

Note from the CAREB President

As the summer draws to a close, the CAREB Board and committees have had no rest in the sun. Instead, they have continued to be engaged in the planning of several exciting new projects. I am very thankful to them for their unwavering enthusiasm and look forward to seeing the projects come to fruition in the next few months.

Against this backdrop, we are, regrettably, saying farewell and thank you to Dr. Diane Martz, a long-standing CAREB Board member, as she leaves the research ethics field for a new post at the University of Saskatchewan. Diane has been an important part of CAREB and a powerful force in the establishment of professional development activities since she began serving on the Professional Development Committee (PDC) in 2009.

Diane took over as Chair of the PDC in 2010 and served as Vice-President, PDC from 2011-14. Her commitment to CAREB over the years has been unwavering, as she spearheaded the creation, development and, on several occasions, execution of CAREB pre-conference workshops throughout her tenure. She has participated in the planning of the CAREB National Conference for many years (Diane joined the Conference Planning Committee in 2007) and has been a regular presenter on a multitude of topics. Diane's contribution to the CAREB Board of Directors on other matters has been significant, providing expert advice in the development of policies, position statements and in overall strategic planning.

Diane's "baby" over the last 3 years has been the CAREB REB professional certification program. Starting with a needs assessment survey of the

membership, she has worked tirelessly on developing the business strategy and speaking with various stakeholders to understand how to propose and develop a program that will promote as well as benchmark professionalism in the research ethics field in Canada. As the program enters its next stage we thank her for all of the energy and time she has poured into developing a clear and sound path.

Finally, on a personal note, I would like to speak of Diane as I know her, as a colleague and a friend. She is strong, intelligent, committed and talented. She is both a well-respected researcher and an excellent administrator. She very deservedly won the CAREB President's Award in 2012 for her contributions to CAREB and to research ethics in Canada. I have had the privilege of working with her over the past 8 years and will miss her soothing voice on a tense conference call and her smile at a grueling Board retreat. Although she is now embarking on a new position with new challenges, I know that the professional and personal relationships that she developed through CAREB will remain important to her.

We wish her well.

Rachel Zand
President



Dr. Diane Martz

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Pre & Post

About the CAREB Newsletter

CAREB Pre and Post is not a refereed journal and does not publish full length articles. The opinions expressed are those of the writers, and do not necessarily represent the views of CAREB. CAREB Pre and Post will be distributed via the CAREB listserv and can be read on the CAREB website: <https://www.careb-accor.org/>.

Contributions are welcome. If you have a suggestion for upcoming editions of the newsletter or if you would like to contribute an article, please email: post@careb-accor.org.

Learning to Listen: Reflections on Fieldwork in First Nation Communities in Canada

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Almost all graduate and undergraduate programs now require training in research design and ethics; students learn how to conduct and transcribe interviews, run focus groups, and ensure that they have informed consent from their participants for their research. Yet, even with all of this training, our research is often met with circumstances that challenge us to re-think what we thought we once knew about our research and ourselves. When we began our work with First Nation communities in northern Ontario on issues of water quality and the potential intersections of Indigenous and engineering knowledge in water management, we had likewise given a great deal of consideration to how we would approach our project, how we would enter the field, and the methodologies we would use to gather data. We also spent a lot of time thinking about the ethical implications of our work, and of course we sought and received approval from our institu-

tional research ethics board.

Working with First Nation communities requires particular consideration of the ways in which research impacts local participants, and attentiveness to the power dynamics involved in research relationships both historically and over time. We have learned that much of this is not easily accomplished through employing standard 'by the box' institutionalized ethical protocol, but must go further to engage research partners and participants as persons first, and as research collaborators only after mutual trust has been established. This includes approaching communities and conducting oneself in a respectful manner, collaborating with community representatives on the research design early in the process, and gaining a comprehension of the particular histories, values, epistemological and ontological orientations and, if appropriate, the language of the community with whom you work. It requires spending time in the community, and it requires learning to listen.

Learning to listen is not always easy, and it is always an ongoing process. It requires flexibility; it means letting go of your own timetable and relinquishing control of your project. It means that the community sets the research agenda, and not the principal investigator. It establishes a vision that is a collaborative and emergent process, not a static obsession with the outcomes. All of this requires building strong relationships, and, when successful, allows all of us to take risks and to utilize the expertise that we each bring with us to the research program.

