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Top Ten Things Rheumatologists Should (And Might Not) Know About...

• Reasons to Refer to a Physiatrist
Affinity

By Philip A. Baer, MDCM, FRCPC, FACR

“Getting to know you, getting to feel free and easy. When I am with you, getting to know what to say.”

- Rodgers and Hammerstein, “The King and I”; sung by Gertrude Lawrence, 1951.

Everyone is equal but, with apologies to George Orwell, some patients are more equal than others. I do not set out to give preferential treatment to any particular patient, but some strike a chord of affinity. Detachment is the clinical ideal, supposedly. The dispassionate physician-scientist cannot let his or her emotions interfere with his or her judgement. That is why the regulatory colleges do not favour physicians treating their own family members, except in case of emergency. A very reasonable stance, in my opinion.

In Ontario, where I practice, the College of Physicians and Surgeons (CPSO) states: “Treat all patients equally—function compassionately and free of preferences for some patients.” The one-on-one interaction in the clinic, however, is not so dry and rational. The patient brings a lot of emotions to the encounter: fear, hope, anger, and sadness, among others. The physician is not a blank slate either. Making a connection with a patient in a brief clinical encounter is very important in forging a therapeutic alliance, which determines in large measure the ultimate success of a patient’s therapy.

There is only so much discussion of neutral topics one can tolerate. The weather is an overrated subject of conversation. Even after the hockey lockout, no one wants to discuss the Maple Leafs, and most of Toronto’s sports teams have been so bad for so long that even patients who come in wearing sports jerseys do not really want to dwell on them. Religion and politics are taboo, so I look for something else in a patient’s history that we can find to talk about, if only briefly.

I find certain patients I have a natural affinity with. The reasons change over time, dependent on my own journey through life. Currently, my twin sons are finishing their university studies. Therefore, young patients of my children’s age are of special interest to me. Many are university students, some at the same institutions my children attend. Knowing the names of university residences they might have lived in, or some trivia about the campus, is a very useful icebreaker. The same connection has helped me with middle-aged patients whose children are roughly the same age as mine, and with parents of twins.

Generally, I am not keen to take on patients who have already seen one or several rheumatologists. I have no magic answers unknown to my colleagues. However, when I received a referral to see a patient who had already seen three other rheumatologists, I accepted immediately. Why? Because I noticed that he was a co-op student at a university one of my sons attends. He moved every four months, and required a new rheumatologist in each city to look after his seronegative arthritis. By the time I saw him, he was in remission and I had the pleasant task of weaning his therapy down. This past summer, I watched him graduate at the same convocation as my son with great delight.

In an article on self-disclosure by physicians to patients,1 the CPSO posed the question: “The mother of a young patient asks if you have any children. How do you respond?” Suggested behaviour: “It’s possible to avoid the answer. But there’s no harm in simply replying: ‘Yes, and I know what you’re going through.’” In my office, with photos of my children all over the place, it is not possible to avoid the answer, and I have never found it to be an issue.

My final thought on the subject was shaped by another recent article,2 which concluded that “we take the pain of patients we do not like less seriously than the pain of patients we like.” My take: find something to like about each patient, often through some shared experience in life, and you will enjoy your days in the clinic more.

References:

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Mission Statement. The mission of the CRAJ is to encourage discourse among the Canadian rheumatology community for the exchange of opinions and information.

The editorial board has complete independence in reviewing the articles appearing in this publication and is responsible for their accuracy. The advertisers exert no influence on the selection or the content of material published.
Dr. Rick Adachi is a recipient of the Queen Elizabeth II Diamond Jubilee Medal for his dedicated service to Osteoporosis Canada. He has served as a lead investigator for the Canadian Multicentre Osteoporosis Study, a mentor to junior investigators, and a volunteer for Osteoporosis Canada.

Dr. Adachi is a Past-President of Osteoporosis Canada and has served on their scientific advisory board. He has offered advice and leadership in the development of practice guidelines for the treatment of osteoporosis in Canada, and has been an international leader in the development of treatment guidelines for glucocorticoid-induced osteoporosis.

Commenting on his recent award to the CRAJ, Dr. Rahman noted, “I was honoured and humbled to have been nominated by the CRA for a Queen’s Jubilee Medal, and equally surprised and grateful to have received it. As I reflect on the award, numerous colleagues come to mind who are more deserving, thus it is with humility that I accept this award. Being a rheumatologist, educator, researcher, administrator (Associate Dean of Research), and parent, leaves you not only exhausted but also with a sense that nothing is done really well. I am constantly thinking that more could have been done for my patients, students, or research studies, and I now must settle for ‘good enough’ rather than ‘well done’, after a day’s work. I sometimes worry that I have spread myself too thin. I believe that trying my best to fulfill multiple roles may be the reason I was considered for this award, and it is reassuring to know that my efforts are appreciated.”

Dr. Alan Rosenberg graduated from the University of Saskatchewan’s College of Medicine. Following training in pediatrics at Toronto’s Hospital for Sick Children and the Winnipeg Children’s Hospital he did subspecialty training in pediatric rheumatology at the University of British Columbia (UBC). He returned to Saskatchewan in 1981 to establish the province’s first program in pediatric rheumatology. As the only pediatric rheumatologist in Saskatchewan, Dr. Rosenberg provided care for children in the province with rheumatic diseases. He has maintained an active research program as the director of the Pediatric Rheumatic Disease Research Laboratory.

Dr. Rosenberg was a former Head of the Department of Pediatrics and is the current Director of Pediatric Research at the University of Saskatchewan. His research priorities have included studies of childhood rheumatic diseases. He leads studies that aim to show how genetics, lifestyle, and environment interact to influence the occurrence and outcomes of disease.

Toronto Western Research Institute (TWRI) Senior Scientist Dr. Murray Urowitz has been awarded a Queen Elizabeth Diamond Jubilee Medal. Dr. Urowitz was nominated by the CRA in recognition of his longstanding contributions to lupus research and his work in the field of rheumatology.

The medal, created to mark 60 years of The Queen’s reign, is given to Canadians in honour of their contributions to society and their achievements that have brought prestige to Canada. Dr. Urowitz was presented with the medal at the Annual Scientific Meeting (ASM) of the CRA on February 15, 2013.

The Journal of the Canadian Rheumatology Association (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 katiao@sta.ca. Picture submissions are greatly encouraged.
The burden of rheumatic disease in our First Nations populations is well recognized. For example, rheumatoid arthritis (RA) has a prevalence of about 3% in Aboriginal populations, compared to 1% in Caucasian populations. In addition, the phenotype of the disease is different, with a peak in incidence approximately 10 years younger, higher prevalence of rheumatoid factor (RF), and a more destructive pattern affecting a different joint distribution from Caucasian patients. We also see more multi-case families emphasizing the potential different genetic and environmental factors in Aboriginal patients.

As part of its goal to explore appropriate models of health care delivery, the CRA has identified Aboriginal rheumatologic care as one of the major areas where greater understanding and change is vital to allow us to achieve our goal. We are also conducting a survey of all CRA members to allow us to get a picture of which communities are served by visiting specialists. We aim to identify and document some of the major gaps in care, and thus to develop hard data, without which it is impossible to move forward.

In the fall of 2012, the Section of Rheumatology at the University of Manitoba presented a workshop entitled “Rheumatoid Arthritis in First Nations: Defining the Road Toward Disease Prevention”. This was a forum for international experts to present data on disease prevalence and incidence, to discuss current concepts in the interaction of genetic and environmental risk factors for RA, and to explore opportunities for future research (please see write-up of this conference on page 14 of this issue of the CRAJ). The workshop also considered the experience of researchers working with First Nation communities and families. The next decade presents wonderful opportunities for better understanding the environmental and genetic associations of autoimmune diseases. However, the practical day-to-day issues of achieving early diagnosis and access to care remain, to my mind, the most important area where the CRA must aim to make a difference. Providing services to remote communities is occasionally frustrating but always rewarding, and I strongly recommend it to anybody who has the opportunity.

For those of us who work in remote communities there are a number of common themes across the country. Optimal care of RA includes a window of opportunity for treatment initiation and treatment to target; however, neither of these seems possible, or indeed currently relevant, in many communities, where the burden of joint disease is high, yet the barriers to effective care create almost overwhelming difficulties for the rheumatologist.

The reasons for this situation are multifactorial. In terms of care of patients with inflammatory joint disease there are delays at every step: delays in seeking care, in recognition of the correct diagnosis, and in the time taken to see a specialist. Even for those of us familiar with the Non-Insured Health Benefits (NIHB) Program eligibility process for treatment agent therapies, there is a strong perception that, by the time Aboriginal patients receive biologic therapy, their disease is further advanced than patients who have easier access to health services (albeit recognizing that patients in major cities also face many similar issues).

