

CRAJ SCR

The Journal of the Canadian Rheumatology Association



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Balancing Burnout, Burden Reduction and Appropriateness

By Philip A. Baer, MDCM, FRCPC, FACR

Scenes from my office recently: A patient of mine is transitioning to another rheumatologist closer to where she lives. She said she would miss me, particularly because of my help in obtaining WheelTrans for her (a mobility service for those with disabilities). Could I do one last thing for her, and fill out her disability tax credit (DTC) form? Unfortunately, the answer had to be no, as the criteria for the DTC are more stringent than for mobility assistance.

The next patient arrived with a bright red envelope perched on the seat of her walker. Given we were meeting in January, that could have been a card for our office for New Year or Lunar New Year. But it was not. Instead, I was presented with a form from a small country thousands of kilometers away, asking me to stipulate that my patient was still alive. Reminiscent of old Canadian passport applications, only certain professionals could be trusted as guarantors. Now there are a lot of fraudulent supercentenarians apparently,¹ but my patient was only in her 70s. I laughed when I saw that both a signature and an office stamp were required; yes, I have one of those from 30 years ago, but most doctors probably don't anymore.

Rheumatology used to be called "The Happiest Specialty."² Now studies say we have high levels of burnout, even surveys conducted at the Maui winter rheumatology conference!³ My inbox and medical social media feeds are deluged with links to articles on burnout, burden, and forms. Reading it all is dangerous to one's mental health. As a result, our Editorial Board decided that the *Journal of the Canadian Rheumatology Association (CRAJ)* theme issue on the topic should focus on wellness rather than burnout, to put a more positive spin on the issue.

Everyone seems to agree burnout relates to systemic issues. So, we are now engaged in burden reduction. *The Medical Post* mentioned a burden reduction committee in British Columbia, and Doctors Nova Scotia made the news with their survey on how much time doctors spend on administrative tasks. Even the Canadian Federation of Independent Business (CFIB) has taken up our cause, given the importance of health care to businesses, and the fact that most medical practices are small businesses. One appeal of larger corporate and investor-run medical clinics is their claim to handle the business side, leaving doctors free to concentrate on medical practice. Of course, the forms burden still falls on physicians. At the Ontario Medical Association (OMA), we have a Forms Committee

taking up the challenge, with our own Dr. Jane Purvis highly engaged as a member.

The other side of the burden coin is the issue of appropriateness. We are all familiar with inappropriate test ordering of ANAs^a, RFs^b, anti-CCPs^c, ENAs^d, and imaging such as knee MRIs^e when plain X-rays have already demonstrated osteoarthritis (OA). Choosing Wisely Canada is working on the matter, but based on the referrals that come through my office, they have a lot of work to do to achieve their goals. Our standard provincial lab requisition has tried a different approach, with some tests moving from ordering by ticking a box to having to write or type out the lab test name to order it. That apparently works for tests such as TSH^f and ferritin. For a couple of tests, namely PSA^g and Vitamin D levels, there are tick boxes to designate the test as appropriate and government paid, or as uninsured and billed to the patient.

Speaking of MRIs, a recent blog by Dr. Sohail Gandhi, ex-OMA President, mentioned that to order an MRI as a GP (general practitioner), he had to fill out an MRI appropriateness form in addition to the MRI requisition.⁴ He didn't seem to mind, but that is the battleground between burden and appropriateness that we are all facing.

Other examples of that battle: sending me a referral note with the one word "arthritis?" reduces burden on the referring doctor, but increases the triage burden on the consultant. Sending a hundred pages of duplicated lab results with the referral might also reduce the burden on the GP ("just fax them the whole chart"), but the burden at our end is no less. And what about one of my most common referral sources who doesn't know how to attach documents to their referral letter? We have become experts at merging various categories of imaging tests and lab results into a single document as a result.

The latest office skirmish in the war on burden: I saw a patient a few months ago for knee OA. Injections were given, and I told the GP that the patient could be referred to an orthopedic regional assessment clinic (RAC) if knee replacement surgery was desired in future. The RAC requires a specific referral form (burden). Recently, I received a document from the regional home care service with an updated knee X-ray, my last note, and a blank RAC referral form. The implication was clear: the GP had made a referral, but the key form had not been

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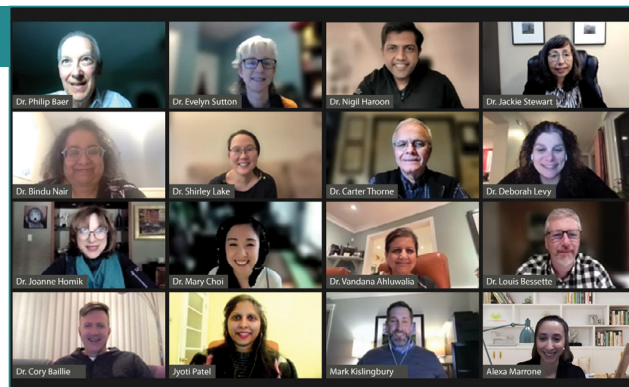
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Balancing Burnout, Burden Reduction and Appropriateness

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completed. My choices: fax the document back to the GP or to home care, stating that the GP needs to complete the form (burden reduction for me, burden increase for GP). Or, since it is a mutual patient, and I had suggested the orthopedic referral, and I have completed the RAC form many times, and it autopopulates much of the required info from my electronic medical record (EMR), I could take care of it myself and feel I had done my good deed for the day. So, I completed the form and sent it to the proper place. But I also noticed that the patient must bring a CD^h of their knee X-ray to the appointment (burden and cost to patient). So, I closed the loop by calling the patient. Much to my surprise, she told me she already had an appointment at the RAC next week! Conclusion 1: The GP must have completed the proper referral form eventually. Very unclear why I would then be sent a blank referral form. Conclusion 2: calling our current state of affairs a healthcare “system” is laughable.

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Glossary:

- ^aANA: antinuclear antibody
- ^bRF: rheumatoid factor
- ^canti-CCP: anti-cyclic citrullinated peptide
- ^dENA: extractable nuclear antigens
- ^eMRI: magnetic resonance imaging
- ^fTSH: thyroid-stimulating hormone
- ^gPSA: prostate-specific antigen
- ^hCD: compact disc

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Attend the ORA Annual Scientific Meeting!

By Sandy Kennedy, Executive Director, Ontario Rheumatology Association

Join us on May 26-28, 2023, at the Kingbridge Conference Centre in King City for the ORA Annual Scientific Meeting. The theme of this year's meeting is **Progress + Promise: Advancing Care in Rheumatology**. The meeting will enable participants to engage in both clinical and scholarly activities with the objective of improving the quality of care in Ontario for patients with rheumatic diseases.

Dr. Janet Pope has assembled an incredible line-up of speakers once again, including international and local talent. Enjoy learning sessions with international speakers, such as Dr. Atul Deodhar, Dr. Georg Schett, Dr. Cynthia Cooper and Dr. Eduardo Mysler. Some of our local speakers include Dr. Zain Chagla, Dr. Stephanie Garner, Dr. Amanda Steiman, Dr. Rae Yeung and more!



Ontario
Rheumatology
Association

Visit the ORA website at www.ontariorheum.ca to learn more! See you there!

*Sandy Kennedy
Executive Director, Ontario Rheumatology Association*

Mindfulness-Based Stress Reduction in Symptomatic Patients with Controlled Rheumatoid Arthritis

By Isabelle Gaboury, PhD; Patricia L Dobkin, PhD; Françoise Gendron, MD; Pasquale Roberge, PhD; Marie Claude Beaulieu, MD; Nathalie Carrier, MSc; Pierre Dagenais, MD, PhD; Sophie Roux, MD, PhD; and Gilles Boire, MD, MSc, FRCPC

Current treatments of rheumatoid arthritis (RA) are very effective at controlling inflammation and preventing joint and bone destruction. Some RA patients continue to report distressing patient-reported outcomes (PROs) such as pain, fatigue, depression or functional impairment despite clinically controlled inflammation (controlled RA) according to the physician. The best approach to improve PROs in these patients is currently unknown.

In a pragmatic pilot study,¹ we offered free participation to group mindfulness-based stress reduction (MBSR) sessions led by a certified therapist. MBSR is an 8-week group intervention shown to be effective to help patients with a number of diseases.² We included patients with controlled RA (2 swollen joints or less; normal C-reactive protein [CRP]) coming to their regular follow-up visit who had high depressive symptoms (Centre for Evaluation Studies-Depression [CES-D] scores ≥ 16) and/or Patient General Assessment of disease activity (PGA) at least 2/10 higher than Evaluator General Assessment (EGA). Evaluations were completed before and 6 and 12 months after MBSR and included CES-D, PGA, the Modified-Health Assessment Questionnaire (M-HAQ), Simplified Disease Activity Index (SDAI), and measures of anxiety (General Anxiety Disorder 7 [GAD-7]), coping strategies (Coping with Health Injuries and Problems [CHIP]), and 0-10 Visual Analog Scales for sleep disturbance and pain.

Out of 306 screened patients, 65 (about 50% of those potentially eligible according to chart data from their previous visit) were referred by their rheumatologist to research personnel, 39 (60%) signed consent, 29 (45%) participated in at least one session and 28 (43%) completed the 8 MBSR sessions. Anticipated burden, timing and frequency of weekly group meetings, commuting issues, age extremes, and comorbidities were barriers to participation.



