

Arthritis Research Centre of Canada

Scientific Plan 2010-2015

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2010-2015

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Executive Summary

Arthritis and related conditions make up a group of more than 100 disorders affecting the joints, ligaments, tendons, bones and other components of the musculoskeletal system. Arthritis is a leading cause of pain, physical disability and health care utilization in Canada, and is the most costly group of diseases. In 2003, arthritis and other rheumatic conditions affected nearly 4 million Canadians aged 15 years and older – approximately one in six people. Two-thirds of those with arthritis were women, and nearly three of every five people with arthritis were younger than 65 years of age.

These data point to an enormous opportunity: that is, the potential to significantly reduce the burden of physical disability and health care utilization, and greatly enhance many years of life for a large number of Canadians, through research. The more we can understand about diagnosing and treating these diseases, the bigger the impact.

In recognition of the tremendous potential that research can bring to arthritis treatment in Canada and beyond, the Arthritis Research Centre of Canada (ARC) was created in 2000 by the Board of The Arthritis Society, BC and Yukon Division to address this need. In April 2002, ARC became an independent, not for profit charitable organization that continues to work closely with The Arthritis Society for the benefit of all people with arthritis. Today, ARC is home to a 15 member multi-disciplinary research team comprised of outstanding medical doctors and research scientists who collaborate with peer professionals around the world (with the invaluable participation of graduate students, research support, consumers, and administrative staff). This relatively young organization has quickly earned international attention as a leading arthritis research environment, as reflected in a three-fold growth of external funding over the past decade.

The future growth and productivity of ARC in its second decade will depend on its ability to continue to recruit and train, the best and the brightest minds in musculoskeletal research. It's no easy task: compared to high profile diseases like cancer, today only relatively small amounts of funding flow to arthritis research. That's why it is essential to ensure that the money which is available is routed to support Canada's leading team of scientists and clinicians whose work will result in the greatest possible improvements in quality of life for Canadians living with arthritis and related conditions.

This scientific plan for 2010 to 2015 lays out ARC's high level plan to work towards that goal in three key domains: research, training, and knowledge exchange. To achieve this goal, the plan lays out ARC's intentions to add complementary population health and methodological expertise to the existing team, in areas of aboriginal health; biomedical engineering and diagnostic imaging; health economics; and health psychology. Also identified in the plan are targeted recruitments of researchers focusing on priority disease areas including juvenile idiopathic arthritis; spondylitis; gout; and systemic lupus and related disorders.

Introduction

Arthritis and related conditions make up a large group of disorders affecting the joints, spinal discs, ligaments, tendons, bones and other components of the musculoskeletal system. Arthritis is a leading cause of pain, physical disability and health care utilization in Canada, and as of 2003 is the leading cause of economic disease burden:

- Arthritis and other rheumatic conditions affect nearly 4 million Canadians aged 15 years and older approximately one in six people.
- Two-thirds of those with arthritis are women, and nearly three of every five people with arthritis are younger than 65 years of age.
- By the year 2026, it is estimated that over 6 million Canadians 15 years of age and older will have arthritis.
- Compared with people with other chronic conditions, those with arthritis experience more pain, activity restrictions and long-term disability, are more likely to need help with daily activities, report worse self-rated health and more disrupted sleep and depression, and more frequently report contact with health care professionals in the previous year.
- Overall, 19% of Aboriginal people reported having arthritis equivalent to 27% if the Aboriginal population had the same age composition as the overall Canadian population.

Together, these data point to an enormous opportunity, in the potential for research to significantly reduce the burden of physical disability and health care utilization, and greatly enhance many years of life for a large number of Canadians. The more we can understand about diagnosing and treating these diseases, the bigger the impact.