Health Canada’s NIHB Program provides coverage for benefit claims for a specified range of drugs and services, along with medical transportation for eligible First Nations and Inuit people. For many patients in these communities, the rheumatologist must apply for biologic agents through the NIHB Program. There are aspects of the NIHB approval process where streamlining and change would be beneficial (please see article on page 12). The CRA is currently working with the NIHB to identify and address these issues. For example, at present, pharmacies have the responsibility for informing the patient of approval or denial; based on recent discussions between NIHB and the CRA, the prescribing doctor can request to be informed of the decision if they indicate this on the NIHB Limited Use form. Moreover, NIHB has provided clarification to the CRA regarding the appeal process in which an appeal may be initiated by the patient or the patient’s representative, which may be their treating doctor. This helps to increase the role of the doctor as a patient advocate in this process. The current NIHB criteria for approval of biologics are currently being reviewed by the
Program. The CRA is working with the NIHB Program and hopes to provide expert input into this review process.

Even simple issues present challenges when providing services to remote communities; visits often involve combining airplane flights with boat or helicopter transport. Many of our patients have significant comorbidities which might influence our choice of therapy. A higher prevalence of tuberculosis (TB), and risk factors for infection, such as diabetes and renal failure, will cause concern to a rheumatologist who may only visit a community every few months, making disease-modifying antirheumatic drug (DMARD) and biologic therapy inherently less safe. Monitoring disease activity presents challenges to the specialist who probably will not have access to medical charts or electronic medical records (EMRs). Ensuring that monitoring takes place regularly, and that these results are seen, remains a problem that discourages use of potentially toxic drugs.

Further barriers to care include a culture of earlier parity and larger families, smoking, alcohol consumption, missed appointments (secondary to communication issues, weather, and psychosocial challenges) and adherence to therapy. Why might Aboriginal patients present later? There may be a culture of accepting and tolerating pain and disability with a reluctance to complain or seek help. Access to medical care is limited. Family doctors in remote locales have a relatively high turnover rate, and their skills and confidence in managing inflammatory joint disease are highly variable. Wait times for specialist opinions are long. Patients do not always have the opportunity to fly to the specialist, and there may be social barriers making a trip lasting three to four days undesirable. There are a number of potential infrastructural solutions which need to be explored. Perhaps trained rheumatology nurses are a way forward; however, at present nurses are stretched and focused on other important diseases (e.g., diabetes, hypertension, renal disease). We need to work to raise the profile of arthritis as a disease deserving of more attention.

We need to understand our patients. It is naïve to imagine that we can use the same models of care as we use in other populations, and we have to integrate treatment approaches with the patients’ own beliefs in terms of healthcare. This requires the rheumatologist to develop a knowledge and respect for the communities, and an understanding of the history that might influence the ability to develop a therapeutic relationship. There are a number of reasons for Aboriginal populations to be guarded in their relationships with doctors from other cultures; it remains our duty to understand some of their beliefs about medication and healthcare. Change works best when it draws on the combined strengths of tradition and community. For many non-Aboriginal physicians, knowledge of these beliefs is lacking, even down to understanding terms such as Nation, Band, Tribal Council, etc. Real change will involve engagement of all stakeholders within a community, not only the patients.

Patient self-management programs need to be adapted to local communities. There is not a single solution for the First Nations population, but rather a manner of approaching health that recognizes the challenges, and which embraces and respects the spiritual, physical, mental, and emotional culture and beliefs of the population.

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Target to Treat: Thoughts on Improving Rheumatic Disease Outcomes in Aboriginal Populations Through Access-to-Care Initiatives

By Cheryl Barnabe, MD, FRCPC, MSc

Arthritis is the most prevalent chronic condition in Aboriginal populations, and is associated with increased rates of disability relative to the general population; yet arthritis is not addressed with a national strategy to support awareness or self-management from an Indigenous perspective. Discrepancies in arthritis-care access and outcomes between Aboriginal and Caucasian patients were readily apparent in the cities I have trained and now work in. Dr. Christine Peschken has documented increased disease severity in the Cree and Ojibway population of Manitoba. The same appears to be true in my experience in Alberta, which has a diverse population of tribal ancestries (Blackfoot, Stoney, Nakoda, Dene, and Cree) and the only recognized Metis settlements in Canada. I have observed ludicrous situations such as bands paying for patient transportation to get gold shots in a primary-care setting, but not approving travelling the same distance for a rheumatology appointment or biologic treatment. These experiences confirmed the need for enhanced access and delivery of rheumatology services in southern Alberta, with the added bonus that the communities and health services leadership of the Treaty 7 Nations also wanted better arthritis outcomes for their people.

At the time I moved to Calgary in 2006, Dr. Liam Martin and Dr. Sharon LeClercq serviced communities two to three hours away from the city with tele-rheumatology. I pursued “commutable” on-site clinic options, and was introduced to the leadership at the Siksika Nation, a Blackfoot community of 3,700 people located 100 kms east of Calgary. Assisted by Dr. LeClercq and Dr. Dianne Mosher, a monthly clinic for established rheumatology patients from that nation was started in 2010. Shortly thereafter, we received funding from the Canadian Initiative for Outcomes in Rheumatology Care (CIORA) to implement an arthritis screening program to improve early arthritis detection and treatment. This program enabled nearly 200 community members to be assessed, diagnosed, and treated for a variety of musculoskeletal conditions without needing a referral through primary care. During the program, 27 new cases of inflammatory arthritis (IA) were diagnosed, and over 20 rheumatology patients who had been lost to follow-up were re-engaged in arthritis care. Building on epidemiologic research into disease prevalence and health services utilization funded by the Canadian Institutes of Health Research (CIHR), and a qualitative study to understand facilitators and barriers to care funded by CIORA and Alberta Innovates–Health Solutions, we are developing a picture of the current burden of arthritis in the Aboriginal population of Alberta and how health services are being accessed. The outreach sites I work at have expanded to include the urban Aboriginal Health Centre and the Elbow River Healing Lodge, while Dr. Mosher conducts clinics at the Morley reserve.

The issues surrounding access to care are complex in the Aboriginal community. Particular to arthritis, awareness of
the disease is one aspect: it is so common in Aboriginal communities that it is seen as a normal phenomenon and not necessarily as a modifiable disease with severe functional consequences. There are widely-held beliefs regarding disease pathogenesis, specifically related to residential schools and generational trauma from the colonialization process. These beliefs need to be heard, acknowledged, and worked through with the patients. Accessing care is difficult without consistent primary-care provision, or when child and elder care or transportation is not otherwise available to attend appointments. Despite my diligent attempts to complete Limited Use (LU) forms for access to biologic therapies, they are still frequently left sitting somewhere along the fax line to Ottawa.

The other key issue is trust within the community and health leadership for our intentions. I encourage readers of the CRAJ to read a new report by the Health Council of Canada, which explores some facets of this. A long-term and consistent commitment to providing care in the community is absolutely necessary. The connection with the community’s primary-care providers is critical; they are extremely motivated to understand rheumatology better, and will be managing medication side effects or disease flares when we are not on-site. I am constantly impressed with the dedication of the local care-providers and how they problem-solve creatively. Overall, it is extremely rewarding to work with others who are not only targeting access to care, but also achieving better health in the community.

References:

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My name is Joyce Greene, and I am a second-generation First Nation Lax Kw’alaams mother, living with severe rheumatoid arthritis (RA). My birth mother, uncle, two sisters, and two brothers all have lived with either RA or osteoarthritis (OA). I was diagnosed in 1993; all my joints, from my jaw to my toes, are affected.

To offer some background information, Lax-Kw’alaams (alternately known as Port Simpson) is an Indigenous village community on the northwestern coast of British Columbia. Lax-Kw’alaams is home to the Nine Tribes, which make up part of the Tsimshian nation. Our land is known as “place of the wild roses”; it was in Port Simpson that the Hudson’s Bay Company established a trading post in 1834. Historically, this was the first Aboriginal community in British Columbia to officially revert its English name back to its Aboriginal one, from Port Simpson to Lax Kw’alaams. Today, Lax Kw’alaams is the largest of the seven Tsimshian village communities in Canada, with a population of 3,219 members in 2009. The Allied Tsimshian Tribes Association represents the legal and political interests of the people of the Lax Kw’alaams to the provincial and federal governments.1,2

I am an Emeritus Member of The Consumer Advisory Council of the Canadian Arthritis Network (CAN), and acted as the Aboriginal Representative between 2004 and 2008.3 We recognized that arthritis research was greatly needed within the Aboriginal community. Collaborating with consumers, researchers across Canada and internationally, together we have started to identify the ongoing issues, and assess the needs of the Aboriginal arthritis community through research.

I was an Arthritis Consumer Advocate, Manitoba/Nunavut Division, for The Arthritis Society (IAS) between 1994 and 2005.4 I am also a retired member of Patient Partners in Arthritis, where I served from 1998 to 2008. This hands-on program demonstrated a standardized musculoskeletal exam to a variety of medical students and healthcare professionals, and showed first-hand the difficulties of living with RA. Presently, I am a member of numerous advisory boards, and participate in on-going arthritis research projects.5

Health in Aboriginal People

According to the 2006 Aboriginal Peoples Survey (APS),6 the most commonly reported chronic health conditions among Métis aged 15 years and older were arthritis/rheumatism (21%), followed by high blood pressure (16%) and asthma (14%).