The proportion of patients with CES-D ≥ 16 decreased from 67.9% at baseline to 36% ($p=0.01$) and 11.8% ($p=0.002$) at 6 and 12 months, respectively. M-HAQ ≥ 1 , indicative of at least moderate disability, decreased from 57.1% at baseline, to 32.1% at 6 months ($p=0.007$), and 26.1% at 12 months ($p=0.008$). At 12 months after completion of MBSR, anxiety, emotion-oriented coping and sleep also significantly improved. Yet, no significant impact was observed on pain, PGA or SDAI. Interviews of 9 patients at 6 months after completion of MBSR sessions revealed that benefits to patients including integration of effective coping strategies into regular activities were maintained.

We addressed MBSR feasibility issues and the selection of outcomes in patients with controlled RA patients still expressing distressing PROs. For patients who chose to participate in group MBSR, lasting benefits were evident for anxiety, depression, sleep, and function. Less demanding interventions, such as web-based MBSR groups, might allow better participation. Larger studies will be required to evaluate the weaker impact of the intervention on pain and PGA.

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Who's in the Rheum – CRA Staff Edition

Meet the Newest Members of the CRA Team!



Sarah



Erin



Madalyn

Please describe your role at the CRA in one sentence.	I am the Board and Committees Coordinator, supporting a number of CRA committees to progress and fulfill their various initiatives.	As the Marketing & Communications Coordinator, I keep our members informed with the latest news and information.	As the Program and Membership Coordinator, I oversee membership, respond to all general inquiries, and connect residents with membership benefits and travel bursaries. I am also the main contact for sponsors and exhibitors.
How long have you been with the CRA?	Since August 2022.	Since October 2022.	Since July 2021.
What is your favourite CRA memory to date?	The gala at the most recent Annual Scientific Meeting (ASM) in Quebec City. I enjoyed seeing the award winners receive their accolades from their peers and loved watching everyone on the dance floor!	My favourite CRA memory to date is definitely the ASM in Quebec City. It was wonderful being able to meet CRA members in person and celebrate their work.	The CRA ASM 2023 Gala night! It was such fun dancing, and meeting everyone in-person has been the highlight since I joined.
What are your summer plans this year?	A lot of gardening, hiking and paddleboarding; visiting family in the U.S.; and cottaging with friends on Georgian Bay.	I hope to spend as much time outdoors as possible and I'm crossing my fingers that a trip to Europe will work out.	I plan to do lots of fun outdoor adventures with my family, go to as many conservation parks as possible and a quick long weekend trip to either Montreal or Quebec.
Where is your next travel destination?	Traveling around Portugal in October.	My next two travel destinations are Florida and New York City, two places I have never been.	Grenada in August.
Can you share any of your hidden talents or hobbies?	I do papercutting (<i>Scherenschnitt</i>), cutting elaborate designs from a single piece of paper. It involves a high degree of patience and a very steady hand. My work has been displayed in a number of galleries.	None of my talents or hobbies are hidden, but I do have a knack for nail art and enjoy exercising daily.	I love to cook and bake. Dancing is my not hidden but favourite talent. I love dancing.
What are you watching or reading these days?	I usually read both a fiction book and a non-fiction book at any given time. Current fiction book: "The Deep" by Alma Katsu. Current non-fiction: "The Arbournaut: A Life Discovering the Eighth Continent in the Trees Above Us" by Meg Lowman.	I recently read "Where the Crawdads Sing" by Delia Owens and have been watching "Down to Earth" with Zac Efron on Netflix, highlighting very interesting, healthy and sustainable ways to live.	Currently reading "Keep Your Love On" by Danny Silk.
What's your favorite 80s or 90s jam?	A lot of great music came out of the 80s and 90s — maybe "Wheat Kings" by the Hip, or "Free Falling" by Tom Petty.	I was born in the 90s so Britney Spears, NSYNC and the Backstreet Boys bring back fond memories!	"Girls Just Want To Have Fun" & "Un buen perdedor."

The University of Toronto Lupus Clinic Turns 50

By Dafna D. Gladman, MD, FRCPC

The University of Toronto Lupus Clinic was started in July 1970, under the leadership of Dr. Murray Urowitz. At the time, it was a novel approach to study the correlation between clinical and laboratory manifestations of lupus. Dr. Urowitz developed a standardized data retrieval protocol, which was completed at each patient visit by trainees who spent 6-12 months in the Lupus Clinic. In 1995, the Lupus Clinic moved from the Wellesley Hospital to the Toronto Western Hospital and has been there ever since.

Since its inception, the Lupus Clinic has provided exemplary patient care to more than 2,100 patients with systemic lupus erythematosus (SLE), while making important contributions to lupus research. This research has resulted in 521 peer-reviewed publications. During this period, the Clinic provided a venue for the education of 241 clinical and research fellows, 10 graduate students and post-doctoral fellows, 27 medical residents, and 51 summer students.

Seminal publications include the recognition of early atherosclerotic complications in lupus, serologically active clinically quiescent disease, and studies of pregnancy, mortality, and individual organ disease in SLE, to name a few.

Due to the COVID-19 pandemic, the planned 50th-anniversary commemoration was postponed from the original date in 2020 (the actual 50-year mark) to December 1st, 2022. By that time, Murray Urowitz, who had remained the Director of the Clinic since its inception, had retired. Thus, the celebration of the 50th anniversary of the Lupus Clinic was also an opportunity to recognize Murray's achievements on the occasion of his retirement.

The event included a symposium that featured presentations by several physicians who had trained in the Lupus Clinic, with a plenary lecture by Professor David Isenberg of London, England. Because of the pandemic, only 50 people could attend in person, while the remainder attended virtually. It was a very informative symposium.

The celebration continued at a dinner with many of Dr. Urowitz's colleagues, friends, and family attending. Dr. Gillian Hawker, Chair, Department of Medicine, University of Toronto, highlighted Dr. Urowitz's contributions to the Department of Medicine and to the Uni-



The Scientific Symposium celebrating 50 years of the Toronto Western Lupus Program and the contributions of Dr. Murray Urowitz took place in Toronto on December 1st, 2022.

versity of Toronto. Drs. Nigil Haroon and Robert Inman commented on Dr. Urowitz's contributions to the Division of Rheumatology and the Schroeder Arthritis Institute, and one patient provided a testimonial on behalf of the patients attending the Clinic. Professor David Isenberg of London, England, who gave the keynote address at the symposium, had written a song to celebrate the Clinic and Murray, and the song was performed at the end of the symposium and at the closing of the evening celebration.

The Murray Urowitz Chair for Lupus Research will be established at the Toronto Western Hospital, to be held by the Director of the Lupus Clinic. Close to one million dollars have been raised so far, but the overall amount needed to support the Chair is much higher. Donations to support the Chair may be sent through the link available by scanning the QR code on this page or by visiting uhnfoundation.ca/

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Riding the Long Road to Health and Happiness

By Regan Arendse, FRCP, PhD

My priorities and perspective on life changed quite dramatically in the months leading up to my 50th birthday. Not only was this landmark date somewhat daunting, but the sudden cardiac death of a close friend at a similar age made me take a closer look at where I was headed in life as a busy community rheumatologist. I realized that unless I made some substantial changes in my lifestyle, I would significantly reduce my chances of maintaining good health in the final few decades of my life.

With the encouragement of my wife Germaine, I started with the one physical activity that I often advocated for my patients: riding a bicycle to enjoy a cardio session without stress on the knees. So, after purchasing a second-hand bike at my local bike store, I joined a local cycling club that taught me all the basics of riding safely and responsibly on the road with traffic, in a group with similarly aged and intentioned riders. Germaine joined the club a year later, and we both eventually graduated from struggling to complete 30 km rides to being able to comfortably ride 100 km in a day.

A year later, our cycling club then introduced us to a unique discipline of bike riding called randonneuring, which involves progressively increasing the distance we ride in an event from 200 km to the unbelievable distance of 1,200 km. Over the three-year COVID-19 pandemic period, we extended our riding range and, in the year 2022, completed a series of rides that included distances of 200 km, 300 km, 400 km, 600 km, 1,000 km, and eventually 1,200 km, each within the prescribed time limit. Each distance we attempted was a challenge, from learning how to use our cycling equipment for these extended distances, to how to mentally overcome our fears and insecurities of riding for such long periods and, finally, to training our bodies, especially the tender contact points, to withstand the demands of the required physical exertion.

Our aim in 2023 is to participate in the most prestigious randonneur event of all called the Paris-Brest-Paris (PBP). This event covers a distance of 1,200 km from the City of Paris to the west coast of France and an elevation



Drs. Regan and Germaine Arendse

gain of 11,000 m in the hills of the Province of Brittany. We, along with an 8,000-strong field of cyclists from around the world, will try to complete this randonneuring challenge within the time limit of 90 hours.

We intend to document our preparation for this ride and our participation in the PBP by producing YouTube videos to help and inspire others who intend to make a significant change in their lives. We believe that if we can successfully transform from couch potatoes to endurance athletes in just five years, then anyone can. Have a look at some of the popular videos we have posted on YouTube that provide step-by-step advice on how to start and succeed at randonneuring. Our YouTube site is available at www.youtube.com/@reganarendse6157.