Yet today, compared to high profile diseases like cancer, only relatively small amounts of funding flow to arthritis research. In 1998, the economic burden of musculoskeletal conditions in Canada accounted for 10.3% of the total economic burden of all illnesses but only 1.3% of health science research funding. That's why it is essential to ensure that the money which is available is routed to support the work of scientists and clinicians whose studies can lead to the greatest improvements in quality of life for Canadians living with arthritis. In Canada, one team stands out as presenting the best opportunity for return on investment in arthritis research: the Vancouver, BC-based Arthritis Research Centre of Canada.

About the Arthritis Research Centre of Canada

The Arthritis Research Centre of Canada (ARC) was created in 2000 by the Board of The Arthritis Society, BC and Yukon Division, in recognition of the tremendous potential that research can bring to arthritis treatment in Canada and beyond. In April 2002, ARC became an independent, not for profit charitable organization that continues to work closely with The Arthritis Society for the benefit of all people with arthritis.

Back in 2000, ARC consisted of one scientist (the founding Scientific Director, Dr. John Esdaile), one student (Dr. Diane Lacaille) and a part time administrative assistant. Growth has been rapid, and constant, ever since. Today, ARC is home to 15 clinical investigators, 14 graduate students, and 18 scientific and clinical trials staff, a 9 member Consumer Advisory Board, and three administrative staff. The Centre's strong, multi-disciplinary research team is comprised of outstanding medical doctors and research scientists, all of whom willingly collaborate with peer professionals around the world. This relatively young organization has quickly earned international attention as a leading arthritis research environment, as reflected in the three-fold growth of external funding over the past decade described in Figure 1.



Figure 1: External Funding for ARC Research

The ARC team is dedicated to understanding, advancing and sharing knowledge about the causes of arthritis, and addressing issues that are impacting people with arthritis right now. The Centre is proud to be affiliated with The University of British Columbia and the Vancouver Coastal Health Research Institute, and has established a partnership with Simon Fraser University to host an endowed Chair in Arthritis Research.

Achievements to Date

The growth in numbers of ARC's scientific staff and the increase in external research funding described above are just two indicators of ARC's success as a centre of clinical research excellence. Here are some other highlights of ARC achievements in research, training and knowledge translation.

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	• ARC scientists are also leaders in their profession in other ways: for example, Jacek Kopec advises Statistics Canada about arthritis and quality of life for surveys of the Canadian population; and Catherine Backman was elected President of the Association of Rheumatology Health Professionals in the US. Diane Lacaille is part of an International group of researchers setting standards for how to measure employment outcomes in arthritis research.
	 Since 2000, more than 62 graduate students and fellows have been supervised by ARC scientists, including 27 at the Masters degree level; 24 PhD students; and 11 post-doctoral fellows. Some highlights from the past five years include: Charles Ratzlaff received a Health Professional Fellowship from the Canadian Institutes of Health Research. Antonio Aviña-Zubieta was successful in obtaining Post-Doctoral Fellowships from three separate agencies: the Canadian Arthritis Network, the Michael Smith Foundation for Health Research, and the Canadian Institutes of Health Research/Wyeth Canada competition. He could only keep one and declined the other two. Allen Lehman was recognized by the Vancouver Coastal Health Research Institute with an Outstanding Trainee Award. Mary De Vera was awarded a Frederick Banting and Charles Best Canada Graduate Doctoral Award from the Canadian Institutes of Health Research. Winnie Tam was awarded a Graduate Student Award from the Canadian Arthritis Network. Rick Sawatzky was awarded Post-Doctoral Fellowships from the Michael Smith Foundation for Health Research and the Canadian Arthritis Network. Vidula Bhole and Eric Sayre received the Canadian Arthritis Network. Vidula Bhole and Eric Sayre received a Graduate Student Award from the Canadian Arthritis Network. Robin Roots received a Studentship from the Canadian Arthritis Network to obtain her Master's degree. Chuck Ratzlaff was awarded a Canadian Arthritis Network Trainee Travel Award. Eric Sayre, Chuck Ratzlaff and Rick Sawatzky received the Best Poster Award, in the category of "Clinical Health Services Research" at the Canadian Arthritis Network Annual Scientific Conference. Several former ARC trainees have subsequently joined the Centre as investiga
	ARC's first trainee, Diane Lacaille, trained at ARC as a clinical epidemiologist after