- Arthritis is one of the most prevalent chronic diseases in all three Aboriginal populations: First Nations, both on- and off-reserve (19% and 18% respectively), Inuit (13%), and Métis (21%).
- The arthritis prevalence estimate for First Nations adults living on-reserve, First Nations adults living off-reserve, and Métis adults was 1.3 to 1.6 times higher than the national estimate for arthritis in the Canadian adult population, after adjusting for differences in the age distribution in these populations.
- The prevalence estimate of arthritis/rheumatism in the Inuit population was similar to the total Canadian population, after age standardization.
- In all three Aboriginal populations, the prevalence of arthritis was higher among women compared to men.
- Close to two-thirds of First Nations individuals living on- and off-reserve who reported arthritis were between 30 to 59 years of age (64% and 61%, respectively).

Improving RA Care for Aboriginal Peoples

RA runs rampant both on- and off-reserve. Research has shown that detecting arthritis as early as possible will impact the whole disease process and the costs involved.7-11 Access to the full range of RA treatments on public formularies is sub-standard compared to that of non-First Nations people.

What training incentives are there for First Nations physicians and allied health professionals to better deal
with early detection, diagnosis, and treatment? Existing research literature describes how moderate-to-severe RA needs to be diagnosed, and treatment initiated, within six weeks or almost certain permanent damage will be done to the joints and their supporting structures.

Musculoskeletal disease is the disease category with the highest cost due to illness, with particularly high indirect costs to society. Within this category, arthritis accounts for 53% of the direct costs and 29% of the indirect costs. The Canadian Institutes of Health Research (CIHR) spent $19 million on arthritis-related research in 2005-2006, representing $4.30 for every person with arthritis. By comparison, diabetes research received three times as much funding (or about $12.83 per person), while cancer research received 32 times as much funding (or about $138.60 per person). Although it is difficult to directly compare the burden and costs of diverse diseases, these findings warrant greater attention in funding and policy decisions.

Training nurses, nurse practitioners, occupational and physical therapists, as well as providing financial incentives for First Nations medical students to return to their villages to support and educate the nursing staff and community members would be a huge boon to the people. Educational awareness programs need to be created by the communities from the ground up, not the top down, to be able to utilize the communities’ first-hand knowledge, and develop better understanding about their unmet needs and requirements.

A National Aboriginal Arthritis Strategy needs to be implemented, using a multi-pronged approach from the communities across our country; efforts towards integrating awareness, education, and research, starting at the school level, can lead to knowledge transfer and exchange.

Healthcare, Personified

I am an urban aboriginal mother, and thus extremely fortunate to have access to my healthcare team, and support for my ever-changing needs met with usually only a phone-call. I have always believed that educating my family and myself, creating awareness about the first-hand effects of arthritis, would bring real change.

Over the past 20 years, I have experienced treatments through ongoing blood work, physiotherapy, and occupational therapy appointments. There have been numerous splints to support the swelling and inflammation of various joints, including ACL braces for my knees. I wore a brace on my neck for four months after my C1-2 surgery, without which I would have been paralyzed within six weeks. These issues are all due to the severity of my arthritis. As a result of my arthritic condition, I have:

- Had countless CT scans, X-rays, and MRI scans.
- Had home-care on a daily basis for six months prior to starting on a biologic agent study in 1999.
- Participated in that life-altering treatment-agent study for eight years, before treatment became ineffective.
- Been on my second biologic for the past four-and-a-half years.
- Been on ever-changing combination disease-modifying anti-rheumatic drug (DMARD) therapy over the past 20 years.
- Been hospitalized on numerous occasions, including having both hips replaced.

Prior to the treatment agent-study, my RA was completely out of control; I was unable to function without home-care, use of a wheelchair, and my family’s support and assistance. I will be having both my knees replaced simultaneously, in the summer of 2013.

My birth-mother was one of the first Aboriginal women in British Columbia to participate in a study in the 1960s involving methotrexate. She was incredibly proud to make a difference and help others. I have personally benefitted from using methotrexate in my combination therapy for almost 20 years. It is because of women like my birth-mother that real change happens. Even so many years later, there is no standardized holistic model of care to help First Nations peoples understand, accept and deal with their arthritis diagnosis. We can work together to change this.

Supporting Aboriginals with arthritis needs to become front and center of the discussion about healthcare.

Thank you.

Resources and Recommended Readings:
1. Lax Kw’alaams Band: First Nation Community of Lax Kw’alaams. www.laxkwalaams.ca
2. Lax Kw’alaams, British Columbia. en.wikipedia.org/wiki/Lax_Kw’alaams_British_Columbia
8. The Health Status of Aboriginal Peoples in Canada: Reflection, Realization, and Response. www.ucalgary.ca/1353117/The_Health_Status_of_Aboriginal_Peoples_in_Canada_Reflection_Resolution_and_Response
10. Arthritis Alliance of Canada. www.arthritisalliance.ca
12. Canadian Arthritis Funding Landscape Review, www.arthritisnetwork.ca/about_can/downloads/Arthritis%20Funding%20Final%20Final.pdf

Joyce Greene
The Non-Insured Health Benefits (NIHB) Program of Health Canada provides coverage for approximately 900,000 registered eligible First Nations and recognized Inuit clients, with a limited range of medically necessary health-related goods and services not provided through private or provincial/territorial health insurance plans. These benefits complement provincial and territorial healthcare programs, such as physician and hospital care, as well as other First Nations and Inuit community-based programs and services. Benefits include treatment agents, medical transportation, dental care, medical supplies and equipment, crisis intervention counselling, and vision care.

With the advice of the Canadian Drug Expert Committee (CDEC) and the NIHB Drugs and Therapeutics Advisory Committee (DTAC), eligible treatment-agent benefits have been identified and compiled in the NIHB Drug Benefit List (DBL). The CDEC is coordinated by the Common Drug Review as part of the Canadian Agency for Drugs and Technologies in Health (CADTH). They provide listing recommendations for new treatment agents and agents with new indications to federal, provincial, and territorial public drug plans (with the exception of Quebec). The DTAC includes practicing pharmacists and physicians, some of whom are First Nations. In their review of treatment agents, the CDEC and DTAC follow an evidence-based approach and consider current medical and scientific knowledge, current clinical practice, healthcare delivery, and specific client health needs. It is the goal of the NIHB Program to maintain a comprehensive list of cost-effective treatment agents, which will allow practitioners to prescribe an appropriate course of therapy to patients.

The NIHB Program provides coverage of a variety of disease modifying anti-rheumatic drugs (DMARDs) used to treat rheumatoid arthritis (RA), including methotrexate, leflunomide, hydroxychloroquine, and sulfasalazine. The Program also lists a number of treatment agents used to treat RA including infliximab, etanercept, adalimumab, golimumab, tocilizumab, abatacept, certolizumab, and rituximab. The coverage criteria associated with these various treatment options can be found on the NIHB DBL, which is available on the Health Canada website (www.healthcanada.gc.ca/dbl). The NIHB Program is in the process of reviewing current coverage criteria for RA treatment-agent options to ensure the Program continues to follow current evidence and clinical practice, thereby allowing First Nations and Inuit clients reasonable access to these treatment agents in a timely manner.

Treatment agents listed on the NIHB DBL are provided as either open benefit, meaning that no prior authorization is required, or limited use (LU), meaning certain criteria need to be met before coverage is granted. For agents classified as LU, the diagram on the following page (Figure 1) describes the NIHB LU review process.

For more information, please visit the NIHB section of the Health Canada website at www.healthcanada.gc.ca/nihb.

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NIHB Review Process for Approving Treatment Agents

Physician (prescriber) writes prescription.
Patient (client) takes prescription to pharmacy (provider).
Provider submits a claim to NIHB Program.

NIHB claims system (Express Scripts Canada) identifies the treatment agent as a limited-use (LU) benefit.

DEC staff (pharmacist) assesses the LU form and refaxes the prescriber if information is missing/incomplete or if more information is required.

DEC staff (pharmacist) assigns case number and faxes LU form to prescriber (within the same day). LU form is prepopulated with the treatment agent name and client information.

Provider is asked to call NIHB Drug Exception Center (DEC).

Provider submits a claim to NIHB Program.

DEC assigns case number and faxes LU form to prescriber (within the same day). LU form is prepopulated with the treatment agent name and client information.

Prescriber completes LU form and returns it to DEC.

DEC staff (pharmacist) assesses the LU form and refaxes the prescriber if information is missing/incomplete or if more information is required.

Decision on approval or denial is made and the provider is informed.
Provider is responsible to inform the client. Prescriber may request to be informed as well.