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Our primary instruction in learning to listen came from spending time with people in the communities with whom we have worked. It was through visiting with people and having tea with them that we learned the most; it also came through spending time with people on the land. When asked by colleagues and acquaintances in southern Canada: "what exactly do you do for all of those months in the North," our honest response is "mostly we hang out with people." During this 'deep hanging-out' we are both persons and researchers simultaneously, and perhaps it is our engagement in the mundane aspects of everyday life that helps us to learn to see and hear in an appropriate way, one that seeks to break down the insider-outsider dialectic. Yet, this does not inherently address the power imbalances that are characteristic of the research process itself, what anthropologist Stanley Barrett has called the "subversive dimension of fieldwork."^{*} For example, many researchers gain career advancement from their work with First Nations communities, either through grants, publications, jobs or tenure. And, while many institutions now require agreements for intellectual property and more equitable sharing of the benefits of research, the history of research engagement with many First Nations in Canada has been one of appropriation, where researchers enter into communities, dictate methodologies and research questions, extract data, and return to academic institutions for analysis, often times without involving community members in meaningful ways and without designing projects that would provide tangible benefits to communities.

In our work, we made it a priority to come together to identify questions

and methodologies that were important for people in the communities. We hired community-based researchers to help direct the project, and we listened to them when they told us that our methodological approaches were not working, and when they suggested new ones. We hoped to foster a capacity for inquiry and for research that would extend beyond the life of our project, so that with the equipment and the experience gained by the community based researchers, the community could take over the project and direct its future in years to come. It was our hope that rather than providing the community with a report or an academic paper at the end of our work, that we could collaboratively design a project that people could point to and see themselves in, in a meaningful way. For us, it involved turning what started out as one on one interviews about people's experiences with water quality in their community, into a project that involved story circles, digital storytelling and cultural mapping. In the end, we learned a great deal more about people's experiences with and relationships to water by employing methodologies developed by the community rather than we would have clinging to our initial research design.

At times, the process was frustrating. At one point when one of the community-based researchers called us late one evening with concerns about the methodology, we put a moratorium on the project until we could all receive guidance from legal counsel about the potential impacts of our data collection. There were often times when we felt like we had little direction, that we were even scattered. In this sense, one of the most important lessons that we

have learned is that collaborative research is necessarily an emergent, long-term process that may not yield immediate results. Yet, if we trusted one another, and if we were patient, we sincerely felt as though we could accomplish something meaningful together.

The significance of sincere interpersonal connections in knowledge transfer is nothing new to many people in the communities in which we have worked. Nor is the value of spending time getting to know one another. The importance of working together is echoed in stories and in Prophecies, and forms an important part of how people approach the establishment of relationships. In our work, we have found that many community members approach decision-making processes as opportunities to do what human beings should do when a big decision is to be made: to sit down and talk with one another. This assertion speaks to the value of the creation of intersubjective space over time, and to the ongoing collaboration involved in the two-way transfer of knowledge. To our surprise, many people in the communities that we have worked in welcomed us as human beings *and* as researchers. Perhaps this is because there is a hope that when human beings work together as human beings first, and as researchers second, the process of building relationships, trust, and knowledge can be translated into the service of inquiry *and* to the benefit of communities. This is not an uncomplicated process, especially given the logistics of working in Northern communities, but it is one that is vital if we are to build research practices that extend beyond cooptation and imposition, to begin to listen appropriately.

^{*} Barrett, Stanley (1984) Racism, Ethics and Anthropological Inquiry. *Philosophy of the Social Sciences*. 14:1-25.

CAREB President's Award Recipient - Janet Manzo

The President's Award recognizes a CAREB member for advancing CAREB's objectives through outstanding contributions and commitment to enhancing the protection of human research participants and improving the effectiveness and efficiency of the processes of ethics review of human research. This individual fulfills the criteria perfectly, and has been instrumental in their contributions to both CAREB and to the Canadian research ethics more generally.

