ANSWER-2 (Animated, Self-serve, Web-based Research) to assist people with rheumatoid arthritis (RA) make informed decisions about using biologics. ANSWER-2 is the second in a series of online decision aids for RA patients. The first – ANSWER – supports RA patients to make informed choices about using methotrexate and can be found at http://answer.arccanada.org.

Focusing on physical activity is also important because we know it can reduce pain, improve mobility, and enhance quality of life. My team recently discovered that it is feasible for RA patients to wear a physical activity tracker for an extended period. A range of studies is ongoing to learn more about the role that these interactive tools could play in helping patients be more active. The Arthritis Care in the Digital Age study aims to understand how the latest physical activity trackers can help to manage arthritis from the perspectives of patients and doctors. The Osteoarthritis Physical Activity & Exercise Net (OPEN) study is testing if arthritis patients’ physical activity improves when they use this new website to set safe exercise goals. If digital tools are found to be effective in supporting people with arthritis to be active, they could lead to improvements in health. Anyone interested in getting involved can visit our website at arthritis.rehab.med.ubc.ca.

How can we get more women interested in studying the science of bones, joints, and muscle?

It may help to increase the engagement level from a young age—by encouraging girls, for instance, to participate in activities such as science fairs and competitions. By taking part in these activities, girls may develop a better understanding of what careers in the science of bones, joints, and muscles look like. Providing educational and professional opportunities for girls is as important as building the confidence they need to pursue them.

Do you consider yourself a role model?

I’m fortunate to have had the support of excellent role models and mentors who have supported my growth throughout my career, and I continue to learn from the examples of success they set. In my supervisory roles at UBC and ARC, I believe it’s crucial to nurture students in ways that help them to get to where they want to be in their professional lives. I think the best role models help us to realize the possibilities within ourselves.

Successful organizations are paying more attention to the needs of employees living with arthritis. Recognizing the significant role 4.6 million Canadians living with arthritis have in the work force and economy, ACE is conducting a nationwide search for Canada’s Best Workplaces for Employees Living with Arthritis.

Companies with their head office or principal place of business in Canada may apply for Canada’s Best Workplace for Employees Living with Arthritis program. Companies of any size may apply, whether private or public sector. ACE will evaluate companies based on four arthritis best practice criteria: Physical Workplace, Health Benefits, Employee Education, and Organizational Benefits.

Employers or employees can submit a single application for the 2014 Canada’s Best Workplace for Employees Living with Arthritis program. The deadline for application is 5:00 p.m. EST on August 15, 2014. Winners will be announced during Arthritis Awareness Month in Canada in September 2014.
ACE was pleased to talk with Dr. Julia Alleyne, a Family Physician with a focus on sports and exercise medicine. She is the Medical Lead Outpatient Musculoskeletal Services at the Toronto Rehabilitation Institute at the University Health Network. Dr. Alleyne is Past President of the Canadian Academy of Sport Medicine and was honoured by the Canadian Association for the Advancement of Women in Sport and Physical Activity as a recipient of the Most Influential Women in Sport and Physical Activity List.
Who we are
Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit www.jointhealth.org

Guiding Principles
Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a practical necessity. Any profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities, and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal “in-kind” support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and healthcare providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any “brand”, product or program on any of its materials or its website, or during any of its educational programs or activities.

Thanks
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About Arthritis Consumer Experts

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