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	completing her training as a specialist in internal medicine and then arthritis at McGill University and The University of British Columbia , respectively. She was recently granted tenure at The University of British Columbia, in large part because of her unique work on the lack of appropriate drug treatment for the majority of people with rheumatoid arthritis, a finding now confirmed by other studies from around the world.
	 Jolanda Cibere completed her internal medicine training in Saskatchewan and her rheumatology training as an arthritis specialist at The University of British Columbia, before receiving her PhD in Epidemiology from The University of British Columbia. Dr. Cibere performed a landmark study showing that glucosamine did not reduce the symptoms of osteoarthritis of the knee. She has been acknowledged by the US government for her work on osteoarthritis of the knee. Her recent study showing that urine tests may lead to earlier diagnosis of osteoarthritis has just been published to acclaim.
	• Carlo Marra, after completing his doctorate in Pharmaceutical Sciences, received his PhD in Epidemiology at The University of British Columbia based on research at ARC. Dr. Marra is expert in assessing the cost benefit of interventions to help people with arthritis, has demonstrated how pharmacists can help to diagnose people with arthritis early and advises the government of BC on which new drugs to pay for under PharmaCare. Dr. Marra holds a Canada Research Chair in the Faculty of Pharmaceutical Sciences.
	• Catherine Backman took leave from teaching occupational therapy to complete her PhD in Health Care & Epidemiology at The University of British Columbia, studying the impact of arthritis on participation in paid and unpaid work. She is now associate professor at The University of British Columbia in the Department of Occupational Science & Occupational Therapy, continuing her research on ways to help people with arthritis engage in everyday activities like parenting, employment, and social relationships.
Knowledge Exchange	• People with rheumatoid arthritis die sooner than they should, mainly because of a 60% increase in deaths from heart attacks and stroke. Research by Diane Lacaille and Hyon Choi has shown that these premature deaths can be completely prevented by treating the rheumatoid arthritis appropriately. The 50% of people with rheumatoid arthritis who are treated solely by their GP only get appropriate treatment 10% of the time. ARC scientists are now working with GPs, the medical associations and the Ministry of Health to remedy this huge gap in good medical care.
	• Outside of large cities, many lack access to both physiotherapy and occupational therapy. In a pioneering series of studies, Linda Li has demonstrated that a single person can be trained to perform both jobs, to great advantage for the person with arthritis. And, it is cost-effective. This model is now the standard for The Arthritis Society in areas where it provides rehabilitation services.

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	• Jolanda Cibere determined for the first time, how to examine the knee joint in a very standardized way. The technique has been adopted by a \$48 million study of osteoarthritis of the knee in the US and most recently by a large study in the UK.	
	• The demonstration by Drs. Lacaille, Choi, Esdaile and others, that heart attack and stroke are the cause of premature deaths from rheumatoid arthritis and systemic lupus erythematosus, and the demonstration how to prevent these deaths will save the lives of tens of thousands every year.	
	• Fear of infection caused by powerful anti-arthritis drugs causes under-prescriptions by doctors and underuse by patients. In a study of more than 25,000 people with rheumatoid arthritis, Diane Lacaille showed that one drug increases infection, but that good control of arthritis with a dozen others actually reduces serious infections! This has huge implications for arthritis treatment around the world.	
	• Dr. Greidanus together with ARC research scientists developed innovative studies to improve rehabilitation for patients following joint replacement surgery. The results of this work will have far-reaching impact.	
	• Dr. Garbuz and colleagues have developed randomized trials to determine which of new prosthetic implants in hip surgery provide the best long-term results.	
	• Marie Westby, a PhD trainee, identified the huge variation across North America in access to and provision of rehabilitation services following total hip and total knee replacements. She is developing evidence-based practice guidelines for post-operative rehabilitation, to improve functional outcomes for the more than 20,000 people having hip and knee replacements every year in Canada.	