If no response is received within four weeks, case is cancelled. A cancelled case can be re-opened within two business days when new information is received.
Emerging scientific evidence in the fields of autoimmune diseases and genetics has spotlighted real-time prevention strategies that might not only halt the progression of rheumatoid arthritis (RA), but ultimately prevent RA development. University of Manitoba rheumatologists, as clinician-researchers, felt a workshop/symposium was needed to discuss state-of-the-art findings within this area of rheumatology.

Dr. Hani S. El-Gabalawy is the principal investigator spearheading the Early Identification of Rheumatoid Arthritis in First Nations study at the University of Manitoba. The project includes Irene Smolik, PhD research associate, Donna Hart, RN, a research coordinator and several rheumatology colleagues, in particular, Dr. David Robinson, who sees RA patients in two remote Manitoba northern communities (which have research agreements with the university).

In these communities, the research team has the valuable assistance of two local research assistants: Mr. Hubert McDougall of St. Theresa Point and Ms. Olivia Hart (BN, RN) of Norway House. At this event, Hubert and Olivia presented demographic and cultural details about their communities, spoke about recruitment, and offered a reflection on the first-ever rheumatology prevention focus group, held in each community.

Recommendations Focused on RA Prevention
Out of the formal and semi-structured sessions, researchers from various institutions (Stanford University, University of Colorado, University of Toronto, University of Calgary, McGill University, Alaska Native Tribal Health Consortium, Assembly of Manitoba Chiefs, and Arthritis Research Centre [ARC]), learnt that within First Nations communities are persons who, in the 21st century, still “suffer in silence” with RA. Important research themes that emerged from this event include, but are not limited to, the following:
1. First Nations communities must be engaged at the inception of any research strategy.
2. Environment and the socio-economic situation of First Nations peoples in Canadian society may predispose these individuals to risk factors associated with RA development, as well as other diseases (smoking and oral health impact on RA development).
3. Any research design and collected data must be situated in a manner that is iterative; there must be on-going, transparent, and clear dialogue between all involved.
4. A prevention trial must be tailor-made to each community, considering its location politically, spatially, geographically, and historically.
5. Researchers would benefit the entire community if prevention activities were partnered with other programs within the community.
6. Scientific evidence shows a higher frequency of predisposing shared-epitope (SE) alleles in many North American First Nations populations. However, this alone does not explain their high prevalence of RA.

7. Researchers know of biomarkers relevant to predicting imminent RA. Science is in a position to apply RA-risk models, and do so in communities willing to engage prevention strategies.

8. Prevention strategies provide a vehicle to employ and educate individuals in First Nations communities; at the same time, they sensitize researchers to health needs in these communities. Such models engage First Nations as co-researchers within Community Participatory Action Research.

In order to break the pain and suffering of RA, stemming from delayed diagnosis and inadequate treatment of First Nations peoples, all attendees of this conference realized that the scientific and medical community holds knowledge that can influence early detection of RA and establish early RA-prevention strategies within local communities.

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Arthritis Centre,
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Mary Pack Arthritis Program: Outreach to First Nations People in British Columbia

By Alice Klinkhoff, MD, FRCP C; Angela How, MD, FRCP C; and Paul Adam, MSW

The Mary Pack Arthritis Program (MPAP) operates under the auspices of the Vancouver Coastal Health Authority with a provincial mandate to provide outpatient and inpatient services in British Columbia from standing clinics in Vancouver, Victoria, Penticton, and Cranbrook. Communities with limited access to care are serviced through separate travelling occupational therapy and rheumatology services that provide care to 13 and 26 communities, respectively (see map on next page).

As arthritis places a disproportionate burden on First Nations people in Canada, MPAP has intentionally focused on outreach to aboriginal communities. Using Ministry of Health annual funding for physician, nursing, and allied health services, there has been an expansion from the first travelling consultation trip in 1951, to a network of physician and occupational therapy trips, and nascent tele-health and distance nursing support services. In 2012, there were 14 British Columbia rheumatologists funded by two full-time salaries and four part-time occupational therapists engaged in outreach to all patients in the province, including those of First Nations descent, at an approximate cost of $1,100,000.

In one example, in the last 18 months Dr. Angela How instituted tele-health services from Vancouver to the Gitxsan community of Hazelton. The First Nations people in this community experience a high prevalence of multiple inflammatory autoimmune diseases. Dr. Jenny Lee, who has spent time in Dr. How’s practice, facilitates the service at that site. Exit interviews have shown the service to be well received and the wait list has been dramatically reduced. Expansion of this tele-health program to other isolated communities will allow more people living
with arthritis access to appropriate rheumatologic care.

In the past decade, a team including a nurse, physical and occupational therapists, and a rheumatologist has provided contracted travelling and/or tele-health clinics to the Namgis and Carrier Sekani First Nations communities. While this service offered a satisfactory short-term solution, there were few lingering benefits when contract funding ended. Future contracts will ideally build on pre-existing community services, such as adapting community exercise programs, gardens, or kitchens to be arthritis-friendly, with the aim of developing long-term community capacity.

Over the last 15 years infrastructure for inpatient arthritis rehabilitation has been impacted primarily by reduced demand, which we interpret as related to improved and earlier drug treatment. Demand fell from 36 full inpatient arthritis rehabilitation beds in 1997 to an average of 11 beds currently, half of which are typically occupied by First Nations patients with rheumatoid arthritis (RA), ankylosing spondylitis (AS) and psoriatic arthritis (PsA) coming to Vancouver for rehabilitation.

In British Columbia there is manifest pride in these outreach successes, but more needs to be done. There remain small First Nations communities with few or no services, including a black hole in the downtown Eastside where city-dwelling First Nations people often live in substandard housing and poverty, often with coexisting mental illness and addictions. For complex reasons these individuals remain disadvantaged despite having close proximity to care. If there were more rheumatologists in British Columbia there might be an opportunity for extending service to the poorest postal code in the country, as other specialties, including HIV medicine and B.C Women's Hospital, have established local clinics to develop relationships, and improve care and outcomes.

Recommended Readings:

Alice Klinkhoff, MD, FRCPC
Clinical Associate Professor, Medical Director,
Mary Pack Treatment Program,
Mary Pack Arthritis Program
Vancouver, British Columbia

Angela How, MD, FRCPC
Mary Pack Arthritis Program
Vancouver, British Columbia

Paul Adam, MSW
Rheumatology Liaison & Outreach Services Coordinator,
Mary Pack Arthritis Program
Vancouver, British Columbia

OT = occupational therapy; AHP = allied health professionals; TCS = travelling rheumatology services.
My own research interest in rheumatic disease in Aboriginal populations began during my fellowship training. Training in rheumatology in Winnipeg, it was hard not to notice the marked health disparities that existed for Aboriginal patients: they were overrepresented in our clinics and our wards, and seemed to have the most severe forms of rheumatic disease, with the worst outcomes. There was no shortage of research questions! Questions relating to epidemiology, healthcare access and delivery, genetics, environmental influences, and comorbidity abounded, to name a few. In fact, it was much harder to know where to begin research, since there was such a paucity of knowledge and research activity in the area. I started with an epidemiological study of lupus, under Dr. John Esdaile's supervision, and continue to be interested in lupus, as well as rheumatoid arthritis (RA). Current Aboriginal research projects at our centre are aimed at determining the burden of RA and systemic autoimmune rheumatic diseases (SARDs) in Aboriginal populations in Manitoba, documenting the care gaps we suspect in this population, and improving medication access, in addition to the large community-based program aimed at understanding the evolution and, ultimately, prevention of RA in this high-risk population. This program is led by Dr. Hani El-Gabalawy and funded by the Canadian Institutes of Health Research (CIHR).

There are unique aspects to Aboriginal research, including the primary need to build trust and relationships, along with the need for community consent and community participation. There is a history of mistrust of research and researchers by Aboriginal people. This mistrust has been generated by past research abuses and misuses, from lack of informed consent, absence of respect and understanding of Aboriginal culture, and failure to return research results/knowledge translation to Aboriginal communities. Similarly, Aboriginal individuals will often approach a healthcare encounter with suspicion, because of prior poor experiences with the healthcare system. Relationship-building with Aboriginal people and communities is therefore the key to a successful research endeavour, and this requires time. Fundamental to this is the provision of appropriate care. Rheumatology section members, nurses, and support staff at the Winnipeg Arthritis Centre have made care of Aboriginal patients a priority, and have become adept at navigating the mysteries of the Non-Insured Health Benefits (NIHB) Program, negotiating travel requirements, and other common pitfalls in distance care. Even more importantly, Dr. David Robinson leads an outreach program to provide rheumatology care in remote communities. Without attention to the provision of care, research is not feasible and, one could argue, not ethical.

Community consent and participation for research is required (even for urban-based research) to ensure that guidelines developed for research with Aboriginal people are respected. These guidelines, in brief, state that research should: provide clear benefit to Aboriginal peoples and communities; help develop Aboriginal research capacity; increase Aboriginal control of information and research processes; recognize and respect the jurisdiction and rights of Aboriginal people; and support self-determination, cultural preservation, and development. Negotiating community participation and consent can be complex and time consuming, and may conflict with pressures to meet grant application deadlines and get publications out. Research costs may also increase as a result of these additional requirements; a challenge in this era of sparse and precious research funding. However, with relationship-building comes a greater understanding of the Aboriginal community’s research agenda, and likely methodologically stronger studies. Ultimately, we hope this will result in more innovative and transformative research.