Please keep your fingers crossed for a safe and successful year for all of the long-distance cyclists participating in various randonneur events around the world this year.

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Is Professional Fulfillment the Wellness and Sustainability Solution? Exploring the Relationship Between Professional Fulfillment, Burnout, and Sustainability Among Canadian Physicians

By Taylor McFadden, PhD; Caroline Gérin-Lajoie, MD; and Christopher Simon, PhD
(Canadian Medical Association, Physician Wellness and Medical Culture Team)

Disclosure: The opinions and conclusions expressed are the writers' own and are not those of the Canadian Medical Association.

What keeps physicians going, through the pandemic and beyond, despite the long hours and challenging work environments? Does professional fulfillment (PF) — which encompasses happiness, meaningfulness, contribution, self-worth, satisfaction, and joy in medicine — provide the necessary drive? Can PF mitigate against burnout or the temptation to reduce clinical hours or leave the profession altogether? The Stanford Model of Professional Fulfillment, one of the most well-known in the area of physician wellness, recognizes the importance of PF by placing it in the model's centre and surrounding it with three key pillars: personal resilience, a culture of wellness, and efficiency of practice. However, during the COVID-19 pandemic in Canada, what were the links between PF, burnout, and intention to leave the profession? The Canadian Medical Association (CMA) conducted the 2021 National Physician Health Survey (NPHS) to provide some insight into these questions.

Why Is Professional Fulfillment So Important in Medicine?

Professional fulfillment is the intrinsic positive reward we derive from our work. While research on PF in medicine is somewhat limited, the concept of intrinsic motivation has been widely studied and has been positively linked to wellness, optimal functioning, productivity, and behaviour change/maintenance. When we experience inherent satisfaction and enjoyment from doing something, we feel good and are motivated to continue doing it. Considering this, we hypothesized that PF could mitigate burnout and positively influence sustainability in medicine.

The CMA NPHS, which is administered on a three-to-four-year cycle, measures and tracks physician wellness indicators over time, as well as wellness-related behavioural and occupational factors. The 2021 iteration of the NPHS includes the first national professional fulfillment



Taylor McFadden, PhD



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data among Canadian physicians. For full details on the methodology, participant characteristics, prevalence data, and the questionnaire, see the "2021 National Physician Health Survey – Foundational Report" available at [cma.ca/sites/default/files/2022-08/NPHS_final_report_EN.pdf](https://www.cma.ca/sites/default/files/2022-08/NPHS_final_report_EN.pdf).

Results from the 2021 NPHS revealed that 79% of physicians and medical residents score low on PF, with only 21% scoring high (N = 3864). In line with our hypothesis, further analyses indicated that low PF is a leading driver of burnout and increases the likelihood that a physician will reduce their work hours ($p < 0.05$). Indeed, the 2021 NPHS binomial logistic regression analyses identified PF as one of the strongest drivers of burnout, which aligns with previous research. That is, those who score low on PF are 2.5 times more likely to experience burnout. Moreover, physicians who score low on PF are 1.5 times more likely to say they intend to reduce their work hours in the next 24 months. This has also been found previously and is quite concerning given Canada's healthcare crisis and challenges with physician shortages and access to care, which are increasingly reported in the media. See "From data to action: Understanding the drivers of physician wellness" (available at [cma.ca/sites/default/files/2022-11/NPHS-Regression-Analysis-EN.pdf](https://www.cma.ca/sites/default/files/2022-11/NPHS-Regression-Analysis-EN.pdf)) for full details on the regression analyses.

How Do We Enhance Professional Fulfillment to Promote a Sustainable Workforce?

The 2021 NPHS results also offer some insight into ways that PF can be enhanced, including increasing opportunities to accomplish worthwhile tasks, ensuring physicians feel that they are positively influencing other people's lives, optimizing time spent working closely with patients (and reducing time devoted to administrative tasks), making sure professional values are aligned with those of the department, increasing control over workload, promoting a collegial workplace, increasing job satisfaction and reducing fatigue, stress and burnout levels. Targeting organizational factors (e.g., reducing administrative load) and workplace culture (e.g., enhancing collegiality) to promote professional fulfillment and reduce burnout are consistent with recommendations made by others.

Where Do We Go From Here?

While the fundamental system-level changes that need to occur to improve physician wellness, professional fulfillment and healthcare sustainability may take time, many of the suggestions above can be readily implemented at the local levels. The findings from the 2021 NPHS, that low PF is a driver of burnout and increases the likelihood that a physician will reduce their work hours, is simply a starting point and future research in this area is recommended. Additional questions that warrant further investigation include:

- What factors promote and hinder PF in medicine (e.g., administrative load, quality of leadership, meaningful recognition, equitable remuneration, etc.)? Among them, which is the strongest?
- Does increasing PF decrease burnout and increase retention?
- What is the link between low PF and other outcomes such as quality care, patient experience, physician productivity, recruitment, and retention?

To conclude, professional fulfillment is a factor that researchers, healthcare organizations, and stakeholders should focus on moving forward, as a potential solution to wellness challenges experienced by Canadian physicians and to the health workforce crisis we are facing today.

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Reconnecting, Renewing, and Reimagining: Perspectives on Burnout

By Stephanie Garner, MD, MSc, FRCPC

Walking into stores, I still have a knee-jerk reaction to look for my mask. While the acute stage of the pandemic may be over, its impact on physicians and the healthcare system is not.

Prior to the pandemic, estimates had prevalence of burnout in physicians at 51%.¹ After two years of living and working in a volatile, complex, and uncertain environment this climbed as high as 79.5% in some groups.² Physician burnout is largely rooted in healthcare organizational and system factors including excessive workload, inadequate resources, loss of support from colleagues, and loss of control and autonomy within the system.³ Women, parents of children under the age of 21 years and early career physicians are at particular risk.⁴ The dreaded term “work-life balance” often comes up as a protective factor but this is elusive for most physicians. We know the consequences of burnout include an increase in medical errors and a decrease in the healthcare system’s capacity (increased turnover, more retirements, and a decrease in productivity^{5,6}). Rheumatology in Canada was already facing a staffing crisis prior to the pandemic.⁷

As a female, early career faculty member with three young children, reviewing the literature for a manuscript on burnout after midnight on a worknight, the irony was not lost on me. However, I did have cause for celebration — I realized that we were talking openly about burnout and how to address it. The conversation shifted away from blaming work-life “imbalance” on the individual physician.

In 2021, the Ontario Medical Association published five recommendations for addressing burnout at the system level. The recommendations were 1) streamline and reduce required documentation and administrative work; 2) ensure fair and equitable compensation for all work done; 3) increase work-life balance by making organizational policy changes; 4) promote the seamless integration of digital health tools into physicians’ workflows; and 5) provide institutional supports for physician wellness.⁸ These are lofty goals that will require constant pressure and advocacy from our provincial and national physician organizations to be implemented.

However, we can as individuals work on addressing these issues in our own environment. The steps can be small, such as talking about burnout with our colleagues and learners to normalize the conversation. As rheumatologists, we have the unique ability to decide how and



Drs. Faiza Khokhar, Saara Rawn, Maggie Larché and Stephanie Garner at the CRA's Annual Scientific Meeting gala dinner, which took place in February 2023.

where we practice. Changing our work environment to reduce the administrative burden and offload tasks to allied health professionals can be a huge step forward in attaining a manageable workload. The use of alternative models of care, scribes, and optimizing electronic medical records for billing and documentation are other strategies that can also effect change.

I recently had the opportunity to attend the Canadian Rheumatology Association Annual Scientific Meeting in Quebec City. This was not an easy feat as it required lay-over flights, arranging for my in-laws to watch my three “spirited” children, and leaving the mental load of the family behind. The theme of the meeting was “Reconnect, Renew and Reimagine,” which is what was delivered. It brought back the sense of connectedness that had been lost during the isolation of the pandemic. While biased, having been four nights child-free, the return to the social norm of connecting with colleagues and sharing challenges, opportunities, and interests was incredibly fulfilling.

The system-level changes required to address burnout are going to take time and perseverance. Nonetheless, we should celebrate that we have started the process by identifying that this is a system rather than provider problem and there is now a movement nationally to address it.

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The Bensen Models of Care Initiative

By Sandy Kennedy, Executive Director, Ontario Rheumatology Association

The Bensen Models of Care Initiative was established in 2018 by members of the Ontario Rheumatology Association (ORA) leadership team at that time: Dr. Arthur Karasik, Dr. Thanu Ruban, Dr. Henry Averno and Dr. Rick Adachi. Together they formed a steering committee to oversee critical aspects of the program, such as governance, sponsorship, terms of reference and regular correspondence with the ORA Executive Officers and Board of Directors. Today, the Bensen Models of Care Initiative is led by Dr. Amit Ghelani. We are thankful for the contributions of everyone involved in this project.

The Bensen Models of Care Initiative was designed to honour the memory of the late Dr. William Bensen, an exceptional rheumatologist who advocated strongly for team-based models of care. His community practice in Hamilton, Ontario, included an interprofessional allied health professional team who worked together to improve the patient experience. His advocacy work, pioneering strategies and overall legacy are promoted in this initiative.