These accomplishments are among many by ARC's team that have been recognized nationally and internationally with a wide range of prestigious honours and awards:

- Catherine Backman was awarded the American Association of Rheumatology Health Professionals Distinguished Scholar Award, the Muriel Driver Memorial Award from the Canadian Association of Occupational Therapists (their highest honour), and was named a fellow of the Canadian Association of Occupational Therapy.
- Jolanda Cibere was acknowledged as a leading young scientist in Canada by The Young Innovator Award from the Networks of Centres of Excellence. She also received the Martin M. Hoffman Award for Excellence in Research from the Department of Medicine, University of British Columbia.
- John Esdaile received the Vancouver General Hospital Research Award, The University of British Columbia Killam prize for Research, the Distinguished Scientist Award from the Canadian Rheumatology Association, the US Kirkland Foundation Award and was elected to the Canadian Academy of Health Sciences.

- Diane Lacaille received the award for the top grant in Quality of Life research from the Canadian Institutes of Health Research, Le Prix Jeffrey Shiroky from Quebec and the Canadian Association of Rheumatology Distinguished Young Investigator Award.
- Carlo Marra received the Canadian Pharmacists Association Patient Care Achievement Award for Innovation. This award recognizes outstanding innovation in pharmacy practice aimed at improving patient outcomes.
- Linda Li received the American College of Rheumatology Research and Education Foundation Health Professional New Investigator Award – the only non-Canadian to do so.
- Nelson Greidanus received the Young Investigator Award from the Canadian Orthopaedic Foundation.
- Don Garbuz received the Hip Society Charnley Award for excellence in hip arthritis research.

External Review

In November 2007, The Arthritis Society of Canada arranged for an External Review of ARC by Dr. Edward Yelin, Professor of Medicine and Health Policy, University of California at San Francisco; and, Co-Editor-in-Chief of Arthritis Care and Research, the medical journal with the highest influence for arthritis research. He noted, "Dr. Esdaile (is) clearly considered one of the two or three best clinical epidemiologists in the rheumatic diseases in the world. Similarly, Dr. Liang would have to be considered in the same light. Drs. Lacaille and Choi are on the path to the same level of reputation ... and Drs. Li and Kopec, with whose work I am less familiar are probably also on that path." As to Drs. Anis, Marra and Backman, Yelin commented, "There are few universities in North America that would not hire (Anis and Marra) in a minute ... Backman would have to be considered among the two or three most eminent physical therapy researchers in North America."

Yelin concluded, "Dr. Esdaile has, in the short space of less than a decade, created one of the most acclaimed research groups in North America through foresighted leadership and diligent pursuit of the mission of the organization. As I indicated, morale is uniquely, and apparently, universally high, giving the investigators the space to succeed in and extremely competitive environment for research funding. It was a joy to see this morale.

ARC Today

The team at ARC conducts consumer-driven clinical research and trials related to arthritis diagnosis, prognosis, prevention, care outcomes and quality of life issues. As part of a patient-oriented research centre, the ARC team approaches their work from a wide range of disciplinary perspectives, including rheumatology, rehabilitation science, public health, epidemiology, biostatistics, health psychology, health economics and education. Figure 2 below illustrates the current complement of scientists affiliated with ARC according to their disciplinary specialties, with overlapping domains representing the areas where their respective knowledge-base complements and combines to produce new knowledge and translate it to action for prevention, diagnosis and treatment.



Figure 2: The Integrated ARC Scientific Team 2009, by Principal Discipline Focus

Another way to understand the breadth of scientific expertise at ARC is to look at the distribution of scientific interest in various types of musculoskeletal disease. Figure 3 below shows how ARC-affiliated scientists cluster according to their focus on a given type or family of diseases. Groups with dotted outlines indicate areas in transition (e.g. Dr. Choi's appointment with ARC ends in 2010).