The 2014 President's Award winner is Janet Manzo, Executive Director of the Ontario Cancer Research Ethics Board. The award was given in Montreal at the April 2014 CAREB National Conference and AGM.

Before entering research ethics, Janet had a 20 year career in clinical research. In 2002 she joined the Ontario Cancer Research Network (now the Ontario Institute for Cancer Research) where she was responsible for the creation of a successful Clinical Trials Network to meet the needs of over 250 oncology clinical trials professionals across Ontario. In 2006, she was appointed as the Executive Director of the Ontario Cancer Research Ethics Board (OCREB) and led the development of an innovative model of centralized research ethics review across oncology centers in Ontario. To this day, this model has been referenced by many other harmonization efforts across the country.

In 2008, Janet was elected to the CAREB board for a 3-year term as a Member at Large, where she was instrumental in leading the development of the CAREB guidance document for Serious Adverse Event Reporting and provided critical information to the CAREB board regarding our vote on the Canadian General Standards Board (CGSB) Committee. She has been involved in several workshops and conference-related planning throughout her term and beyond.

In 2012, Janet was appointed to the External Advisory Committee for the Streamlining of Health Research Ethics Review (SHRER), in support of the Strategy for Patient Oriented Research (SPOR) sponsored by CIHR, ACAHO and Rx&D. More recently, she was seconded to Clinical Trials Ontario (CTO) to assist CTO in their REB harmonization efforts.

Janet has developed a solid reputation within the CAREB membership and across the country for strategic collaboration, energy, enthusiasm, and a great love of all things Italian. We know that she will continue to work with CAREB to promote research ethics efficiency and effectiveness from process to strategy.

CAREB asked Janet a few questions about her career in research ethics; we are pleased to share her responses with you below:

1. How did you get started in research ethics?

It was completely unplanned. I had worked in clinical research for years, on both the researcher side and the sponsor side. I knew little about research ethics boards and even less about REB operations. In late 2005, I had been working at the Ontario Cancer Research Network (OCRN) for three years as the Director of the Clinical Trials Network (OCRN was the predecessor to the OICR). OCREB had been in operation for almost two years by then, so I was certainly aware of the program when the previous Executive Director of OCREB decided to move on, and the CEO of OCRN asked if I would be willing to take over. I wasn't terribly confident that I had the necessary skills or experience to take on the challenge, but thanks to encouragement and support from the oncology research community, I took the plunge. And the rest is history - a long and stressful history for me, but ultimately a rewarding one.

2. What are some of the biggest challenges you have faced in this field?

When I officially became the Executive Director of OCREB in January 2006, I realized that although some of the groundwork had been done, I was facing considerable challenges. I had to get up-to-speed on research ethics operations in general AND figure out how to successfully expand and operationalize a new model of ethics review while at the same time familiarizing myself with a very different culture and finding ways to demonstrate value and build trust in the model. I was certainly familiar with a highly regulated environment, but not one that included shades of grey in the interpretation and application of ethical principles and guidelines. Trying to decide



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what needed the most attention felt like a juggling act. Thankfully OCREB (the REB) was solid, but the processes in support of the centralized model had not kept pace. At the time that I got involved, the volume of new submissions was low with few active studies and only a handful of sites were using OCREB, so things worked with fairly informal process. However, I knew that scalability would become critically important, and that we didn't have much time. Preparing our systems would include the development and implementation of formal policies and procedures. In addition, we would need extra office staff and succession plans for REB members. With "a little help from my friends" (colleagues in the field and beyond) and the implementation of an online submission system in early 2011, OCREB began to soar.

3. What are some of the most important things you have learned while working in this field?

Gosh. I've learned so many things in my role in research ethics. First and foremost, I learned that those who serve on REBs truly are special people. Without a doubt, they put the participant first when deliberating over complex scientific and ethical issues. No matter how bad a day, week or month I've had, I find attending REB meetings enlightening and rejuvenating.

Although my expertise is in operations, I've learned that the field of research ethics is complex and constantly evolving and it is important to consider different perspectives. The application of ethical principles is rarely black and white.