Each year, eligible members of the ORA are invited to apply for a Bensen Models of Care Grant. Applicants are encouraged to propose an initiative that 1) promotes improved care for patients through rheumatologist-led, team-based models of care; 2) encourages novel solutions to improve access to rheumatology care; and 3) helps direct health policy toward funding of team-based models of care.

A Selection Committee is identified each year that includes an ORA Executive member, a Board of Directors

member, a Regular ORA member, an Allied Health Professional and a member of the Bensen family. Up to two successful applicants may be selected annually to receive a maximum of \$40,000. An application for a second year of funding, up to a maximum of \$20,000, will be considered, based on merit and quality of the final progress report.

Over the years, the program has received 15 excellent applications, and has allocated a total of four grants, two of which have been successfully implemented. The program was paused in 2021 due to the pandemic. The Steering Committee was excited to resurrect it in 2022, as was the ORA membership based on the high calibre of applications that were received! The 2022 recipients are Dr. Stephanie Gotthiel and Dr. Derek Haaland. We look forward to sharing the results of their projects in the future.

The ORA is proud of the Bensen Models of Care Initiative and are pleased to have found a way to honour the late Dr. William Bensen. We are especially grateful to the sponsors who enabled the project through their generous funding.

For more information on the Bensen Models of Care Initiative, please contact the ORA's Executive Director, Sandy Kennedy at skennedy@ontariorheum.ca.

Sandy Kennedy

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Reconnecting, Renewing, and Reimagining: Perspectives on Burnout

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Rheumatology for All in East Africa

By Carol A. Hitchon, MD, FRCPC, MSc; and Rosie Scuccimarri, MD, FRCPC

Access to rheumatology care varies globally but is particularly limited in resource-poor countries such as those in East Africa. In these regions, there are few or no rheumatologists to provide rheumatology specialty care. Rheumatology education to medical trainees is often limited, with only limited rheumatology infrastructure and issues with access to diagnostic testing and medications.

In 2016, following a visit to the rheumatology clinic of Tikur Anbessa Hospital in Addis Ababa, Ethiopia, our group established “Rheumatology for All” (RFA) (rheumatologyforall.org), an American-based registered charity whose mission is to increase access to rheumatology care in under-resourced regions. We have adopted a “train-the-trainer” approach in order to create self-sustaining rheumatology units. This has been done by 1) funding the education of local physicians to become rheumatologists; and 2) providing educational programs to the local residents until this can be provided by the returning rheumatologist. All programs are conducted with the full support and collaboration of local medical faculties.

Fellowship support: Our initiatives started in Ethiopia, a country of nearly 115 million people previously without a practicing rheumatologist. RFA funded a two-year rheumatology fellowship for two internists who completed this training at the University of Kwazulu-Natal, in Durban, South Africa, in 2021. Drs. Birhanu Demelash Desyibelew and Becky Abera Adugna are now affiliated with Addis Ababa University and have established busy rheumatology practices seeing more than 150 patients weekly, are contributing to rheumatology clinical education for medical trainees in Addis Ababa and are supervising several trainee research projects. Their success was recently highlighted by their Internal Medicine Department, when the rheumatology unit was recognized for its excellence in clinical services and resident education. This is outstanding considering that there were no rheumatology services at Tikur Anbessa Hospital before 2021. RFA, through charitable donations, is now also able to fund a pediatric rheumatology fellowship for Dr. Hanna Lishan who will start training in Cape Town, South Africa, in 2023. Dr. Hanna Lishan will join Drs. Desyibelew and Adugna in providing rheumatology clinical care and advocating for rheumatology resources for Ethiopians of all ages.

Rwanda, one of the most densely populated countries with a population greater than 13 million, had no practicing rheumatologist. Rheumatology education and rheumatology clinical care were provided by internists and non-rheumatology specialists. With the full support of



Drs. Birhanu Demelash Desyibelew & Becky Abera Adugna Dr. Hanna Lishan

the Department of Medicine in Kigali, we have recently obtained funding from the Royal College of Physicians and Surgeons (RCPS) through the International Development Aid and Collaboration program, to provide rheumatology subspecialty training for Dr. Jean Paul Basbose, who will be starting his adult rheumatology fellowship in 2023. Our group will continue to support and provide mentorship to these new rheumatologists as they advance their clinical and academic careers.

In addition to funding fellowship training, we have developed a rheumatology curriculum that can be provided in person or virtually to trainees in resource-limited regions. In 2018, visiting professors from Canada and the U.S. provided an intensive rheumatology program to senior internal medicine residents in Addis Ababa. The visiting rheumatologists provided lectures and clinical skills training. The participating residents also gave presentations, thereby developing their skills to teach their junior colleagues. A virtual adaptation of the visiting professor program (due to COVID-19) was continued until the return of Drs. Desyibelew and Adugna.

In 2021, at the request of the University of Kigali Medical School in Rwanda, we developed an expanded 16-week virtual rheumatology program for second-year internal medicine residents. The lectures and interactive tutorials were provided virtually, in English, by an international faculty with representation from Africa, the U.K., the U.S. and Canada, thereby ensuring culturally and regionally relevant content. Lectures and tutorials were supplemented with clinical skills videos. The course was repeated in 2022 and 2023. Resident feed-

The Latest from Arthritis Society Canada: New Gout Hub and Early Diagnosis Campaign

By Trish Barbato, President and CEO, Arthritis Society Canada

Arthritis Society Canada is constantly updating resources with the latest evidence, and reaching out to educate the public about Canada's most common chronic disease.

Please check out and share our newest resource — a new hub all about the symptoms, causes and treatment of gout at www.arthritis.ca/gout. Here we explain that gout is the most common form of inflammatory arthritis, affecting as many as 1 million Canadians, and help people manage it with up-to-date info on risk factors for gout, tips for self-management of gout and online learning guides on everything from staying active to eating well.

Also new on the market is our campaign designed to help people with common joint symptoms ask themselves, could it be arthritis? With digital ads across Canada this spring, we are encouraging people to check their symptoms online to learn more.

Our message to those at risk is that it's better to know because early diagnosis and treatment of arthritis are critical to minimizing the impact of joint damage and disability.

If people have joint pain, they shouldn't ignore it. Millions live with arthritis, and there are millions more who have this disease but don't know it yet. Understanding their symptoms is the first step to finding relief.



Anyone in Canada can take the Arthritis Symptom Checker at www.arthritis.ca/BetterToKnow.

Rheumatology for All in East Africa continued from page 14

back was positive, although most participants requested in-person teaching, especially for clinical skills. Thus, in 2023, to supplement the virtual teaching, Drs. Hitchon, Scuccimarri, Colmegna, and Meltzer have planned an in-person visit to provide clinical skills teaching and tutorials for both internal medicine and pediatric resident trainees.

The combined approach of supporting funding for fellowship training and providing rheumatology educational programs to medical and pediatric residents in under-resourced regions aims to develop sustainable rheumatology capacity for clinical care and education, and thereby improve outcomes for individuals with rheumatic diseases in these regions. This work could not be possible without the generous support of our donors, the

project-specific funding from organizations such as the RCPSC, and the commitment of our volunteers, all of which are important to help achieve the mission of RFA.

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ACR Convergence 2022 Review

By Philip A. Baer, MDCM, FRCPC, FACR

This information is brought to you by the Journal of the Canadian Rheumatology Association (CRAJ) and is not sponsored by, nor a part of, the American College of Rheumatology.

The expression “I’d rather be in Philadelphia” is derived from a fictional epitaph that locally born entertainer W.C. Fields (1880-1946) proposed for himself in 1925: “Here lies W.C. Fields. I would rather be living in Philadelphia.” Contrary to popular belief, this joke did not ultimately grace his tombstone.

While I would rather have been in Philadelphia for ACR Convergence 2022, I ended up attending virtually again. Other than a few select sessions such as the ACR Business Meeting and Rheumatology Knowledge Bowl, every session was available simultaneously virtually and in-person. The audio and video quality on the platform were generally excellent, and the in-session polling worked smoothly. PDFs of presenter slides were unfortunately not usually available at the time the sessions occurred but were promised for later if and when presenters made them available. The pre-recorded poster videos were high quality, and PDFs of the posters were all available from the start of the meeting. The platform remains open for review until October 31, 2023, which is a very generous timeframe.

We live in an “Attention Economy” where key social media platforms seek to attract and monetize our attention. Some believe that our attention spans are decreasing consequently. Society has adapted, with movies and advertisements getting shorter in recent years. Professional baseball games remain a work in progress. Medical meetings have also had to change. I noted that the Dubois SLE lecture was 30 minutes long this year versus one hour in the past. The ACR also introduced Ignite Talks, which were sessions covering 213 key posters each presented orally in 5 minutes, back-to-back, without a question-and-answer period. The other session format which was very prominent was the Community Hub type, of which there were multiple instances covering the gamut of clinical, research and business aspects of rheumatology. These generally occurred on Zoom rather than the main meeting platform.

I enjoyed the Opening Session, featuring ACR President Dr. Ken Saag and ARP President Barbara Slusher. Both organizations were highlighted for their trustworthiness and responsiveness. The Plenary Keynote was noteworthy, with Dr. Abraham Verghese of “Cutting for Stone” fame presenting a memorable lecture. He is a noted author and Professor for the Theory and Practice of



Medicine at Stanford University Medical School. He has always emphasized the value of physical examination, a competency highly regarded in rheumatology.