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Figure 3: The Integrated ARC Scientific Team 2009, by Principal Disease Focus

ARC has had a Consumer Advisory Board since shortly after it was created and is the first research centre in Canada to have such a group. Consumers are people with arthritis. They volunteer to work alongside the scientists. The Consumer Advisory Board members make a unique contribution to ensure ARC science is relevant to people living with arthritis, and exemplify meaningful collaborations between science & society – no "ivory tower" here, but "practice research for everyday living" and the ultimate in chronic disease self management.

Whether viewed through the expertise or interest lenses, the resulting team ARC environment thrives on cross-fertilization of methods and knowledge, all combined to address a common focus: practical research for everyday living. To the researchers and clinicians at ARC, that means finding the answers NOW to reduce the burden of arthritis, and giving people with arthritis better, more timely, and costeffective solutions for living with their disease.

Where We're Going

Today the Arthritis Research Centre of Canada is poised on the brink of an exciting new decade. The table below summarizes the major areas of activity that together comprise the Centre's work in the next three to five years:

Research	 Diane Lacaille is leading a large team that will show that work disability due to arthritis can be prevented and productivity improved.
	• Diane Lacaille, Linda Li and Carlo Marra are using a novel approach, called academic detailing, to update family physicians on the new treatment approach for rheumatoid arthritis – an approach that can eliminate the need for surgery, hospitalization and premature death.
	 Linda Li is leading efforts to eradicate the underuse of effective medications in people with rheumatoid arthritis. The potential impact is substantial.
	• Carlo Marra is pursuing the role of the pharmacist in the early diagnosis of serious arthritis. The average Canadian sees their pharmacist 7 times more often than their doctor, so the possible benefit could be significant.
	• Donald Garbuz, Jolanda Cibere and Jacek Kopec are working on the cause of osteoarthritis of the hip, which they believe may be due to a combination of specific physical activities and a slightly abnormal shape of the hip. It could be preventable.
	• Nelson Greidanus, Donald Garbuz and colleagues are working on innovative studies related to the surgical management of arthritis of the hip and knee. These studies will refine the indications and timing for surgical intervention, define the role of new technologies in joint replacement and reveal the costs and consequences of techniques and implants of the future.
	 Jolanda Cibere, Jacek Kopec and John Esdaile are working on understanding the natural course of knee osteoarthritis and whether blood or urine tests for biomarkers or clinical examinations help predict who is at risk of developing worse disease over time. This will lead to intervention strategies for early knee osteoarthritis.
	• Jolanda Cibere and John Esdaile are evaluating the effect of knee injuries on cartilage damage using state-of-the-art imaging technology.

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Training	• The number of trainees at ARC has grown steadily. This summer (2009), in addition to the 13 graduate and 2 post-graduate students, ARC has seven medical and other students involved in research - a record number. For those medical students who continue in research, it will likely be another 12 years before they become independent scientists.
	• Arthritis research training is being integrated into health professional education programs. For example, in 2010, 13% of the occupational therapy graduates entering practice will have completed arthritis research projects under the guidance of Catherine Backman.
	• Simon Fraser University has matched ARCs contribution to the Maureen and Milan Ilich/Merck Frosst Chair in Biostatistics of Arthritis with money from its own endowment. Simon Fraser University is committed to building a training program around the Chair holder.
Knowledge Exchange	 CAB, as the Consumer Advisory Board is called, holds an annual Roundtable On Arthritis Research (ROAR) which brings ARC's arthritis research results to the public. ROAR has been filmed and resulted in media interviews locally. Nationally, the Canadian Arthritis Network now holds its own version of ROAR. CAB members have acted as advisors on many research grants. Several CAB members were named co- investigators on a Canadian Institutes of Health Research New Emerging Team grant on osteoarthritis for \$1.5 million. This is unique. Both because of their commitment to arthritis research and the expertise they gain as CAB members, CAB members have been invited to sit on many national, (including federal government) and international committees, as well as being invited to speak at national and international scientific meetings. CAB is a win-win for ARC and for people with arthritis. Linda Li has received funding to build an animated decision aid with the help of the Centre for Digital Media, a UBC/Simon Fraser University-affiliated training centre
	 specialized in cutting edge digital technology. The project is called ANSWER – for ANimated Self-serve WEb-based Research. The tool will help people with newly-diagnosed rheumatoid arthritis to decide on therapy. This promises significant health benefits, since delay in deciding is a proven contributor to increased long-term disability and earlier death. This tool will take the answers to any English speaking person with access to the Internet and can be adapted to other languages. Diane Lacaille and her team are developing a web-based version of their program to
	 prevent work disability. This will improve dissemination to all across BC, and beyond. Jolanda Cibere, Linda Li and John Esdaile are developing educational videos, including one on YouTube with Leslie Nielsen, for teaching of standardized knee examinations to family practitioners, medical students and other health care professionals.