Recommended Readings:

Christine Peschken, MD, MSc, FRCPC
University of Manitoba
Winnipeg, Manitoba
Duncan passed away on December 2, 2012 in his 83rd year. Duncan was born in the original Queen Victoria Memorial Hospital in North Bay, June 15, 1930, and remained strongly connected to North Bay and Northern Ontario throughout his life. He was a graduate of Upper Canada College and the Faculty of Medicine at the University of Toronto. He studied internal medicine at the University of Toronto and McGill, and rheumatology and immunology with Dr. John Vaughan at Strong Memorial Hospital at the University of Rochester, in Rochester, New York.

Duncan had been a tremendous mentor to an entire generation of Canadian rheumatologists. He was a consultant in the Rheumatic Disease Unit (RDU) at the Wellesley Hospital from 1964 to 1974. Many senior rheumatologists learned their clinical skills in rheumatology from Duncan and held great affection for him. Amongst these early trainees were Dr. Barry Koehler, Dr. Gunnar Kraag, Dr. Isaac Dwosh, Dr. Howard Stein, Dr. Edward Keystone, Dr. Dafna Gladman, and Dr. Arthur Bookman. Those who came before us and those who came after are far too many to enumerate, yet all fondly remember ward rounds with Duncan at the Wellesley Hospital RDU.

Free-association characterized Duncan’s teaching rounds. Beginning at the bedside, his house-staff would traipse behind him to the x-ray department, to the pathology department, and then back to the bedside in rounds that extended for two hours or more. When the exhaustion would seem inescapable, and all around the bedside would wonder what in heaven he was thinking, Duncan would pull a brilliant diagnosis out of the hat, and he was usually right. We have seen him diagnose an Ewing’s sarcoma at the bedside in a young woman, just by noting a subtle bulge of one buttock. We have seen him diagnose a synoviosarcoma in a finger that everyone thought was simply synovitis. Duncan was the first to report that you could diagnose ochronosis (alkaptonuria) from the synovial fluid (the “ground pepper sign”1) as well as amyloidosis.2 He noted that a ruptured popliteal cyst could be diagnosed from looking at the skin of the lateral malleolus (the “crescent sign”3). He found that hemochromatosis arthropathy could occur without liver involvement in hemochromatosis,4 and he reported the first comprehensive patient series on the extra-articular manifestations of rheumatoid arthritis (RA).5

He was the Director of Rheumatology at McMaster University from 1974 to 1976, and was responsible for recruiting Dr. Gunnar Kraag to McMaster University. Said Dr. Kraag, “Dr. Fred Bianchi was the only fully active community clinician at that time with no one at the university. When he asked me to join him, it took about 18 seconds to say yes. The opportunity and challenge were irresistible. To establish a strong clinical program, develop and actually carry out the undergraduate and postgraduate teaching, start a clinical research program, and meet all the administrative requirements seemed daunting, to say the least. Duncan was unflappable and we even managed to establish an approved Royal College training program; Duncan quickly attracted several international and Canadian trainees.”
Dr. Kraag also reminisced, “There were, as well, the inevitable politics. Everyone knows the calm, gentle, conciliatory side of Duncan, but let me tell you, when his family, friends, rheumatology, or the Journal of Rheumatology (JRheum) were threatened or maligned, he was one tough dude and could rely on a wealth of data and experience to take care of business. I remember the shock when people thought he was going to be a pushover. He never screamed, pushed, or demanded, but he was someone that you just wanted to please and, if at all possible emulate; a true role model who walked the walk. He loved his golf, and he loved to ski. I do remember Duncan developing pulmonary edema at altitude in Snowmass. A minor setback for Duncan, who was up and at ‘em the next day.”

From 1976 to 1991, Duncan was Director of the Division of Rheumatology at the Toronto Western Hospital. He remained on staff as a Senior Rheumatologist and Professor Emeritus until his retirement earlier this year. He was responsible for recruiting Dr. Robert Inman to Toronto Western Hospital and the University of Toronto.

Dr. Inman said, “Duncan’s leadership style was to lead from behind, and he was always prepared to let others take credit for the achievements of the division. Indeed, it became apparent over time that we might be dealing with a distinctive diagnostic category. Gordon’s syndrome. The diagnostic criteria for the syndrome appear to be: (i) recalcitrant optimism, (ii) refractory good will, (iii) chronically low levels of cynicism, and (iv) a titre of humour above the normal range. Although the syndrome is now well described, it may be many years before we see a second case. In the final analysis, Duncan was actually one-of-a-kind. He brought rheumatology back to Toronto Western Hospital and the University of Toronto. Duncan was appointed Editor-in-Chief of JRheum in 1979 after the untimely death of founding editor Dr. Metro Ogryzlo. Dr. J. Desmond O’Duffy tells of sitting around the table for an editorial board meeting with Arthritis and Rheumatism at that time. Someone said that they were going to start a new rheumatology journal in Canada. One of the editors chuckled, “In Canada? Who’s going to read it?” They had a good laugh. But Duncan upheld Dr. Ogryzlo’s rationale that a new journal could stimulate interest in rheumatology and the study of arthritis. Since there were only 200 rheumatologists in Canada at that time, JRheum could not contemplate a future as a domestic-based journal but needed to cast its net as a Canadian-based international publication.

Some of the challenges in the early years included establishing a presence for JRheum, attracting contributors, getting accreditation, and achieving a listing in the U.S. National Library of Medicine’s Index Medicus. Despite the early skepticism, JRheum has thrived. A number of innovations introduced by Duncan have been copied by other journals. He often stirred up controversy by publishing provocative editorials and less-than-flattering letters to the editor to get people thinking and discussing. He used crossfire editorials that showcased different points of view, and pieces on publication ethics, as well as historical vignettes on Canadian rheumatology, to deepen perspective. JRheum branched out to include a regular supplement on pediatrics under the co-editorship of Dr. Ron Laxer and Duncan’s eventual successor, Dr. Earl Silverman. All these new features won JRheum recognition, and it has since maintained an international perspective. Perusal of JRheum reveals editorials from Italy, Israel, and Brazil, as well as contributions coming from Japan, France, and the Netherlands. American, Chinese, Canadian, and Greek investigators all publish in JRheum.

The Canadian rheumatology community has regarded Duncan with great affection as a key figure in the evolution of the specialty. He was a proponent for recognition of Canadian achievement in the international arena. Duncan received many honours for his contributions; notably he was elected a Master of the American College of Rheumatology (ACR), and was Past-President of the Pan-American League of Associations for Rheumatology (PANLAR), and a Vice-President of the International League of Associations for Rheumatology (ILAR) between 1990 and 1994. For his leadership in hosting the international rheumatology editors meeting for a decade, Duncan is highly respected among his fellow rheumatology editors. He has been a contributor to textbooks by Kelley, Cecil-Loeb, Dieppe and Klippel, and the Primer of Rheumatology. He received the Award of Merit of The Arthritis Society (TAS) in Canada and was named Distinguished Rheumatologist of the CRA in 1992.

He leaves a legacy of leadership and accomplishment, and the CRA can be proud to honour him for his contribution to our profession.

References:

Arthur A. M. Bookman, Gunnar Kraag, Robert D. Inman

Donations to the Duncan Alexander Gordon Fund at The Arthritis Society will honour Duncan by going towards an annual award for a rheumatology medical publication by a Canadian author. To date, this fund sits at $26,000 through private donations as well as a contribution from the CRA.

Read more of Dr. Gordon’s contributions to the CRA:
http://bit.ly/WjiTT1
http://bit.ly/TPXbMm
There are few rheumatologists in Canada who will have their name engraved on the Stanley Cup, or serve as team physician for an NHL team, as Hugh Smythe did. But it is with respect to rheumatology in Canada that Hugh set innovative precedents, which bear directly on the challenges that face our specialty today.

First, Hugh prioritized the centrality of the patient in research, as well as in education and care. Long before patient-related outcomes (PROs) became fashionable, Hugh emphasized that precision in the history and physical examination was the cornerstone of clinical research. His description of cervical spine syndromes and the importance of referred pain reflect this meticulous attention to detail. The following is his direction for locating one of the cardinal tender points of fibromyalgia: “Palpate along the second costal cartilage to the costochondral junction. Here, a very distinct region of deep tenderness is found, not localized precisely at this junction, but extending 1 cm laterally, and often more marked on the superior surface than elsewhere on the rib.”¹ In an age when ultrasound and magnetic resonance imaging (MRI) are proposed by some investigators as the new standards of clinical measurement, Hugh’s attention to detail in the physical examination is a reminder that careful attention to detail in patient assessment is one of the pivotal strengths of rheumatology.