Many Canadians were prominent as presenters and session chairs as usual. We were also well represented as ACR/ARP award winners, and all these awardees will be highlighted in upcoming issues of the *CRAJ*. One of my favourite sessions was The Great Debate. The question was whether disease-modifying anti-rheumatic drugs (DMARDs) should be used to treat subclinical rheumatoid arthritis (RA) to prevent full-blown RA. The “no” side featured an all-Canadian powerhouse duo of Janet Pope and Hani el-Gabalawy. Their dialogue pretending to be a doctor and patient discussing the issue, including both what was said and what was left unspoken by both sides, was masterful in highlighting the difficulties of getting a patient to accept such treatment, even if we had better evidence that it might be helpful. The online poll was over 90% in favour of the “no” side by the end of the debate.

COVID-19 scientific studies were of course prominent. A key study was Abstract 950: Obstetric Outcomes in Women with Rheumatic Disease and COVID-19 in the Context of Vaccination Status: Data from the COVID-19 Global Rheumatology Alliance Registry. A greater number of preterm births (PTB) were noted in unvaccinated women compared to fully vaccinated women (29.5% vs. 18.2%). This was presented as a poster, in an Ignite session, and at an ACR press conference by Dr. Sinead Maguire, who is currently a clinical fellow at the University of Toronto, though formally based in Ireland. More Canadian content!

Posters were only presented virtually, so there was no poster hall for mingling and networking. Accepted abstracts totalled 2,240, with 17 presented at plenary sessions, and 282 as oral presentations.

Other sessions I enjoyed were the Year in Review, both adult and pediatric rheumatology versions, and



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the Wrap-Up session, as well as the FDA Update, Thieves Market and Curbside Consult sessions, and several of the named lectureships, including the Hench, Gluck, Daltroy and Klemperer talks. Dr. Wigley's Hench lecture on scleroderma was comprehensive, and cited William Osler among other clinicians. I learned that pulmonary hypertension has been redefined to start at a mean pulmonary artery pressure of 20 rather than the previous 25 mmHg. As well, his parting advice that "While I have treatment goals (skin, lung, GI, kidney improvement)...Remember the patient's (pain, pruritus, coping)" hit home. From a Canadian perspective, we should be proud of the work done by our own Canadian Scleroderma Research Group (CSRG) on this topic.

Multiple new, updated, and draft guidelines and classification criteria were presented at ACR Convergence. Topics covered included calcium pyrophosphate crystal deposition (CPPD) disease, steroid-induced osteoporosis, anti-phospholipid syndrome, and vaccinations in rheumatic disease. A novel ACR guideline for exercise, rehabilitation, diet, and additional integrative interventions for RA was also highlighted. Consistent exercise was strongly recommended, while dietary supplements, chiropractic and electrotherapy were conditionally not recommended.

I note the IgGenerals team from Massachusetts General Hospital won the ACR Knowledge Bowl, the ACR's counterpart to CRA's RheumJeopardy. A very appropriate team name.

As usual, ACR Convergence 2022 was jam-packed with interesting sessions, cutting-edge science, and innovative presentations. Attendance statistics showed total attendance was more than 13,000, total scientific attendees numbered 11,000 plus, with in-person scientific attendees just under 7,000, and virtual scientific attendees over 4,300. International attendance showed a near 50:50 split, while U.S. attendees were about two-thirds in person. ACR Convergence 2023 will again be presented in hybrid fashion in early November 2023, with the in-person sessions returning to San Diego, a familiar venue for ACR meetings. I will see you there, one way or another.

*Philip A. Baer, MDCM, FRCPC, FACR
Editor-in-chief, CRAJ
Scarborough, Ontario*

Innovations in Data Collection in Rheumatology

By Denis Choquette, MD, FRCPC

Rhumadata™ celebrates its 25th year of existence in 2023. When it was started, it collected data on rheumatoid arthritis (RA) only. With time and progressive subsequent technological improvements, the registry now collects information on axial (AxSpA) and peripheral (pSpA) spondyloarthropathies, including arthritis associated with inflammatory bowel diseases. All visits with rheumatologists (total 15) are included in the database. Data collected include demographics, disease history, comorbidities, and disease activity scoring (disease activity score [DAS], clinical disease activity index [CDAI], simplified disease activity index [SDAI], the ankylosing spondylitis disease activity score [ASDAS], psoriatic disease activity [DA], and more). Patient-reported outcomes (PROs) are collected through different channels such as in-clinic visits with the help of a nurse or directly by the patient on a tactile screen or tablets. Patients can also access their questionnaires online, following an invitation reminding them to answer before their clinic visit. All medications and comedications are also collected with start and stop dates, and with reasons for discontinuation, if this is the case. All pertinent labs are also accessible and directly input to the database if patients are residents in the Optilab region of Montreal. Rhumadata can also be used as an electronic medical record (EMR), can generate lab, imaging, and consult forms, and retain historical data. It is also a self-evaluation and practice self-reflection tool, allowing one to compare one's practice to that of the other members of the registry.

Rhumadata is also connected to another EMR as of the last 5 years, from which we can also extract data from patient visits. Other rheumatologists desiring to participate have only to sign off on chart access approval. This way, our database managers will be able to retrieve the data if, and only if, the patient has signed an informed consent form.

There are multiple facets to a tool like Rhumadata. Of course, it is an important research medium exploring efficacy, safety and pharmacoeconomic questions. But it is also an instrument to optimize rheumatology practice and follow practice pattern evolution over time.

For example, in partnership with the International Psoriasis and Arthritis Research Team (IPART), a consortium of registries on SpA across Canada, we examine the residual burden of diseases in RA, psoriatic arthritis

(PsA), and ankylosing spondylitis (AS). More than a thousand patients were included in the analysis, and we found out that many patients are left with significant residual disease activity at the 6- and 12-month time points. This information should be of great interest to the rheumatologic community, as it illustrates a significant gap in treatment optimization. Many reasons are suspected but time constraints are certainly an area to evaluate. More and more administrative work to access biologic treatments is required by the payers, increasing the work burden on rheumatologists. Another example has been published by the Rhumadata team: Which subsequent treatment offers the best sustainability after a first anti-TNF failure? Certain therapeutic choices show a higher likelihood of retention, and also demonstrate pharmacoeconomic advantages. The evidence thus shows that a medication with a different mechanism of action should be used in this situation. Lastly, a Canadian Institute of Health Research (CIHR)-supported project was accepted for a poster at the 2022 American College of Rheumatology (ACR) meeting in Philadelphia, comparing originator and biosimilar biologics. Similar efficacy and safety profiles were shown. This is reassuring for both practitioners and patients.

Rhumadata also participates in a pan-Canadian initiative comparing the different registries in Canada. There is some heterogeneity from one to another, leading to interpretation challenges.

As more and more rheumatologists are using EMRs, participation for everyone should soon be possible. It should and will become part of usual practice, as it permits each of us to reflect on the quality of their practice, and will eventually be used for maintenance of competence purposes as suggested by the *College des Médecins du Québec*.

*Denis Choquette, MD, FRCPC
Scientific Director, Rhumadata
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Patient Perspective: Natasha Trehan

Elementary school is hard enough to navigate without having to come to terms with developing a life-long illness. In the summer of 2016, I noticed my left wrist and fingers were inflamed. I was actively playing tennis and assumed that I had suffered a sprain. An X-ray and ultrasound proved that there was something more. My family doctor then ordered blood work and immediately referred me to a rheumatologist at The Hospital for Sick Children who diagnosed me with juvenile idiopathic arthritis (JIA). I was only 13 years old. My family and I had never heard of this disease before, and the diagnosis changed my life.

I struggled to respond to remarks and questions from my peers when I did not participate in physical education class due to the intense pain in my feet. My limited ability to write and complete assignments led many to discourage me from pursuing my chosen science subjects. I was forced to advocate for myself during the next few years in high school. Besides the challenges that I faced in school, my disease was not fully managed as my body did not respond to several medications that I was prescribed. Magnetic resonance imaging (MRI) reports revealed that I had damage to my feet, fingers, and wrists. Finally, after having tried non-steroidal anti-inflammatory drugs (NSAIDs) and biologics, 10 corticosteroid shots in my small joints and triple therapy helped bring down the blood test markers as well as the inflammation.

Although my family and friends supported me every step of the way, I felt alone. I wanted to know about the experiences of other people who were diagnosed at my age. When I tried seeking out support groups, I found that none of them were youth-led. I recognized a huge need, and I was determined to fill this gap. During the pandemic lockdown, I learned about my disease and how it affects my joints. I reached out to research organizations, doctors, and hospitals to get involved in research. I became a patient partner with the Choice Research Lab, a citizen partner with the COVID-END team and a member of the National Advisory Board on Pain Canada. I completed a summer internship in the department of eHealth Innovation at the University Health Network and, the following year, I was a research student in the Cell Biology program at The Hospital for Sick Children.

