

Canadian Arthritis Patient Alliance

by: Anne Dooley
December 2003

The Canadian Arthritis Network is designated a Centre of Excellence (NCE) in Arthritis Research by the Network of Centres of Excellence, a federal research-funding agency, because it meets the stringent requirements that are demanded of such an organization. CAN was first created in 1998 and awarded NCE status along with an initial \$14.4 million grant. Since then CAN's researchers, employing a 'team approach', have made great strides in knowledge about arthritis and CAN is recognized as a leader in osteoarthritis research.

NCE status must be renewed at regular intervals for this research to continue. The renewal process is lengthy and involves federal scrutiny at every level. Letters of support are important to the process. The following letter was written in support of CAN renewal on behalf of CAPA. Individual letters of support are welcomed.

December 12, 2003

Drs. Robin Poole and Jane Aubin
Co-Scientific Directors,
Canadian Arthritis Network
Suite 402
250 Dundas Street
Toronto, ON, M5T 2Z5

Dear Drs. Poole and Aubin,

The Canadian Arthritis Patient Alliance (CAPA) supports the renewal of the Canadian Arthritis Network (CAN) as a Network Centre of Excellence (NCE) for Arthritis Research. CAPA is a national organization, which creates links between Canadians with arthritis, assists them to become more effective advocates and seeks to improve the quality of life of all people living with arthritis. The innovative research carried out by the Canadian Arthritis Network is crucial to the health and well being of CAPA members, and of all people living with arthritis.

The most prevalent form of arthritis is Osteoarthritis (OA), and CAN's effective and efficient, trans-disciplinary team-approach to research and research planning has made it a recognized leader in this field. CAN was one of the lead partners in organizing the first international consensus conference on OA, an extremely important event for advancing

arthritis research. The OA Consensus conference, with significant input from people with arthritis, resulted in a strategic initiative on OA.

CAN has a critical role to play in implementing that strategic OA initiative. The three CAN OA research projects announced in November of 2003, will provide many crucial answers to the riddle of this disease, including knowledge of pain and fatigue mechanisms and information to enable earlier and better disease detection and management. Because this painful and debilitating disease costs individuals, families, workplaces and governments billions of dollars annually, these answers are incredibly important. People with arthritis who bear the heaviest physical, emotional, economic and social burden of this disease stand to reap important benefits from this research. CAPA is truly grateful.

The expert in arthritis is the person who lives with it. One reason why CAN's 'team-approach' is so effective is because this 'expert' is included as part of the research team. Among the NCEs, CAN is unique in the degree to which it involves consumers. CAN has had a consumer on its management team from the beginning and has integrated a consumer group into its structure. This body, the Consumer Advisory Council (CAC), is made up entirely of informed and dedicated people with arthritis. In so doing, CAN has led the NCEs in the concept of active consumer participation. This is seen through consumer membership on all CAN committees and at all levels of research planning. However, CAN's commitment to the principle of consumer participation extends well beyond its own membership. A good example of this is the knowledgeable CAPA member that CAN invited to join its Research Ethics Advisory Group.

CAN's experience with consumer involvement is having an impact beyond CAN. The efforts of our organization to expand consumer influence to other policy and program decision tables has benefited from the example set by CAC. Other organizations observe what CAN has done and, as a result, Canadians with arthritis are invited through CAPA to participate at arthritis related policy and research planning tables of various organizations and provincial and federal governments.

The benefits of CAN are, therefore, greater than the sum of its research, training and product development program. Through its integrated approach, CAN has greatly accelerated the process of bringing research to practical applications. CAN is one of the key features in today's arthritis landscape. It plays a unique and essential role. We cannot overstate the importance of CAN for people with arthritis.

Sincerely yours,

Anne Dooley, Chair
CAPA, Research Committee

On behalf of the Canadian Arthritis Patient Alliance (CAPA).