Secondly, at a time when the young specialty of rheumatology was defining its place in the curricula of Canadian medical schools, Hugh ensured that rheumatology was firmly embedded in internal medicine. One of his earliest publications described the aortitis associated with ankylosing spondylitis (AS),² anticipating that the spectrum of rheumatology would extend beyond bone and joint disease, and that over time rheumatologists would become quintessential internists involved in the management of multi-organ diseases. While defining the Division of Rheumatology as an integral member of the Department of Medicine, there were two distinctive aspects to this young specialty; these were embodied in the concept of the Rheumatic Disease Unit (RDU). The RDU was a distinct geographic entity, with its own outpatient clinics and inpatient wards. This allowed a concentrated focus on medical education and clinical research that set the standard for rheumatology programs in Canada and abroad, and established the RDU as a distinct entity in the academic health science scene. The RDU concept also set the stage for integrated, multidisciplinary care of patients with rheumatic
diseases, involving not just rheumatologists, but also orthopedic surgeons, physiotherapists, occupational therapists, and nurses. Hugh’s time as team physician with the Toronto Maple Leafs left him with a deep appreciation of the importance of allied health professionals in the management of arthritis and allied conditions. Commenting on his learning curve as team physician, Hugh stated, “It meant I was in the dressing room, and learned to respect the trainers and the physiotherapists, with a relationship that evolved over my years as team doctor, from 1950 to 1969.”

Thirdly, Hugh’s career highlights the importance of strategic partnerships with patient organizations, which for Hugh was The Arthritis Society (TAS). Hugh served on the TAS Board of Directors from 1961 to 1999. Working closely with Edward Dunlop (Managing Director of TAS from 1949-1981), a strategic plan was developed which envisioned an RDU within each medical school in the country. In 1959, Hugh joined the Medical Advisory Committee (MAC) of TAS; in 1961 he co-authored the Society’s submission to the Royal Commission on Health Services. This submission spelled out the need for an RDU within each teaching hospital, operating as an integral part of the Department of Medicine. This submission had a profound effect, ensuring that rheumatology had a viable presence in the academic health science centers of each Canadian university, and that subspecialty training in rheumatology had visibility and profile in the respective Departments of Medicine. TAS played a critical role in this initiative, providing fellowship funding which matched the respective provincial postgraduate residency funding. Not only did this lay the groundwork for training a generation of Canadian rheumatologists, it positioned TAS at the forefront of research funding and manpower development in rheumatology. It highlighted the potential impact of strategic partnerships between physicians and patient advocates. An effective partnership achieves more than each party alone can accomplish, and this synergy was embodied in the collaboration of rheumatology and TAS, in which Hugh took a vital leadership role.

Hugh brought to rheumatology the same intensity and focus which he brought to sports. His enthusiasm for new knowledge and his impatience with uncritical thinking set a high standard for performance in rheumatology. The strength of the rheumatology program at the University of Toronto reflects that high standard to this day. Hugh would not suffer sloppy methodology (“Post hoc ergo poppycock” being one of his critical commentaries) any more than he would tolerate a sloppy defence by the Leafs. He had a scientific scepticism which made him a superb editor, a critical reviewer, and a creative investigator. This scientific scepticism co-existed with a sustained encouraging and supportive approach to trainees and junior faculty.

It was his unwavering commitment to his patients, faculty colleagues, and friends which will be remembered by so many.

References:

Robert D. Inman, MD

Read more of Dr. Smythe’s contributions to the C Raj:
http://bit.ly/NaQ06u
Northwestern Ontario is a large territory encompassing a region about the size of France. Within this region there are about a quarter million people, more than half of whom live in and around Thunder Bay. About 20% of the population is Aboriginal (compared to 2.2% of the Canadian population), most from the Obijway, Cree, or Oji-Cree nations. The region has long struggled with shortages of health professionals; those who work in this region use a combination of innovation and hard work to fill the void. The citizens of Northwestern Ontario have to deal with long drives, often in treacherous, winter conditions, to see their doctors. Heroic family physicians, nurse practitioners, and nurses manage numerous difficult and complex medical problems.

In September of 2011, Dr. Irene Vasiliiu came to Thunder Bay to set up practice and increase the number of full-time rheumatologists in the region from one to two. In my office, I was joined by Anne MacLeod, a registered physiotherapist with Advanced Clinician Practitioner in Arthritis Care (ACPAC) training and certification. This three-year partnership with Anne has allowed me to increase the number of patients seen in my office. Referrals are triaged by Noel Heath, an ACPAC-trained occupational therapist from the Rheumatic Diseases Program (RDP) of St. Joseph’s Care Group. I have continued to dedicate a half-day per week to tele-rheumatology consults.

Tele-rheumatology exists with the support of North Network, the partnership with many communities in Northern Ontario, and the dedication of many therapists and nurses in these communities. Many of these professionals participated in training sessions on arthritis assessment, organized by the RDP Team of St. Joseph’s Care Group, The Arthritis Society (TAS), and me. Two years ago, in Sioux Lookout (“the hub of Northwestern Ontario”), this team taught a group of medical professionals (mainly nurses and nurse practitioners) that work at the First Nations communities (such as Mishkeegogamang, Eabamatoong, and North Caribou Lake) serviced by Sioux Lookout Physicians. These professionals are now able to do the assessments needed in remote communities so that I can properly follow patients with rheumatic diseases through tele-rheumatology.

Regional patients can also access the first-class services of the RDP in Thunder Bay thanks to the commitment of St. Joseph’s Care Group, which has courageously supported a few crucial inpatient rheumatology beds at the hospital site. For those Aboriginal patients who cannot be reached or properly assessed via tele-rheumatology, the federal government’s Non-Insured Health Benefits (NIHB) Program still provides funding for travel. The team members of the RDP are amazing advocates for these patients, acting as mediators with NIHB personnel.

The Aboriginal persons in this region have a high prevalence of rheumatic diseases, particularly rheumatoid arthritis (RA). It is also established that RA in Aboriginal populations begins earlier and is more severe. Providing optimal care for these patients is critical. This care can only be provided by a team of committed organizations and professionals. I am fortunate to be part of just such a team.

Wes Fidler, MD, FRCPC
Rheumatologist
Thunder Bay, Ontario
Last year’s housing crisis in Attawapiskat was in my mind when Dr. Henry Averb and I recently arrived in the small community of approximately 1,500 people. Our visit was part of a trial to bring rheumatology services to this remote northern community.

Rheumatologists from Queen’s University have flown in to the Moose Factory and Moosonee area for several years. Patients from the more remote northern communities, such as Attawapiskat, have typically been flown down to Moose Factory to be seen by the consultant rheumatologist. Occasionally there may be 10 to 12 no-shows from the more northern communities, which are often related to inclement weather preventing airplanes from flying or unspecified organizational difficulties in arranging for transportation.

We were flown to Attawapiskat, located approximately 1,000 km north of Kingston (see map), by Air Creebec. After landing on the dirt runway at the Attawapiskat airport we were transferred to the Attawapiskat hospital, which had been without a physician for two weeks. Due to the shortage of physicians the hospital is often run by nurses. The nurses deal with a huge range of medical presentations including trauma, fractures, and overdoses as well as run preventative diabetic and pre-natal clinics. Given the high staff turnover and diversity of health issues, the health professionals find it challenging to ensure all aspects of patient care are optimized. Laboratory tests are flown out and are not available on a daily basis. There is no x-ray or other imaging on site.

Our first patient had standard methotrexate-monitoring blood work drawn a week-and-a-half prior to our visit to have on file for our review. He was in acute renal failure. In addition to stopping his methotrexate, we requested a transfer to Moose Factory to allow a full renal workup. He was scheduled on the flight out the next morning but, as he missed his flight, he did not reach Moose Factory until approximately 48 hours later. In these remote northern communities, you learn to expect the unexpected and know that nothing is going to work quite according to plan.

From a rheumatology perspective, it is very difficult to ensure the patients obtain monthly blood work, attend follow-up visits, minimize alcohol use, and have appropriate contraception when on teratogenic medications. The access to rehabilitation professionals is limited; there are only two physiotherapists and one occupational therapist providing services to all of the west-coast communities of James Bay. Air travel is the most efficient way to travel between communities. Despite the paucity of services, many individuals who live in the more remote communities, such as Attawapiskat, are not comfortable travelling to Moose Factory, let alone to a center with tertiary care. This limits one’s access to investigations. Despite the challenges of providing care in these more northern settings, the appreciation expressed by the patients and requirement for creative problem-solving make it rewarding to treat individuals in these remote locations.

Heather Waymouth, MD
MD PGY-5 Adult Rheumatology,
Queen’s University
Kingston, Ontario
Patient communication is a key point of interest for physicians; for this issue, the CRAJ surveyed readers to determine the various uses and means by which social media is used in Canadian clinical practice. Social media broadly included any online tools that enable users to interact with a community of other users. Content is user-generated; the social media platform allows for the creation and exchange of information.

