

## **Consumers and Arthritis Research : Valued Partners or Just Strange Bedfellows??**

And so we begin at the beginning.

In the late 1990's at a conference called "Arthritis 2000" the idea of an organization dedicated to arthritis research was born, it was named the Canadian Arthritis Network, and it was the first disease specific offspring of the Networks of Centres of Excellence, which fosters powerful partnerships between universities, government and industry, but little did they know that this particular offspring would step way, way out of the mold and also foster equally powerful partnerships with arthritis consumers. This change in tact for the new born CAN was largely due to the tenacity of Cheryl Koehn who, in attendance at "Arthritis 2000", refused to have her voice silenced against the deafening roar of the key players in the arthritis community.

And so it was fitting that Cheryl took the lead as the first Chair of the Consumer Advisory Council of CAN in February of 2000, and she chose 4 arthritis consumers from across Canada, from different backgrounds and walks of life to join her in this ground breaking endeavour of assimilating arthritis patients into the inner sanctum of arthritis research as full partners OR in other words trying to pound a round peg into a square hole. I joined the Council just in time for the Osteoarthritis Consensus Conference in April of 2002, which was indeed baptism by fire. In the fall of 2002, at the CAN Annual Scientific Conference, at the inaugural meeting of the Alliance for the Canadian Arthritis Program, four consumers were asked to go back to the arthritis community and survey them to see if CAN was 'on the money' (so to speak) about the 6 research priorities identified at the Osteoarthritis Consensus Conference and they gave us 60 days to bring back our findings. And we did, returning with the evidence in hand that in fact, the priorities were close, but then close only counts in horseshoes. Arthritis patients had spoken loud and clear that as important to them as the issue of pain was (and pain was identified as a research priority), equally important was the issue of fatigue. And so the research questions were tweaked and the value of consumer participation in research was validated. We were able to go back to our community and tell them that their voices had been heard and would be acted on.

The Consumer Advisory Council has never looked back from that time on. As high as the networks expectations of us have been, ours for ourselves have always been higher. We never ride on our laurels, but continue to stretch ourselves to meet the new challenges we face.

And so where are we today?? Our Mission is this: "On behalf of people with arthritis, the Consumer Advisory Council meaningfully contributes to improve the relevance and accessibility of CAN's work." We developed Terms of Reference, a Strategic Plan and a Succession Plan to work from, and these are living documents which are reviewed and adjusted as the needs and demands of the Council and the Network dictate. We have a budget that we are responsible for and accountable to which is approved and funded by CAN each year. We broadened our representation from the original handful of volunteers to now having representation from all but 2 provinces and we have had a representative

from the Northwest Territories and the Aboriginal community. We have sought and achieved alliances with the Canadian Arthritis Patient Alliance, Patient Partners in Arthritis, Arthritis Consumers Experts, the Children's Arthritis Foundation, Arthritis Montreal, the Arthritis Research Centre's Consumer Advisory Board and the Cochrane Collaboration's Musculoskeletal Group. The members of CAC wear many, many hats in the arthritis community, putting in extensive hours of volunteer work to advance the arthritis agenda. In 2006 alone the members of CAC logged over 5300 hours of volunteer service in the arthritis community. We do extensive training at our in person meetings, inviting researchers to speak to us about their research, touring arthritis research labs, the Canadian Light Source synchrotron in Saskatoon, and learning more about other forms of arthritis by inviting disease specific associations to come and speak to us and where ever we have gone and what ever we do, we always invite local arthritis consumers to these education sessions to foster relationships, to mentor other advocates and to build capacity. While some members on the Council have a scientific background, most do not and so in order to contribute meaningfully to the activities of the network, we faced a learning curve that looked more like a hairpin turn. We struggled initially in learning 'research speak', and were furiously looking up definitions in our dictionaries in order to follow the discussion. We now work with a glossary of scientific terms and those universally dreaded acronyms. The concepts were at times difficult to grasp, but we worked valiantly to get up to speed for indeed, arthritis research is not for the feint of heart. We fought for, and the network established, a policy of lay, or plain language, summaries with all grant applications. This wasn't just an effort to dumb down the wording so that we would understand it, we felt very strongly that it would benefit the network and it's researchers from a knowledge translation and exchange perspective. For surely if we can't understand and communicate the benefits of the research to the broader community, who does it actually benefit??

The Consumer Advisory Council collaborates on most if not all research projects, and even though it started by just adding the name of a consumer to the project to technically qualify for network funding, it has become truly a collaborative effort with consumers adding the relevance and the perspective of someone actually living with the disease. We have representatives on all established and ad-hoc committees, themes, disease cores, consensus conferences and peer review panels, and in fact, consumers have gone from being the in-vogue addition, to an integral part of any initiative throughout the arthritis community in Canada. It is no longer a politically correct, altruistic decision to include consumers, it just plain and simply good business. The perspective of the consumer has brought a new and distinct motivation to trainees and researchers alike. We have recently been offered a seat on the board of directors of CAN, and although it's as an observer only at this point in time, we feel confident that as we demonstrate the merit in having a consumer representative on the board, the position will be given voting privileges.