Another thing I've learned that might be specific to OCREB is that it IS true that most new initiatives take way longer and require much more effort than you think to make them successful. Especially if they require a very new way of doing things. All change is difficult, and significant change naturally more-so. When managing change, the importance of engaging stakeholders early and communicating with them often cannot be understated.

On a personal level, I think I've always been persistent, but I've learned that it's a good quality to have, particularly for anyone trying to implement a new, innovative program. To build a successful OCREB model required per-

sistence. To be the first REB to be qualified under the Clinical Trials Ontario (CTO) REB Qualification Program feels like a crowning achievement.

I've also learned to be more resilient and that certainly helps.

4. Do you have any advice for newcomers to research ethics administration?

Be patient. It takes time to learn the ropes in such a niche area. Reach out to your colleagues including REB members and researchers. Keep an open mind. Consider various perspectives. If possible, find out how other REB offices operate in addition to your own and attend meetings of other REBs. Join CAREB and attend its national and regional meetings, including the pre-conference REB 101 workshops. Seek out ethics education sessions offered by REBs and universities. Some of these sessions, such as those offered by the Joint Centre for Bioethics at the University of Toronto, can be viewed online. Find a mentor. Get involved in the ethics community. Join your policy and procedure committee or create one if it doesn't already exist. Keep abreast of the guidelines and regulations. Engage in relevant provincial and national initiatives.

5. What are your future endeavors?

Whenever I am asked that question, I say that I would just like to "coast" for a while, but by "coasting" I mean working 100% of a normal working day! And I'm only half joking. I do enjoy having more balance in my life. The OCREB members and staff are stellar, so OCREB pretty much runs itself now. OCREB is currently working towards becoming the central REB for a select group of pediatric studies. That is keeping me challenged. Also, preliminary discussions are underway with other provinces to explore ways to streamline ethics reviews more broadly. In addition, I have been seconded to CTO for up to a day a week to provide input on their REB streamlining efforts. I have also been asked to serve on various provincial and national committees related to the streamlining of ethics review processes. Oh and by the way - OCREB isn't perfect so there is still room for fine-tuning on the home turf too.

Thank you, Janet, for taking the time to respond to our questions. Congratulations on your much-deserved award!

Membership and Communications Committee

The CAREB Membership and Communications Committee (MCC) is dedicated to facilitating communication between CAREB members via a number of mediums. In March 2014, the first edition of the CAREB newsletter – CAREB Pre & Post – was launched. CAREB Pre & Post is a quarterly newsletter touching on current events in the field of research ethics. It also serves as a medium for CAREB members to announce various workshops and conferences taking place across the country.

The MCC is also responsible for the CAREB website, emails, listserv, and forum. The listserv* is currently one of the most active mediums CAREB members use to distribute ideas, announcements, and queries. The MCC is working towards having CAREB members use the forum – <https://www.careb-accr.org/forum> – for queries requesting a response from REBs across Canada. With the use of the forum, CAREB members are able to view all queries and responses in a clear and concise format.

The CAREB website has undergone a number of changes over the past year, with more to come. This fall, the website will be re-vamped; all older content will be replaced with current content. CAREB is conscious of the need for members to have an updated, current website which will facilitate

REB administration across Canada.

Over the course of the next year, the MCC is working towards developing and fine-tuning CAREB social media, such as Twitter and Facebook. Currently, the CAREB LinkedIn group is very active, with many articles of interest being posted on a regular basis. Join our LinkedIn group today to get in on the discussions!

***If you are not receiving listserv emails, please contact post@careb-accr.org in order to be added to the distribution list.**

Professional Development Committee

This year the Professional Development Committee has been tasked with an enlarged set of responsibilities in addition to organizing the agenda and speakers for the pre-conference workshop and poster competition. The CAREB Board has asked the professional development committee to develop a proposal for offering webinars focused both on training for practical skills and also on emerging issues in research ethics. As a result, three subcommittees of the Professional Development Committee have been formed.

Subcommittee 1 is responsible for developing and executing the Pre-Conference Workshop day which will precede the CAREB 2015 Annual Conference and for managing the poster competition. In order to ensure the most relevant

topics are identified, the PDC is collaborating with the MCC to develop an online Needs Assessment Survey. Look for the survey to be circulated to members via the CAREB Listserv, this fall. This subcommittee will also shortly be circulating a call for workshop presentation proposals and a call for poster abstracts. We hope for a strong response from within CAREB.