In March 2021, I launched a podcast called “Take a Pain Check”. In each episode, I host and interview guests directly or indirectly involved with or affected by autoimmune diseases. They could be youth living with the disease, caregivers, researchers, or healthcare professionals. Each individual gets to share their experience and story



Natasha Trehan, founder of the Take a Pain Check Foundation and host of the “Take a Pain Check” podcast, available at www.takeapaincheck.com.

with the goal of empowering listeners. To date, more than 60 guests have been featured and have discussed their health journeys, life with chronic illness, advocacy, school, relationships, successes, and challenges. The podcast is widely available on a number of platforms including YouTube, Spotify, Apple, Google Podcasts, and iHeartRadio. In October 2021, I created the Take a Pain Check Foundation, a not-for-profit organization with the mission of forming a safe and inclusive community and creating awareness, as well as supporting others through connection and content creation on social media. To spread more awareness, I have been featured on the Canadian Broadcasting Corporation (CBC) Ottawa Morning radio show, as well as releasing a documentary about community support and friendship in relation to chronic illness. I have also shared my story with the York Region newsletter.

The podcast has grown into a community of approximately 2000-plus guests, ambassadors, health care professionals, volunteers, listeners, and followers. The Take a Pain Check platform has expanded to Instagram, Twitter, TikTok and Facebook. We host bi-weekly podcasts, run ambassador programs for health professionals and youth, pilot rheumatic disease-related events, feature stories on our blog platform and lead monthly Joint Chat Rheum hangouts. My overall goal is to continue to give and be a voice, as well as support and connect those living with chronic illnesses for years to come.

Natasha Trehan
Founder, Take a Pain Check Foundation
Founder and Host, “Take a Pain Check” podcast
Undergraduate student, Biomedical Science
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AWARDS, APPOINTMENTS, ACCOLADES



Dr. Philip Baer
CRA Master Award

Dr. Philip Baer received a CRA Master Award at the 2023 Canadian Rheumatology Association (CRA) Annual Scientific Meeting (ASM). This is a lifetime achievement award bestowed upon members aged 65 and older who have made outstanding contributions to the field of rheumatology. Dr. Baer is the Editor-in-Chief of the Journal of the CRA, Vice-President of the Board of the Journal of Rheumatology, Past-President of the Ontario Rheumatology Association, and a former Chair of the Section on Rheumatology of the Ontario Medical Association. He has been the showrunner for RheumJeopardy at the CRA ASM since 2016. For over 35 years, Dr. Baer has practiced as a community rheumatologist in Scarborough, a diverse multicultural community with a high burden of rheumatic diseases.



Dr. Heather McDonald-Blumer
Lindy Fraser Award

Through the Lindy Fraser Award, Osteoporosis Canada recognizes one individual annually, who has made an outstanding contribution to the field of osteoporosis research and/or education in Canada. The 2022 recipient is Dr. Heather McDonald-Blumer. Heather is known for her clinical expertise in the field of osteoporosis and as a highly recognized teacher and educator in the field. She has served on the Osteoporosis Canada Executive and has been Chair of the Guidelines Committee for the past 6 years, including chairing the Conflict-of-Interest Oversight Committee during the current guideline development process. Heather's contributions have had meaningful and significant impact nationally for Osteoporosis Canada and the osteoporosis community in Canada.



Dr. Jane Purvis

*Appointed Co-Chair of the Ontario Medical Association
Physician Services Committee (PSC)*

Dr. Jane Purvis was appointed the Ontario Medical Association's Co-Chair on the Physician Services Committee (PSC) in December 2022. The Physician Services Committee (PSC) provides a broad and structured process for regular liaison and communication between the Ministry of Health and the OMA, both to implement the 2021 Physician Services Agreement and also to consult on broad health-system transformation and policy initiatives involving Ontario physicians. Dr. Purvis is a Past President of the Ontario Rheumatology Association (ORA) and is the ORA Government Affairs Committee lead.



Dr. Alan Rosenberg

Distinguished Professor Award

Dr. Alan Rosenberg has been designated a University of Saskatchewan Distinguished Professor. This honorary title is an award that celebrates exceptional achievement in research, scholarly, or artistic work by University of Saskatchewan faculty. Dr. Rosenberg is considered worthy of this prestigious accolade based on his dedicated and numerous contributions to children's health, particularly contributions to advancing the care and knowledge of children afflicted with rheumatic diseases. The award also reflects Dr. Rosenberg's commitment to promoting and facilitating transdisciplinary collaborations and his dedication to mentoring the next generations of care providers and scholars.

AWARDS, APPOINTMENTS, AND ACCOLADES

The *CRAJ* would like to recognize the contributions of its readers to the medical field and their local communities. To have any such awards, appointments, or accolades announced in an upcoming issue, please send recipient names, pertinent details, and a brief account of these honours to JyotiP@sta.ca. Picture submissions are greatly encouraged.

How to Manage Retroperitoneal Fibrosis?

By Vandana Ahluwalia, MD, FRCPC; Luke Y. Chen, MD, FRCPC, MMed; and Mollie Carruthers, MD, FRCPC

Patient Case:

A 42-year-old man of Iranian descent presented originally with peri-umbilical discomfort. He had a computed tomography (CT) scan in Iran showing soft tissue attenuation surrounding the aorta from the infrarenal vessels to the common iliac bifurcation. This mass measured 5.7 cm x 3.0 cm x 5.9 cm. He received a course of prednisone empirically but, when he was completely weaned off steroids, his mass recurred. He underwent a CT-guided biopsy which showed chronic inflammation enriched with lymphocytes, plasma cells and eosinophils, consistent with retroperitoneal fibrosis. He was restarted on prednisone and then placed on mycophenolate which he continued taking at presentation to us.

His labs in Canada showed normal kidney function, with a creatinine of 81 $\mu\text{mol/L}$ (normal 60-155 $\mu\text{mol/L}$) and an estimated glomerular filtration rate of 103 ml/min (normal is >59 ml/min). His complete blood count, electrolytes, liver enzymes, and urinalysis were normal. His C-reactive protein (CRP) was elevated at 19.1 mg/L (normal <3.1 mg/L). His total protein was elevated at 84 g/L (normal 62-80 g/L). His IgG4 level was normal at 0.719 gram/L (normal 0.052-1.25 g/L).

The patient was referred for recommendations on the diagnosis and management of his retroperitoneal fibrosis.

Introduction

Retroperitoneal fibrosis (RPF) was first described by John Ormond, an American urologist in 1948.¹ He described it as sclerotic tissue in the retroperitoneum, commonly peri-aortic or peri-iliac, and encasing adjacent structures. Common presenting symptoms include abdominal, back and/or flank pain along with constitutional symptoms.² Patients may also present with acute renal failure due to ureteric obstruction, with retroperitoneal fibrosis found on abdominal/pelvis CT scanning. Peripheral edema may also be present due to compression of the iliac veins in the pelvis.³

RPF is a rare disease; for example, a Dutch study reported an incidence of 1.3/100,000.² There is a male predominance, and the median age of onset is 64 years old.² Patients were historically managed by urology with serial monitoring for hydronephrosis and serial ureteral stenting.³

A definition of RPF by Scheel et al. has been proposed that is not reliant on pathology. This includes: 1) identification by computed tomography (CT) or magnetic resonance imaging (MRI) of a soft-tissue density surrounding the infrarenal or iliac vessels; 2) absence of aneurysmal dilation of the infrarenal aorta; 3) absence of an intra-abdominal or pelvic mass; 4) lack of suspicion of malignancy from history and physical

examination; and 5) negative age-appropriate cancer screening.⁴ A radiographic-focused definition is important but does not precisely address the etiology of RPF, as management differs depending on the underlying cause. The pattern of aortic involvement, ureteric involvement, presence of lymph nodes or extension into the pelvic wall are not predictive radiographically of the underlying disease.⁵

What Are the Causes of RPF?

The pathogenesis of RPF is not known.⁶ However, when pathology is obtained from surgical or CT-guided biopsies, certain patterns emerge. Unfortunately, there have been no prospective analysis of biopsy results in retroperitoneal fibrosis. There is a high prevalence of both idiopathic and IgG4-related RPF in cases of RPF reported.⁵ In Khosroshahi's study, any patients who carried a prior diagnosis of malignancy were excluded. This fits with the literature in which the association or causal relationship of RPF and malignancy is hard to quantify.⁶ It is safe to say that IgG4-related disease is the cause of RPF 30-57% of the time.⁶ Determining whether the patient has IgG4-related disease may represent one of the most important considerations, as it is a systemic disease that may progress over time.

Table 1

Causes of Retroperitoneal Fibrosis

Immune-mediated

- Erdheim Chester disease
- Giant cell arteritis
- Granulomatosis with polyangiitis
- Idiopathic retroperitoneal fibrosis
- IgG4-related retroperitoneal fibrosis
- Sarcoidosis

Infection

- Actinomyces
- Mycobacterium

Malignant

- Inflammatory myofibroblastic tumor
- Lymphoma
- Metastatic carcinoma
- Plasmacytoma
- Sarcoma

Contributors to this list include the following experts:
Drs. Luke Chen, Emmanuel Della Torre, Arezou Khosroshahi,
John H. Stone, and Zachary Wallace

There have been associations proposed between RPF and other conditions such as atherosclerosis, certain medications, and connective tissue disease.³ In cases where the tissue clearly shows one of these conditions, then one can make a case for causality. This occurs with lymphoma, for example, where the retroperitoneal soft tissue infiltration shows B-lymphocyte clonal proliferation.⁷ Similarly, when the adventitia of the aorta shows granulomatous infiltration and antineutrophil cytoplasmic antibodies are positive, this is consistent with granulomatosis with polyangiitis.⁸ The list in Table 1 represents a more tailored differential diagnosis for RPF based on histopathologic evidence and expert opinion.