This Scientific Plan for the next five years proposes to establish the following strategic targets:

Inflammatory Arthritis

- Developed and tested a tool to prevent work disability in those with inflammatory arthritis, such as rheumatoid arthritis.
- Increased appropriate management of rheumatoid arthritis to >80% within three months of diagnosis (versus <40% now).

Osteoarthritis

- Dramatically increase early diagnosis of osteoarthritis of the knee by primary care physicians.
- Identify those with early osteoarthritis of the knee at high risk of progressive disease and develop forgotten treatment regimens.
- Pioneer protocols to test new agents to prevent osteoarthritis progression.
- Determine the cause(s) of osteoarthritis of the hip.

Training

• Increase the number of new trainees to five per year to accelerate arthritis control and improve the delivery of cost-effective care.

Filling the Gaps: Discipline Focus

The ARC team's ability to reach these targets will depend in large part on the ability to recruit scientific talent to fill existing gaps in scientific/methodological expertise. Figure 4 below illustrates the additional domains or areas of methodological specialty that are currently lacking or under-represented at ARC. Domains represented by dotted lines are foci for recruitment and/or growth.



Figure 4: Targeted Growth Areas for ARC by Principal Discipline Focus

Aboriginal Health

In 2000, 19% of Aboriginal people reported having arthritis. Because Aboriginal people are on average younger than the rest of the population, this is equivalent to 27% if the Aboriginal population had the same age mix as the overall Canadian population. In addition, the Aboriginal population of Canada is growing faster than any other single demographic group. Thus, the arthritis impact will magnify dramatically with the increase in size and the aging of the Aboriginal community. It is also apparent that the types of arthritis present in Aboriginals may not be identical to that seen in the non-Aboriginal population's unique needs. ARC therefore puts a high priority on research focusing on the needs of Aboriginal people with arthritis.

To date, an ARC trainee has worked hard in building bridges to the Aboriginal community. Today ARC is collaborating closely with the Aboriginal community to obtain better data on the frequency and impact of arthritis in selected areas. The next step is to develop a research program and to hire a scientist in this area.

Biomedical Engineering and Diagnostic Imaging

New imaging techniques have allowed scientists to see the changes of arthritis much earlier than was ever possible before. Magnetic resonance imaging (MRI) is just one example – half of those with osteoarthritis on MRI, even advanced arthritis, have normal x-rays and as a consequence their diagnosis is missed without the more sophisticated (and expensive) test. ARC is working with physicists and biomechanical engineers to fuse the latest technologies with clinical science. We now know that there are tests that will allow us to find cartilage abnormalities (the first sign of osteoarthritis) when even the conventional MRI image appears normal. Thus, it may be possible to determine who will get osteoarthritis before any permanent damage has occurred. This is a rapidly growing area of research. ARC was a key player in getting funding for a \$2.5 million dollar stand up MRI machine – the first in Canada. There is a need for start-up trainee support to jump start this area of research.