Asked whether they use social media in their clinical practice, the vast majority (90%) of respondents said they did not. Only a few (6%) replied that they did make use of social media, while several (4%) noted that their clinic or practice does, but that they were not directly involved in its usage.

Personal websites (33%), YouTube (28%), LinkedIn and Facebook (both 22%) were the media utilized the most in professional settings. The increasing prevalence of Twitter only just seems to be entering the rheumatologic sphere (17%), and I wonder when the hashtag (#) will make an appearance at more of our meetings, as it already has the American College of Rheumatology (ACR).

From general patient information (45%) to disease overviews (40%), educational resources (40%), patient support (35%) and patient forms (35%), the possible uses for social media in clinical practice are diverse and forward reaching. Stay tuned for the Fall issue of the CRAJ, where we will probe further into these practices.

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

Table 1. Do you use social media in your clinical practice?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>My clinic/practice does, but I am not directly involved with its usage</td>
<td></td>
</tr>
</tbody>
</table>

Table 2. If yes, which of the following media do you utilize professionally? (Please select all that apply)

<table>
<thead>
<tr>
<th>Media</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facebook</td>
<td>22%</td>
</tr>
<tr>
<td>Twitter</td>
<td>17%</td>
</tr>
<tr>
<td>LinkedIn</td>
<td>22%</td>
</tr>
<tr>
<td>YouTube</td>
<td>28%</td>
</tr>
<tr>
<td>Personal website</td>
<td>33%</td>
</tr>
<tr>
<td>Blogs</td>
<td>0%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>17%</td>
</tr>
</tbody>
</table>

Unfortunately our hospital computers block access to these websites or I would, I refer patients to specific websites, such as NIH.

Table 3. What clinical information do you communicate via social media? (Please select all that apply)

<table>
<thead>
<tr>
<th>Information Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>General patient information</td>
<td>45%</td>
</tr>
<tr>
<td>Disease overview information</td>
<td>40%</td>
</tr>
<tr>
<td>Online access to patient forms</td>
<td>35%</td>
</tr>
<tr>
<td>Educational resources for patients, other attending physicians, and caregivers</td>
<td>35%</td>
</tr>
<tr>
<td>Assessment and screening tools</td>
<td>15%</td>
</tr>
<tr>
<td>Patient support information/programs</td>
<td>35%</td>
</tr>
<tr>
<td>Dosage and administration information</td>
<td>20%</td>
</tr>
<tr>
<td>Healthy-living lifestyle tips</td>
<td>20%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>30%</td>
</tr>
</tbody>
</table>

Information to colleagues, links to reliable websites, mini management information.
As many of you are aware, major changes to the reimbursement of biologic agents via third-party payers have been occurring; many insurance companies providing group health plans are moving to a “prior authorization form” system, similar to the Exceptional Access Programs implemented by many provincial governments. To ensure that these changes are being implemented with evidence-based medicine and patient welfare in mind, an Ontario Rheumatology Association (ORA) committee was struck. Our committee has engaged in ongoing dialogue with three of the largest insurance companies, presenting them with the CRA guidelines for the treatment of rheumatoid arthritis (RA), as well as commenting on their proposed forms, to try and make their questions rational and appropriate. The insurance companies have, to variable degrees, accepted our comments: they have modified their forms and criteria to, we hope, minimize the difficulties that physicians and our patients will face nation-wide when all these changes take effect.

The realities of escalating expenditures and increased prescribing of biologic agents have made the third-party payers very aware of the use of these agents for the treatment of rheumatic disease. It may be of interest to know that one of the biologic agents that we use frequently is currently poised to become the world’s biggest-selling agent, with sales that will top more than $9 billion in 2012 and more than $10 billion in 2013. With further biologic agents in the pipeline, one can understand insurance companies’ desire to have more control over their use.

Despite our involvement, there will undoubtedly be changes in the prescription of biologic agents that will pose challenges for Canadian rheumatologists and their patients. The ORA plans to maintain an ongoing relationship with the third-party payers, and will strive to make the situation as transparent and open as possible as we move forward in this challenging time.

Jane Purvis, MD, FRCPC
President, Ontario Rheumatology Association
Rheumatologist, The Medical Centre
Peterborough, Ontario
The Pacific Arthritis Center once again hosted the British Columbia Rheumatology Invitational Education Series (BRIESE) this past September 28-29, 2012 at the Fairmont Pacific Rim Hotel. The conference was historically designed as an autumn continuing medical education (CME) event to complement current educational activities for rheumatologists in B.C. Over the past seven years, the educational content continues to resonate with attendees from around the province.

This year was no exception; the event was a resounding success. Guest speakers included Dr. Gordon Dow (University of New Brunswick), who enlightened us on infections in immunosuppressed patients and delivered a very interactive review of tuberculosis screening and therapies. There also was an outstanding talk from Dr. Simon Carette (University of Toronto), who elegantly covered the areas of advances in vasculitis and hepatitis C. International content came from Dr. Arthur Kavanaugh (University of California, San Diego) who delivered a fantastic review of inflammatory arthritis (IA) and challenged the audience regarding medical ethics and clinical trials. Cases to “stump the professor” were presented by faculty and helped open dialogue amongst the attendees.

Once again, the conference was well received and attended. Some significant changes were introduced for 2012. This year saw the addition of a number of new rheumatology nurses, both in attendance and participating in the program. A small nursing workshop was also hosted by the B.C. Society of Rheumatologists (BCSR) to help explore the evolving nursing environment in the province. With the addition of the new multidisciplinary fee code in B.C. in 2011, approximately 50% of rheumatologists have begun to incorporate nursing staff into their practices. With growth comes change; the session was a chance to discuss best practices and challenges in office integration.

This year marked the debut of some new venues for the conference itself, including the UBC Medical Student Alumni Centre and the Fairmont Pacific Rim as the host hotel. The backdrop at the Fairmont Pacific Rim was quintessentially Vancouver: cruise ships, the convention centre, and rain. Some lucky attendees even caught a glimpse of Madonna, who was staying at the hotel while on tour in Vancouver that same weekend.

BRIESE 2013 is scheduled for September 27-28, 2013 in Vancouver.

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The American College of Rheumatology (ACR) 2012 meeting was held in Washington, D.C. from November 9-14. However, Abraham Lincoln appeared to be giving George Washington a run for his money in the eponymously named U.S. capital. On my one free morning at the ACR, I found Honest Abe everywhere. The new movie “Lincoln” had just been released, and huge posters advertising it were everywhere. Lincoln also featured in the recent, though less critically acclaimed, “Abraham Lincoln Vampire Hunter” film. When I walked by the White House, crews were constructing the inaugural stands for Barack Obama’s second term; and many commentators were drawing parallels between the problems facing Obama and those that confronted Lincoln 150 years before. Finally, I ended up at the Lincoln Memorial reading the words of the Gettysburg address. In the early days of Powerpoint, a slideshow depicting how one could butcher Lincoln’s oratory by converting it to bullet points and bar graphs was a staple of the developing internet (www.norvig.com/Gettysburg). This was all before the rise of Facebook, Twitter, Pinterest, and YouTube, of course.

Fortunately, the presenters at ACR 2012 adhered only to the highest standards of scientific clarity in their presentation slides and graphics. The meeting was held in the relatively new Walter E. Washington convention centre, named after the first elected mayor of Washington D.C., and convenient to Chinatown, The Verizon Centre, and numerous hotels. The ACR shuttle service was frequent and efficient. Free wifi at the conference centre and all ACR hotels was very helpful to stay in contact with colleagues and family.

The conference highlighted further data on the long-term safety and effectiveness of biologic therapies, as well as comparative studies among different agents. Biologic therapies were demonstrated to reduce hospital visits, surgeries, and premature deaths in rheumatoid arthritis (RA) patients. Modern technologies were also highlighted, with a Finnish study showing that mobile phone monitoring in...
people with rheumatoid arthritis increases the likelihood that patients with early disease will adhere to treatment. The possibility of tapering biologic therapies in those in RA remission was explored. Anti-tumour necrosis factor (TNF) agents, however, did not seem to be of benefit for osteoarthritis (OA) of the hand. The funding agencies are surely relieved. Further data on the utility of musculoskeletal ultrasound were presented. The increased risk of death in RA related to depression was also confirmed. As well, a Canadian study from the Arthritis Research Centre (ARC) of Canada was highlighted with an ACR press release, showing that the total cost of treating Canadians with OA will quadruple over the next two decades, with costs expected to total $8.1 billion by the year 2031.

The annual ACR meeting features multiple tracks to appeal to the broad panoply of rheumatologists. Whether your primary interest is basic science, clinical science, clinical practice, pain management, patient safety, medical education, or practice management, the meeting holds something for you. I think this is one of the great strengths of the ACR meeting. The ACR Knowledge Bowl was back for a second year, allowing audience members to match wits with the competing teams on rheumatology trivia, Jeopardy-style.

A very entertaining session I attended reviewed possible extra-articular sites which may be implicated in the initiation and pathogenesis of RA. Discussion centred on the periodontal compartment and the lung. The question of whether RA could be prevented with toothpaste or an inhaler was raised, but remains unresolved.