The NCE report after the first cycle of funding made note of the unique nature and success of involving consumers in the Network and suggested that it could serve as a model for other NCE's. Consumer involvement in CAN was highlighted as one of CAN's strengths.

The Consumer Advisory Board has faced a number of challenges over time. I recall my first meeting as a newly appointed council member with what was then the Research Advisory Committee. At a break in the proceedings, one of the researchers came up and introduced themselves to me and I introduced myself as well. They asked me what discipline I worked in and I said that I actually worked in Construction, at which there came a look of puzzlement. I explained that in fact, I was a consumer. That I had Rheumatoid Arthritis. And this person looked at me and said “A consumer?? But you look so happy and you look so healthy”, to which I answered, “Well,..... I AM happy, and I AM healthy” and I thought to myself “Boy, oh boy, we haven’t arrived a minute too soon”. We’ve struggled at where we fit in to the scheme of things in the research of topics more obscure to our reality, such as bioengineering, or preclinical models. But we endeavour to learn about the topic by going to the experts in it, which invariably leads to a revelation and a patient perspective which enables us to give back to the process. One of the stumbling blocks we continue to face is gaining access to the published literature on arthritis. As only a handful of consumers have access to the scientific journals through their affiliation with a university, our access to the knowledge already gained through research remains elusive to the very people that the research was done to benefit. Today, the consumer perspective is a necessary addition to each of the symposium panel discussions at the annual scientific conferences. Although the consumers have always worked so well together, there was certainly a period of adjustment as we learned how to communicate with one another and fleshed out where each of our strengths and challenges lay and how we could best meet the needs of the network, its members and the arthritis community at large. We came from a variety of backgrounds, diagnoses, ages, family dynamics and careers. At my first meeting, I wondered how would I, with my background in construction, work with a professor of pharmacology; a man with a PhD in some kind of biochemical revelation; woman who had been a Olympic bound athlete who had a background in marketing and communications and who was now know quite simply the Queen of arthritis advocacy, and a social worker with a passion for eradicating poverty (which included protesting against government by sleeping in the park with the homeless) and advocating for the disenfranchised and victims of violence in war; all work together to make change?? Actually it was much like the idea of researchers working in trans-disciplinary, multi-institutional teams. It’s rough at the beginning, but if you stick it out, you come to appreciate the value of everyone’s contribution, and over time, it changes the way you see the world, your world and everything in it. I learned so much from that first group and from each and every addition and deletion (and there have been a few) to the council ever since. We have learned to hold our retired members close by naming them ‘emeritus’ and continuing to call on them for advice and guidance as the council moves forward to the future.

It has continued to be a challenge to do this work, balance our lives, and livelihood and live with arthritis too. There are times when our energy lags, the fatigue hits hard or changes in meds or a surgery will lay us low for a period of time.

So what of the future?? Including consumer participation in the allocation of research funding through the peer review process has increased the perception of the broader arthritis consumer community of the relevance of arthritis research. However there is

still a considerable amount of work to be done in KTE and I believe that the consumers can and will play an important role in that. Research findings are of no value to the population the research was done to benefit if they're simply published in a journal and stored on a shelf. That should be the beginning of the story, and not the end. The information needs to be disseminated to those who can make best use of it and benefit from it.

The recent announcement of the International Partnership Initiative is a wonderful opportunity for CAN and for the Consumer Advisory Council to continue their outreach beyond Canada's borders to a diverse international population of people with arthritis. Our experience working within the arthritis research community can be used as a model for consumer inclusion in other countries. The really exciting part about this prospect is the possibility of CAN moving forward beyond the end of federal funding in a few short years. CAN has changed the dynamic and culture of research in Canada but more importantly has given hope to millions of Canadians living with arthritis. Rather than arthritis research being some 'pie in the sky' concept to people with arthritis, it's a reality that has given them solid hope for their future. We have invested our time and perhaps our most precious commodity, our energy, in helping to make CAN a success and to lose that would be devastating. We must continue on the trail we have blazed, there's a lot riding on it for millions of Canadians, today and many more to come in the next number of years.

And so in conclusion, I would submit to you that Consumers have proved to be both **Valued Partners** *and* **Strange Bed-fellows** in Arthritis research. It's that odd, but snug fit that has turned a rather competitive field into a collaborative venture and that which makes the Network successful and a leader in arthritis research.