Health Economics

In 1998, estimates placed the economic burden of arthritis to Canadian society at \$4.4 billion. The most recent data from Statistics Canada is from 2003, and arthritis has gone from the second most costly disease to the most costly disease. Long-term disability accounted for almost 80% of the economic costs; the 35-64 year age group incurred 70% of these costs. The development of new and costly drugs to treat arthritis is increasing the cost of arthritis and the need for scientific research into using limited resources cost-effectively. ARC would benefit by having a part-time scientist in this area.

Investing in this area can lead to better care at an affordable price. British Columbia can be a leader in this arena.

Health & Well Being

ARC has hired scientists with a diverse group of skills, including epidemiologist Jacek Kopec, who is recognized as a world authority on assessing quality of life at the societal level. His new instrument for doing so provides unparalleled information. But, this is not the same as detecting the nuances of a disease on an individual's psychological health, or their psychological state on their disease. "Doing well" is not the same as living well. Most research assesses the medical model of disease (a germ causes a disease) but it is clear that although poorly studied, the psyche has a role in the development and outcome of many diseases including arthritis. This cries out for high-level scientific investigation. ARC needs to hire a scientist in this area.

Filling the Gaps: Disease Focus

As noted in the previous section, key disease areas are yet to be represented at ARC in a robust way, including the need for scientists with an interest in gout, systemic auto-immune rheumatic disease, ankylosing spondylitis and related diseases and juvenile idiopathic arthritis (Figure 5).



Figure 5: Targeted Growth Areas for ARC by Principal Disease Focus

Osteoarthritis and Rheumatoid Arthritis

Biometry Unit

The large datasets that ARC scientists are evaluating to learn about health care for osteoarthritis and rheumatoid arthritis are creating a need for more sophisticated statistical support. While the Maureen and Milan Ilich/Merck Frosst Chair in Biostatistics will provide statistical leadership, there is a need for financial support for a person with Master's level statistical and programming skills to maximize getting research answers from ARC's large datasets.

Systematic Autoimmune Rheumatic Disease (SARD)

SARDs consist of a group of diseases with exotic names such as lupus, scleroderma, polymyositis, polyarteritis nodosa, Wegener's, Sjogren's, polymyalgia rheumatica and giant cell arteritis. While none is

common, most can have devastating consequences. For instance, in the past, half of those diagnosed with lupus were dead within 4 years. Survival was worse for scleroderma, polyarteritis and Wegener's. Better management now has 90+% of people with lupus surviving 10 years, but given that most have the disease start in their 20's or 30's there is still room for considerable improvement. We believe that by studying this group of diseases that share many features and outcomes it will be possible to improve both survival and quality of life for all. ARC has recently hired a junior faculty member, but will need support in the years ahead.

Ankylosing Spondylitis & Related Conditions

The disease grouping, spondyloarthritis includes ankylosing spondylitis and related conditions such as psoriatic arthritis and arthritis with inflammatory bowel disease. It appears that spondyloarthritis is as common as rheumatoid arthritis. Yet, there is limited information on basic facts, such as the frequency of psoriatic arthritis and spondylitis. While new treatments are improving these diseases in the majority, ARC scientists have recently noted an increased number of heart attacks and strokes in people with these diseases. In addition to better data on aspects such as disease frequency, there is a need to better understand which patients will benefit from a given therapy, how long they need to continue a treatment and whether treatment can reduce the number of premature heart attacks and strokes. ARC needs to train a scientist to work in this area.

How Will We Get There?

Research is a very people intensive business, and to attract the best and the brightest requires not only compensation packages (salaries and benefits) but also facilities.

Today as ten years ago, ARC's activities are largely housed in 8,883 square feet of space at the Mary Pack Arthritis Centre, in the same neighbourhood as many of Vancouver's academic health centres. This space has not changed as the organization's activities (and staffing levels) have grown over the years. Both staffing and facilities costs at ARC are underwritten largely by donations received either directly or through The Arthritis Society.