Subcommittee 2 is responsible for creating a Practical Skill Development Webinar Certificate Series for research ethics professionals. The webinar topics to be selected for this series fall outside the proposed CAREB REB Administrators and Practitioners Certification Program. Currently, subcommittee 2 members are in the process of selecting three webinar topics for this Webinar Certificate Series. Their selection will be based on a review of the draft proposal of the Certification Program to ensure that selected topics do not overlap. The committee members will use the Needs Assessment Survey responses to tailor the webinars for ethics professionals' specific needs.

Subcommittee 3 has been working on developing and implementing a suite of webinars focused on emerging issues in research ethics. Feedback will be sought on a number of key pre-implementation indicators of success (such as interest in potential webinar topics, and likelihood to participate in the webinar series) through the Needs Assessment Survey.

Results from the CAREB National Conference Evaluation

Lori Walker
CAREB Vice-President
and Chair of Conference Planning Committee

On behalf of the CAREB 2014 Conference Planning Committee, I would like to thank everyone who helped make this year's conference a success! Over 300 participants attended the two day event that included five keynote speakers, eight breakout sessions and 6 update sessions from relevant organizations. Feedback has been overwhelmingly positive with 93% of respondents rating the conference program as both relevant and stimulating. Further information and copies of available presentations can be found on the CAREB website:

<https://www.careb-accer.org/content/careb-accer-national-conference-agm-2014-materials>

As has become standard for CAREB, the 2014 conference was preceded by a day of professional development workshops, from introductory to advanced, for REB members and administrators. Over 125 attendees participated in 10 workshops, including the popular one-day REB Administrator Basics. These sessions continue to be very well received and represent quality training for REB administrators and members.

This year, for the first time, CAREB partnered with the Canadian Animal Ethics Coordinators (CAEC), extending the conference to include a CAEC workshop/meeting for 30 people. CAREB engaged Jonathan Kimmelman, Associate Professor Biomedical Ethics, Department of Human Genetics, Experimental Medicine, McGill University, to deliver a talk on clinical translation to the group. The meeting was a success and plans are underway to see how we can further collaborate in the future given the number of Research Ethics Administrators cross appointed (so to speak) and also responsible for Animal Care in their institution.

LOOKING FORWARD

This year's Conference Planning Committee is already busy planning CAREB 2015, to be held in Vancouver at the Fairmount Waterfront, and welcome your ideas for session topics (contact lori.walker@brocku.ca).

Mark your calendars now – the Conference and AGM will be held May 1st and May 2nd with professional workshops on April 30th. We hope to see you in Vancouver!

Promotion: National Health Ethics Week

Save the date! The Canadian Bioethics Society (CBS) is pleased to announce that National Health Ethics Week 2015 will take place March 2- 8, 2015.

More details about this year's initiative will be distributed and posted on the CBS website. The CBS thanks the Nova Scotia Health Ethics Network for their support of National Health Ethics Week 2015; and CBS encourages others to contact them to discuss how your organization can also provide financial or in-kind support for the initiative.

In order to help facilitate an increase in the number of participating organizations, there will be no registration fee this year. Please help CBS to spread the word about National Health Ethics Week to your colleagues and partner organizations.

National Health Ethics Week is a time set aside for Canadians to host and attend events that explore health ethics issue, and aims to:

- Encourage the organization of events to raise awareness of ethics issues related to health and healthcare across Canada
- Provide greater visibility for Canadian ethics committees, services and supports
- Provide an opportunity for Canadians to engage in dialogue regarding current health ethics issues facing their communities

For more information about National Health Ethics Week, please visit <http://www.bioethics.ca/ethicsweek> or contact Amy Middleton at ethicsweek@bioethics.ca

UPCOMING EVENT

Save the date!

CAREB Atlantic 2014:
Dalhousie University, Capital Health and the IWK Health Centre invite you to attend CAURA East/CAREB Atlantic 2014 to be held at the Lord Nelson Hotel in Halifax on November 13 - 14th.

For further information please contact research@dal.ca.