The Food and Drug Administration (FDA) cooperated with the ACR news cycle by approving the first JAK inhibitor, tofacitinib, just before the meeting began. The brand name, Xeljanz, did not exactly trip off my tongue. I am sure I will master it in time, as I did when abatacept and tocilizumab, among others, came to market.

As usual at ACR, the CRA took advantage of the presence of so many Canadian rheumatologists to hold meetings of the CRA council and the CRAJ Board, both of which were very productive. Our Canada Night event was also well-attended and an excellent opportunity for networking. The ACR opening reception was held at the Newseum, a superb venue, especially for current affairs and trivia devotees like myself.

Be sure to mark your calendars for the next ACR Annual Meeting, scheduled October 25-30, 2013 in San Diego, California. I will be looking for you there.

Philip A. Baer, MD, CCM, FRCP, FACR
Editor-in-chief, CRAJ
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Save the Date: Northwest Rheumatism Society Meeting

The next Northwest Rheumatism Society (NWRS) Meeting will take place at The Sutton Place Hotel, April 25-27, 2013, in Vancouver, British Columbia.

Highlights:
- Distinguished guest faculty this year include: Dr. Edward Keystone, University of Toronto; Dr. Mark Genovese, Stanford University; Dr. Boulos Haraoui, University of Montreal; and Dr. Yusuf Yazici, New York University School of Medicine.
- Some of the topics on this year’s agenda consist of the following: Emerging Therapeutic Concepts in Rheumatoid Arthritis; New Developments in Seronegative Spondyloarthropathies; Behçet’s Syndrome; Approach to Immune-Mediated Cytopenias; Recent Advances in Pulmonary Hypertension; Causes of Total Hip Arthroplasty Failure; Rheumatoid Cervical Spine: Neurosurgical Considerations; Dermatology Update for the Rheumatologist; “Pain Management” and the Rheumatologist; Immune Myositis; Update on ANCA-Vasculitides; and Pediatric Rheumatology.
- Greet old friends and acquaint yourself with new colleagues at an elegant reception on Friday evening at the Vancouver Art Gallery. Conference concludes on Saturday at 12 noon.

NWRS Membership is $25 and the conference fee is $200. Registration information and program details to follow. Please address inquiries to NWRS/Sarah Rice at King County Medical Society, 206-621-9596, or to President-Elect Maziar Badii, MD at mazbadi@gmail.com.
Top Ten Reasons to Refer to a Physiatrist
By Perry Rush, MD

A physiatrist specializes in physical medicine and rehabilitation medicine. The aim of rehabilitation is to improve quality of life by maximizing function and minimizing the disability resulting from the underlying impairment or disease. Typically, the physiatrist works with a multidisciplinary team of allied health professionals. The team could include physiotherapists, occupational therapists, social workers, prosthetists, orthotists, dieticians, speech therapists, psychologists, and recreation therapists. Any person with an injury or disease affecting the musculoskeletal, neurological, or cardiorespiratory systems could benefit from the expertise of a physiatrist. Physiatrists work in the community, in general and specialized rehabilitation hospitals, and in rehabilitation units found in some acute care hospitals.

Some examples of when a referral to a physiatrist could be helpful:

1. **Your patient needs a prosthesis.**
   Your patient has had a limb amputation (e.g., from vasculitis) and needs a prosthesis. It is preferable for the patient to be evaluated before the amputation. The physiatrist can also provide the prosthetic prescription and manage any complications of amputation and prosthetic issues (e.g., poor fit).

2. **Your patient needs care after a stroke.**
   Your patient has had a stroke (e.g., related to systemic lupus erythematosus [SLE]) and needs follow up and ongoing care. The physiatrist can assess whether the patient may benefit from admission to a specialized stroke rehabilitation unit. Factors suggesting a poor functional outcome include the following: comorbid conditions, severe neurological deficit, inability to maintain an unsupported sitting posture, inability to retain information from day to day, bowel and bladder incontinence, and a poor score on a functional outcome measurement tool.

Rehabilitation and treatment for a stroke patient could include medications such as baclofen and botulinum injections for spasticity, physiotherapy, occupational therapy, provision of assistive devices and/or arrangement of home-care services. Treatment and prevention of stroke complications could include avoiding aspiration due to swallowing disorders, and therapies for depression, pain syndromes, pressure sores, thromboembolic disease, poor nutrition, and seizures.

3. **Your patient needs therapy for a traumatic brain injury.**
   Your patient has been in a motor vehicle accident and has had a traumatic brain injury (TBI) and you are wondering about treatment. Such patients can have complicated physical and cognitive deficits. Complications of head injury requiring treatment could include fractures, seizures, hypertension, cardiopulmonary disorders, endocrine dysfunction including derangement of anterior pituitary function, cranial nerve issues, motor and sensory issues, heterotopic ossification, nutrition, and bowel and bladder issues. Neuropsychological evaluation may be helpful, especially if there are medico-legal issues.

4. **Your patient has unexplained weakness.**
   Your patient has unexplained weakness and you are wondering about myositis. In this case, electrodiagnostic testing may be helpful. Electrodiagnostic testing, performed by physiatrists, neurologists, and rheumatologists, should confirm the diagnostic impression suggested by the history and physical examination. Electrodiagnostic testing has two components, nerve conduction and electromyography (EMG). Nerve conduction studies of the sensory and motor peripheral nerves can determine the site of a peripheral nerve lesion. Electrodiagnostic testing could determine if the weakness is due to a muscle disease (myopathic) or peripheral nerve disease or injury (neuropathic).
5. Your patient might have a peripheral nerve lesion.
Your patient has had a dropped foot, such as after a hip replacement, and you are wondering if this is a peripheral nerve lesion. Again, electrodiagnostic testing would be helpful. For example, is the foot drop due to a sciatic nerve lesion or a peroneal nerve injury? Is the hand numbness due to a lesion in the cervical roots, brachial plexus, at the elbow, or carpal tunnel syndrome?

Your patient is in hospital due to a recent total knee or total hip replacement or a fracture and you are wondering whether the patient would benefit from an admission to a rehabilitation unit. A physiatrist performing a post-operative consultation could determine if the patient has already returned to a sufficient functional level to return home, or whether further inpatient rehabilitation would be helpful in the face of barriers at home (e.g., stairs), comorbid medical conditions and/or a lack of family support. Admission to a post-operative rehabilitation unit can provide intensive daily physiotherapy and occupational therapy. A home visit by a therapist to assess the home situation may also be useful.

7. Your patient requires care for a spinal cord disease or injury.
Your patient has had a spinal cord transverse myelitis (e.g., due to SLE or Sjögren’s syndrome [SjS]). Patients with spinal cord diseases or injuries require ongoing care for prevention and treatment of many potential complications including respiratory insufficiency, pressure sores, spasticity, neurogenic bowel and bladder issues, nutrition, spinal deformity, sexual issues, and may require mobility devices such as a wheelchair.

8. Your patient might need orthotics.
Your patient has sore or deformed feet and you are wondering about foot orthotics, or your patient has primary medial joint knee osteoarthritis (OA) and you are wondering about a brace. Orthotic devices (which can be purchased over-the-counter or custom-made at greater cost) include braces, splints, corsets, collars, and shoe modifications. A properly prescribed orthosis can improve function and decrease pain by altering biomechanics. Orthoses can decrease forces passing through the entire or part of a weight-bearing joint (such as using a knee brace to off-load the medial compartment of a patient with OA of the medial compartment, or a corset to help mobilize a patient with a spine compression fracture), stabilize subluxating joints (such as an unstable knee due to ligament injury), improve motion patterns (such as reducing the energy requirement for ambulation), and maximize functional position (such as using a static splint to put a weak wrist in the best functional position to use the hand, or by using a dynamic wrist splint to replace finger extension in a rheumatoid arthritis (RA) patient with extensor tendon rupture).

9. Your patient has had repeated falls.
Falls in patients with chronic diseases can result in significant morbidity and mortality; they are common, expensive, and preventable. A physiatrist can assess and treat the cause of the falls, which is usually multifactorial. Risks for falls include drugs (e.g., psychotropic agents and diuretics), comorbid conditions such as musculoskeletal, neurological, and cardiorespiratory diseases, and issues of vision, hearing, balance, incontinence, arrhythmia, and orthostatic hypotension. To reduce fall risk, mobility assistive devices could be provided. A home visit by a therapist could be arranged to assess for modification/adaptation of the home to reduce environmental hazards and to install home safety devices.

10. Your patient has heart or lung disease.
Your patient has had a myocardial infarction (e.g., due to premature atherosclerosis and lupus) or has a pulmonary issue (e.g., pulmonary fibrosis due to rheumatoid arthritis) and you are wondering whether the patient would benefit from a cardiac or pulmonary rehabilitation program. These programs can be supervised by a physiatrist or cardiologist/respirologist and typically involves exercise training, education and medications with the goal of improving cardiac and respiratory function and quality of life.

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