Figure 6 below shows how essential donated funds have been in ARC's success. In the graph below, the shorter bars reflect the total donated funds provided for ARC operations in each of the two years presented. The taller bars represent the funds levered: that is, the amount of grant and contract money that have been awarded to and earned by ARC scientists in these years. Firm salary support (funded by donations) allows these scientists the time that is essential to successfully apply for competitive funding and negotiate clinical trial contracts with industry.





Need for Ongoing Salary Support for Scientists

ARC has hired new scientists with monies donated to The Arthritis Society of Canada. All of the new scientists have won salary awards from research agencies such as the Canadian Institutes of Health Research, the Michael Smith Foundation or The Arthritis Society of Canada. These awards provide only partial salary support (generally \$ 50,000/year) and they are generally limited to new faculty and available for a maximum of 10 years. Eventually, the expectation is that The University of British Columbia will provide salary support for the new faculty but there is often a funding gap between the partial awards from external agencies and university support. It is critical to ARC to be able to support the outstanding current faculty and to attract new faculty. To accomplish this, funding must increase in the coming years.

Research funding awards for scientists salary support are becoming slim to non-existent. One example is the Michael Smith Foundation which is funded by the Province of BC. The Michael Smith Foundation announced that due to decreases in funding, they will not have funds to offer scientist salary awards for 2009.

Need for Infrastructure and Administrative Support

To move forward with the visions within the Scientific Plan there will be a need for additional infrastructure and administration support. There are two major concerns facing the centre for funding in the future, one is salary support and the other is space.

• Infrastructure Support

The current plan of moving into the Centre for Hip Health and Mobility will not provide us with the space we require over the next five years. ARC will need approximately another 2200 Sq ft. of additional office space either within the current centre at Mary Pack or will need alternated space within the close proximity for expansion of the ARC team.

Additional infrastructure support of equipment such as copiers, printers, desks and telephones will also have to be considered and will be included as a subsection on the five year budget plan. Of course, the costs could be higher if a new location needs to be found rather than keeping some space at the Mary Pack Centre.

• Administrative Support

On the administrative side we will also need an addition of approximately 1.0 FTE – 1.5 FTE of administrative support to support the additional staff at both sites.

Appendix One - ARC Staff July 2009

Research Scientists

Antonio Aviña-Zubieta Aslam Anis, Senior Scientist Catherine Backman John Esdaile, Scientific Director Hyon Choi Jolanda Cibere Donald Garbuz Neslon Greidanus Jacek Kopec, Senior Scientist Diane Lacaille, Senior Scientist Linda Li Matthew Liang Carlo Marra Kam Shojania Ian Tsang

Appointment Pending:

Maureen and Milan Ilich/Merck Frosst Chair in Biostatistics

Administration

Shauneen Kellner, Executive Director Brenda Kapusta Lisa Singh

Clinical Trials

Nancy Ellis Janet McKenney Patricia Patrick Selena Roy

Consumer Advisory Board

Lianne Gulka Otto Kamensek Allen Lehman Joyce Ma Colleen Maloney Pam Montie Céline Pitre Nadia Prestley Gordon Whitehead

Research Support

Research Coordinators Zubin Amarsi Lorna Ottley Helen Prlic Pam Rogers Daphne Savoy

Research Assistants Karen Joe Weiqun (Courtney) Kang Amy Kirkham Cynthia MacDonald James Rankin Katie Rogers Nicole Prestley Jesse Veenstra

Statistical Team Jaafar Aghajanian Mushfiqur Rahman Eric Sayre

Trainees

Vidula Bhole Mary De Vera Lynne Feehan Courtney Kang Allen Lehman Mushfiqur Rahman Chuck Ratzlaff Robin Roots Rick Sawatzky Eric Sayre Helia Sillem Winnie Tam Marie Westby



Appendix Two – Publications