What Is the Appropriate Work-up of RPF?

Due to the high prevalence of IgG4-related disease with retroperitoneal fibrosis, a full clinical work up for sys-

temic IgG4-related disease makes sense (Table 2). The systemic nature of IgG4-related disease makes pattern recognition difficult when making a clinical diagnosis. Similarly, the IgG subclasses are an unreliable biomarker for diagnosis, with a specificity of 90% and sensitivity of 60% in one single centre study.⁹ The typical pattern of IgG4-related disease has been defined in recent American College of Rheumatology (ACR)/European Alliance of Associations for Rheumatology (EULAR) classification criteria.¹⁰ However, these classification criteria remain heavily reliant on histopathology and, therefore, most cases of IgG4-related disease require biopsy confirmation.¹¹ IgG4-related RPF is defined by storiform fibrosis and enrichment of IgG4-positive plasma cells with a IgG4/IgG ratio of >40%. By contrast, idiopathic RPF shows lymphoid follicles, extensive non-storiform fibrosis and a low IgG4/IgG ratio. The idiopathic RPF patients also have no extra-abdominal involvement.

In RPF, as in IgG4-related disease, a CT-guided or surgical biopsy is often necessary. If there is another organ site that is suggestive of IgG4-related disease, such as a submandibular gland, then the more easily accessed organ would be biopsied preferentially. Given the various causes of RPF listed in Table 1, management would be very different, depending on whether an immune-mediated condition, malignancy or infection is present.

The index patient was assessed in clinic for IgG4-related disease. He was asymptomatic at that time. His physical exam was notable for bilateral submandibular swelling. On CT scan of his neck, chest, abdomen, and pelvis he was found to have bilateral submandibular gland enlargement, and bilateral mediastinal and hilar lymphadenopathy. The RPF mass had decreased in size and now measured 5.1 cm x 2.7 cm x 5.2 cm. Figure 1 shows the characteristic axial view of RPF showing soft tissue encasement of the abdominal aorta at the level of the renal vessels. Histopathology slides of the retroperitoneal mass that he brought from Iran were reviewed at the British Columbia Cancer Agency. The pathology was found to be diagnostic of IgG4-related disease, notably with lymphoplasmacytic infiltration, storiform fibrosis and obliterative phlebitis with an IgG4/IgG ratio of >40%. This patient was diagnosed as having IgG4-related disease after this biopsy review.

Table 2

IgG4-related Disease Manifestations

Organ Manifestation	Symptoms	Physical Exam Findings	Imaging
Pachymeningitis	Headaches Focal neurologic deficit	Abnormal neurologic exam	MRI enhancement of the pachymeninges
Orbital Pseudotumor	Visual changes Eyelid swelling New eye protrusion	Extraocular muscle palsies Enlarged lacrimal glands Proptosis	Extraocular muscle myositis Dacryoadenitis Pseudotumor
Sialadenitis	Sicca symptoms Cheek swelling	Submandibular enlargement Parotid enlargement	Glandular enlargement Glandular enlargement
Riedel's thyroiditis	Neck swelling	Goiter	Diffuse enlargement of the thyroid gland
Pulmonary inflammatory pseudotumor	Cough Shortness of breath	Normal lung exam Decreased breath sounds at site of mass	Diffuse pulmonary nodules Pulmonary mass
Pericarditis	Asymptomatic Chest Pain	Pulsus paradoxus (rare) Friction Rub	Pericardial effusion Pericardial thickening
Autoimmune pancreatitis	Nausea and vomiting Right upper quadrant abdominal pain Pancreatic insufficiency	Epigastric tenderness Right upper quadrant tenderness Jaundice	Pancreatic mass especially at pancreatic head Diffuse pancreatic swelling "sausage-shaped pancreas" ERCP* shows stricture(s) of the pancreatic duct Pancreatic atrophy
Sclerosing cholangitis	Pruritis Jaundice	Hepatomegaly	ERCP shows "beading" of the intra and extrahepatic ducts Dilated intra and extrahepatic ducts
Tubulointerstitial Nephritis	Constitutional symptoms Oliguria	Peripheral edema	Multiple kidney opacities
Retroperitoneal Fibrosis	Nausea and vomiting Constitutional symptoms Flank/back/abdominal pain	Abdominal mass Abdominal or femoral bruits Peripheral edema	Peri-aortic soft tissue infiltration
Sclerosing mesenteritis	Nausea and vomiting Abdominal pain	Diffuse or focal abdominal tenderness Palpable abdominal mass(es)	Peritoneal mass or masses Diffuse peritoneal thickening
Lymphadenopathy	Often associated with constitutional symptoms Pain from lymph node swelling	Lymphadenopathy ranging from mild to massive in any lymph node chain commonly cervical, axillary, and inguinal	Lymphadenopathy commonly seen in the following chains: cervical, mediastinal, hilar, axillary, abdominal, retroperitoneal, pelvic, and inguinal
Rash	Asymptomatic	Flesh coloured papules on face and upper chest	None

*ERCP: Endoscopic Retrograde Cholangiopancreatography

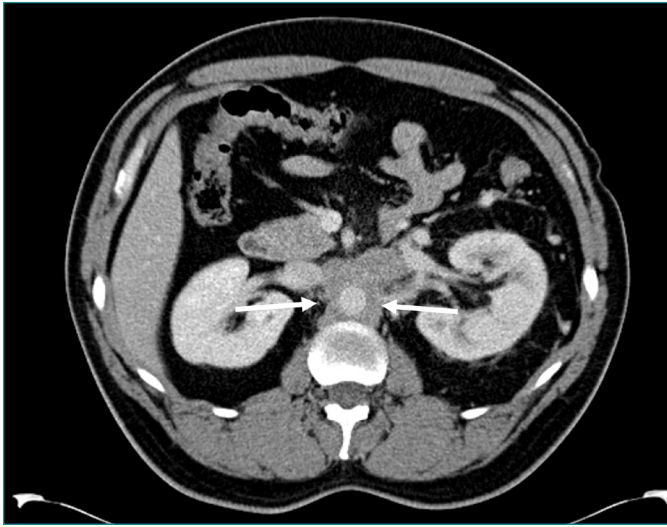


Figure 1: Axial CT with contrast showing maximal 2.5 cm soft tissue thickening encasing the aorta indicated between 2 white arrows.

What is the Appropriate Management of IgG4-related RPF?

The proper treatment of IgG4-related disease is emerging. The mainstay of therapy is prednisone.¹² Other options for IgG4-related disease include disease modifying anti-rheumatic drugs, of which mycophenolate is the most favoured.^{13,14} Rituximab has been observed to be effective in both IgG4-related disease and idiopathic retroperitoneal fibrosis.^{15,16,17} Ongoing studies are being done with respect to newer agents specifically for IgG4-related disease.

The index patient was refractory to both prednisone and mycophenolate. He was commenced on rituximab, but after one course of treatment, he was lost to follow up.

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Tribute to Dr. Denys Ford

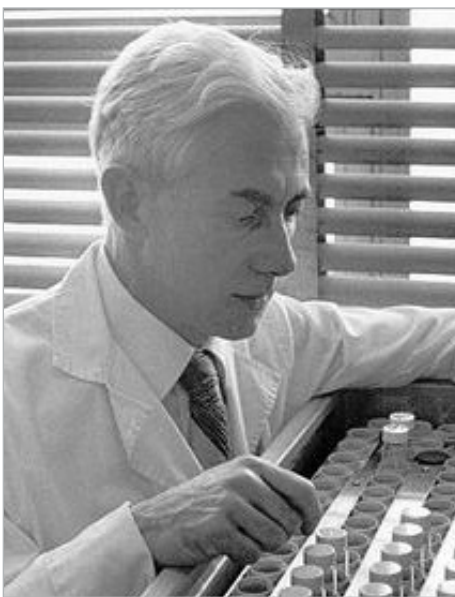
By Barry Koehler, MD, FRCPC; and Graham Reid, MB, ChB, FRCPC

Denys Ford had a long and full life. His determined commitment to research in rheumatology spanned over 50 years at the University of British Columbia (UBC) in Vancouver. Along with Dr. Harold Robinson and Mary Pack, he was a pioneer of rheumatology in British Columbia.

Denys was born near Stoke-on-Trent, England. He spent his initial two years of medical school at Cambridge, completing his BA in Medical Sciences and obtaining a first. In 1944, on the recommendation of his supervisor, he attended Columbia University on a Rockefeller Student Fellowship, where he completed his third and fourth clinical years. (His trans-Atlantic passage was on the Queen Mary, known for her ability to avoid submarines.) He then spent four months at McGill University as an intern, after which he returned to England to spend three years as a house physician, his last rotation being in Rehabilitation at London Hospital. In 1949, his head of service, Dr. W.S. Tegner, arranged for him to attend New York University on a fellowship to study cortisone, along with future rheumatology greats Currier McEwen, Morris Ziff and Joseph Bunim. He then returned to London Hospital as a Registrar, where his lifelong interest in the connection of infection and arthritis continued; his MD thesis was a study on patients with arthritis and urethritis, then termed "venereal arthritis."

