

Ethics in Rheumatology

By Emily J. McKeown, MSc, MD, FRCPC

How often have you left your busy clinic at the end of the day and wondered, “If only that patient with seronegative rheumatoid arthritis (RA) had a positive rheumatoid factor (RF) then the Exceptional Access Program (EAP) would fund her biologic treatment.” Perhaps, you reflected on how you should have responded when a pharmaceutical representative wanted to schedule another meeting with you regarding their new product, or saw the natural history of RA unfold before your eyes because the patient refused disease-modifying antirheumatic drug (DMARD) therapy and you respected their wish for patient autonomy? These are just some of the clinical examples where ethics displays itself in rheumatology.

As a community of rheumatologists, how often have we sat down to discuss these issues? It is about time we did. That is the impetus behind the recent endeavour of myself, Dr. Carter Thorne, Dr. Heather McDonald-Blumer, Dr. Ronald MacKenzie, and a selection of committee volunteers who, with the help of the CRA, aim to address the perceived ethical challenges in rheumatology. This project is building on a similar body of work that was completed in the United States by the American College of Rheumatology (ACR), under the leadership of Dr. MacKenzie, a co-investigator on the Canadian project. The administration of the current study will be conducted through the CRA in support of its mandate to enhance the practice of its members. The survey will address five core areas:

1. Awareness of daily ethical challenges;
2. Perception of ethical issues in clinical and basic research;
3. Perception of potential effects of industry relationships on daily work;
4. Understanding conflicts of interests; and
5. Personal education around medical ethics.

Our objective is to catalogue ethical issues recognized by Canadian rheumatologists, and compare and contrast those with the American data. We are interested in assessing if there any differences given the dissimilarities of our health-care systems, with respect to funding, use of infusion/injectable medications, and delivery of health care.

We have recently organized an Ethics Committee through the CRA. We have nine committee members, including cross-country representation and a pediatric representative. The committee will be provided with the study findings and, subsequently, will be able to assist in providing direction and vision to the CRA in promoting dialogue amongst CRA members. The results of the survey will be submitted for presentation at the CRA Annual Scientific Meeting in 2014 and for possible publication thereafter.

This endeavour has implications for future educational initiatives from the ground up. We hope to be able to identify generic, often unperceived, ethical concerns that may result in development of specific training modules for subspecialty residents in their rheumatology training program. While some trainees have received some formal



ethics training previously, many have no formal education in this domain. Furthermore, the literature reflecting key ethical issues in rheumatology literature is sparse. We hope to extend and develop educational activities for rheumatologists in their clinical practices. At the very minimum, we will be bringing the discussion of ethics in rheumatology to the forefront, a laudable first step.

We are very much looking forward to CRA members' participation in the upcoming survey. The link for the survey will be sent in the near future. We value your input and look forward to reading your responses. If you have questions about our group, please contact Dr. Emily McKeown, the study coordinator (emily.mckeown@sunnybrook.ca).

*Emily J. McKeown, MSc, MD, FRCPC
Rheumatologist, Sunnybrook Health Sciences Centre
Toronto, Ontario*