In 1953, he accepted a Research Fellowship in Clinical Investigation at Vancouver General Hospital and continued his studies in venereally-acquired arthritis, including the association of non-gonococcal urethritis and arthritis, and of arthritis following enteric infection. (His first lab was located in the basement of his rooming house.)

In 1960, Denys was appointed the first Head of Rheumatology at the University of British Columbia, a position he occupied until 1983. He continued to pursue his interest in the possible role of an underlying microbial origin for the overlying autoimmune mechanisms in most cases of rheumatoid arthritis. This included a number of publications on Rubella-associated arthritis. His lab operated until 1991. His scientific publications totaled 81, as well as 8 book chapters. His last paper was published in 2003



1923-2022

at age 80. His last presentation to the UBC Division of Rheumatology educational rounds was in 2016 at age 93, when he summarized his research over the years.

It was a frustration to him that other centres reported failure to reproduce his findings of synovial fluid lymphocyte reactivity to microbial antigenic stimulation. However, Denys always processed the synovial fluid on reception in his lab, no matter the time of day. Investigators in other centres elected to freeze the specimens for more convenient processing, failing to recognize that freezing the specimens altered lymphocyte reactivity.

Some of his other publications addressed his concerns regarding government funding and, hence, control of the delivery and the costs of health care. Well into his eighties, he had continuing correspondence with politicians, members of medical organizations, and of the press. He lived to see how prescient his concerns were.

In 1993, he was named a Master of the American College of Rheumatology and, in 2000, Senior Member of the Canadian Medical Association.

Denys leaves his wife, Marguerite, to whom he was married for 68 years, four children, seven grandchildren, and five great-grandchildren.

On retirement, he volunteered many hours in his community as a Meals-on-Wheels driver and with the Disabled Sailing Association. His energy and enthusiasm were evident throughout all aspects of his daily activities. He continued playing tennis regularly into his eighties and was a local eccentric legend.

His kind, generous and charitable persona is attested to by his trainees (from the first, Manfred Harth, to the last, Graham Reid), by his professional colleagues, and by his community.

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Clinical Professor Emeritus, Division of Rheumatology,
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*Graham Reid, MB, ChB, FRCPC
Rheumatologist (retired), Vancouver, British Columbia*



Update from Vancouver Island

By Kimberly Northcott, BSc (Hons), MD, FRCPC

The Vancouver Island Rheumatology community continues to evolve with well-deserved acknowledgments and announcements. I would like to recognize Dr. Milton Baker who, after 40 years of rheumatology practice, has now retired to the love of his garden, cat, and travel. However, we are far from left with a void. I have the privilege to announce the addition of Dr. Leah Ellingwood, Dr. Julia Tan, and Dr. Drew Bowie, all exceptional graduates of the University of British Columbia Fellowship program who have joined our South Island team.

Further, Dr. Xenia Gukova, trained at the University of Calgary, will be joining our Victoria group in the spring of 2023. The Nanaimo region is excited to welcome the arrival of Dr. Ashley Yip, following completion of her fellowship at the University of Alberta. Vancouver Island will therefore boast a total of 10 adult rheumatologists and one pediatric rheumatologist in “The Garden City”, and four adult rheumatologists in “The Harbour City”. We continue to collaborate closely as an island group through the Vancouver Island Rheumatology Association

celebrating acquisition of knowledge, birthdays, and Dr. Paul Davis’ knee replacement!



The Vancouver Island Rheumatology Association at their meeting on October 14th, 2022.

Kimberly Northcott, BSc (Hons), MD, FRCPC
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 Clinical Assistant Professor,
 University of British Columbia
 Vancouver Island Rheumatology
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Injector not shown at actual size.



ACR
20

BIOLOGIC-NAÏVE PATIENTS WITH ACTIVE PsA TREATED WITH TREMFYA® 100 mg q8w achieved significant improvements in ACR20 response vs. placebo at Week 24 in DISCOVER-2^{1,3*††}

- **ACR20** (primary endpoint): **64%** (159/248) (95% CI: 58, 70) vs. **33%** (81/246) (95% CI: 27, 39) (**31.2% difference vs. placebo** [95% CI: 22.9, 39.5] $p < 0.0001^{§1}$)

ACR
50

DISCOVER-2: LONG-TERM CLINICAL EFFICACY DATA THROUGH TWO YEARS^{4}**

Observed ACR50 response at Week 100 in the TREMFYA® 100 mg q8w treatment group was 61% (n=224)⁴

It should be noted that the duration of the data presented here is beyond the duration of the data in the Product Monograph. This was an uncontrolled (no placebo) extension where investigators and patients were double-blinded to dosing regimen and patients were actively on treatment with TREMFYA®. Response rates derived using observed data.^{4**}

Indication not previously discussed:

TREMFYA®/TREMFYA ONE-PRESS® is also indicated for the treatment of adult patients with moderate-to-severe plaque psoriasis who are candidates for systemic therapy or phototherapy.

Relevant warnings and precautions:

- Do not initiate treatment in patients with any clinically important active infections until the infection resolves or is adequately treated
- Discontinue treatment if patient develops a serious infection or is not responding to standard therapy for infection
- Evaluate patients for tuberculosis infection prior to therapy and monitor for active tuberculosis during and after treatment
- Consider completion of all immunizations prior to treatment
- Concurrent use with live vaccines is not recommended
- Discontinue treatment in cases of serious hypersensitivity reactions, including anaphylaxis, urticaria, and dyspnea, and institute appropriate therapy
- Women of childbearing potential should use adequate contraception
- Use during pregnancy only if clearly needed
- The benefits of breastfeeding should be considered along with the mother's clinical needs

- Effect on human fertility has not been evaluated
- Safety and efficacy in pediatric patients have not been evaluated
- Data in patients ≥ 65 years of age are limited

For more information:

Please consult the Product Monograph at www.janssen.com/canada/our-medicines for important information relating to adverse reactions, drug interactions, and dosing and administration that has not been discussed in this piece.

The Product Monograph is also available by calling 1-800-567-3331.

PsA=psoriatic arthritis; q8w=every 8 weeks; ACR20=American College of Rheumatology 20% improvement from baseline; CI=confidence interval; ACR50=American College of Rheumatology 50% improvement from baseline.

* DISCOVER-2: Multicentre, double-blind, randomized, placebo-controlled phase 3 study in biologic-naïve adults with active psoriatic arthritis (PsA) (≥ 5 swollen joints, ≥ 5 tender joints, and a C-reactive protein [CRP] level of ≥ 0.6 mg/dL) who had inadequate response to standard therapies (e.g., conventional disease-modifying antirheumatic drugs [cDMARDs], apremilast, or nonsteroidal anti-inflammatory drugs [NSAIDs]), a diagnosis of PsA for ≥ 6 months, and a median duration of PsA of 4 years at baseline. Patients were randomly assigned to receive subcutaneous injections of TREMFYA® 100 mg at Weeks 0, 4, then q8w or placebo. Primary

endpoint was the percentage of patients achieving an ACR20 response at Week 24.¹

- † Patients with $< 5\%$ improvement from baseline in both tender and swollen joint counts at Week 16 were qualified for early escape and were permitted to initiate or increase the dose of concomitant medications, including NSAIDs, oral corticosteroid, and cDMARD, and remained on the randomized study treatment. At Week 16, 15.4% and 5.2% of patients in the placebo and TREMFYA® 100 mg q8w groups, respectively, met early escape criteria.¹
- ‡ Patients with missing data at Week 24 were imputed as non-responders. Patients who initiated or increased the dose of cDMARD or oral corticosteroids over baseline, discontinued study or study medication, or initiated protocol-prohibited medications/therapies for PsA prior to Week 24 were considered as treatment failures and non-responders. At Week 24, 6.9% and 4.8% of patients in the placebo and TREMFYA® 100 mg q8w groups met treatment failure criteria.¹

§ Treatment differences, 95% CIs and p -values were based on Cochran-Mantel-Haenszel test stratified by baseline non-biologic cDMARD and prior CRP (< 2.0 , ≥ 2.0 mg/dL).¹

¶ Adjusted and type I error-controlled.¹

** The trial included a 100-week treatment phase (placebo-controlled Weeks 0–24, active treatment Weeks 24–100), and 12 weeks of safety follow-up (Weeks 100–112). Patients and investigators remained blinded with regard to dosing regimen after Week 24. Efficacy was assessed through Week 100, and safety assessments continued through Week 112.⁴

References: 1. TREMFYA®/TREMFYA ONE-PRESS® (guselkumab injection) Product Monograph. Janssen Inc. November 8, 2022. 2. Data on file, Janssen Inc. September 13, 2022. 3. Mease PJ, Rahman R, Gottlieb AB, et al. Guselkumab in biologic-naïve patients with active psoriatic arthritis (DISCOVER-2): a double-blind, randomized, placebo-controlled phase 3 trial. Published online March 13, 2020 at: [https://doi.org/10.1016/S0140-6736\(20\)30263-4](https://doi.org/10.1016/S0140-6736(20)30263-4). 4. McInnes IB, Rahman P, Gottlieb AB, et al. Long-term efficacy and safety of guselkumab, a monoclonal antibody specific to the p19 subunit of interleukin-23, through two years: results from a phase III, randomized, double-blind, placebo-controlled study conducted in biologic-naïve patients with active psoriatic arthritis. *Arthritis Rheumatol* 2022;74(3):475–485.



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