

# THE NETWORK NEWS

JANUARY 2018 | VOLUME 2, NEWSLETTER 3 | New Year, New Network



2017 WAS ANOTHER YEAR OF GROWTH FOR CANVECTOR, IN TERMS OF NEW MEMBERSHIP, NEW PROJECTS, AND NEW OPPORTUNITIES. WE'RE EXCITED FOR WHAT 2018 HAS IN STORE!

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**COMING SOON** 

## Dear CanVECTOR friends,

The transition between calendar years is always an interesting time – one of reflection on the past year, but also one of reinvigoration, inspiring hope of what's to come. Looking back on 2017, we remember our trials and successes, while also resolving to accomplish more in 2018. Perhaps we're starting to sound repetitive but here at CanVECTOR's offices, our year's review has left us largely impressed with our network's progress.

We closed out the tail end of 2017 having accomplished a record number of projects and initiatives. Although challenging and stressful at times, our vision of what CanVECTOR could be and how it could better serve our community, powered us through. In the span of 6 weeks, we held a very well-received 2nd annual conference in Toronto, ON (highlights on page 2); submitted a Letter of Intent application to the Government of Canada Networks of Centres of Excellence opportunity a mere 5 days later; completed a bid to host the ISTH 2023 Congress in Montreal, QC; and finally, completed and submitted our first mid-term report to the CIHR Institute of Circulatory and Respiratory Health on CanVECTOR's overall progress in the last two and a half years. To say that we looked forward to the holiday break is an understatement!

Well friends, we assure you that we have not lost steam; on the contrary, we are entering 2018 with the same zeal that drove us in 2017 - that together, the Canadian thrombosis research community can reach unprecedented peaks. Much like many of you, to accomplish this, CanVECTOR has set a few new year's resolutions:

- 1. Strengthen the CanVECTOR family, by encouraging members to identify with the group;
- 2. Develop additional resources to meet the community's diverse needs;
- 3. Formalize and tighten up processes define and manage expectations throughout the network;
- 4. Focus on connections and further grow our social media presence (see page 5);
- 5. Foster the intangible bond of collegiality (aka have more fun together!).

We hope that you all enjoyed relaxing, quality time with your loved ones over the holidays. We are excited to see how CanVECTOR continues to evolve, with the help of your collaborations and contributions, over the next year.

To 2018 and beyond,

Susan R. Kahn

Susan and Marc



TORONTO, ON • NOV 10-11, 2017

# ELEVATE, EDUCATE, & COLLABORATE

2<sup>ND</sup> Annual Conference Highlights





The day before the conference officially began, the CanVECTOR admin team was on location preparing, while our trainees enjoyed a workshop on grant writing and the first mentorship program event







On the first day of the conference (Nov 10), we were privileged to hear talks from a talented group of speakers! Throughout, mentee and mentor pairs took up the challenge of moderating sessions











lf you had a professional headshot section of the Members' Portal (Documents > 2nd Annual Conference Professional Headshots)



There were a few surprises, like an impromptu game of Family Feud! The team of Non-Docs were the winners!







Of course, there were ample opportunities to network and form new connections with fellow members, trainees, patient partners, research personnel, and partner representatives!











The first day closed out with drinks and refreshments at the Partner Recognition and Network Awards reception, before heading to the social dinner event. Conference attendees were able to relax and get to know each other to recharge for the second day of breakout sessions and meetings.









CanVECTOR's 3rd Annual Conference will be held in Montreal, QC at the end of October 2018! More information and details to be revealed soon.

We look forward to welcoming you to la Belle Province!

## The Patient Perspective:

## Thoughts on the Conduct of Patient-Oriented Research Masterclass

For this edition of The Patient Perspective, we are featuring Carol West's (one of our patient partners), experience attending the Conduct of Patient-Oriented Research Masterclass, offered by the Ontario Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit. The masterclass is designed to prepare a cadre of key individuals among patients and families; healthcare providers; policymakers and managers; and researchers and research trainees, to champion and support the conduct and use of patient-oriented research.

I was fortunate to attend, on Ibehalf of CanVECTOR, the 2017 "Masterclass on the Conduct and Use of Patient-Oriented Research", which was held in Toronto from 6-8 November. I was even more fortunate to attend with Jessica Emed, CanVECTOR'S Co-Lead of its Patient Partners platform.

The Masterclass is divided into four groups of participants: healthcare providers, policymakers, researchers (Jessica was part of this group) and my group of patients (and families/ caregivers). With a total of about 50 participants, the plenary sessions were small enough to generate discussion and engagement, but there was also plenty of time allocated to work in smaller groups. One exercise was in a small "mixed" group, which was especially interesting for me, while the other small group work was done with our own team of patients.

What did the patients/families/ caregivers group look like? There were 11 of us, some very experienced in patient-oriented research and others relatively new to these processes and possibilities. On a personal note, I was struck by the effectiveness and level of engagement of those who had become patient partners within the mature and wellestablished arthritis network. I was also touched by the ferocity and determination of mothers advocating for their children who were patients in the healthcare system. A couple of members of

our team had experience with the world of rare disorders, others with cancer care and, in more than one instance, the patient experience was one in which the person's life had been saved within the health care system, and by research. Each of us — regardless of our individual story — was willing to give back in whatever way we could to add value as patient partners in research.

The following notes from our discussions were presented by our group to the plenary session:

#### **KEY MESSAGES**

- Patients, families and caregivers want and need to be meaningfully engaged at all stages and can be extremely valuable contributors when given appropriate opportunities and support
- Attention to diversity and its challenges for POR (means many things, e.g. gender, ethnicity, stage of life, socio-economic)

#### WHAT KNOWLEDGE IS NEEDED?

- Research goals and process, and our roles in it (including timelines)
- Common language about research terms
- What is the supporting infrastructure (mentoring, compensation, social/health support)?
- Expected outcomes and potential benefits to all parties

#### WHAT SHOULD OUR OUTLOOK BE?

- Confidence and desire to share and contribute to make a difference
- Spirit of co-operation and collaboration
- Mutual respect and trust
- Optimism with realistic expectations

## WHAT SKILLS ARE NEEDED AND NEED TO BE DEVELOPED?

- Ability to share and contribute to make a difference
- Utilize individual skills effectively
- Intra-personal (self-awareness) and inter-personal (listening, speaking, respect, diplomacy) skills

In addition to these important and rather formal messages for patient partners, there were several observations that came up repeatedly and generated some interesting conversation:

- 1) You have to have a "thick skin" to be a patient partner there may be rooms and conversations in which your input is not really welcome and this should not be taken personally.
- 2) Patient partners are often told one of two things: you don't have enough knowledge/experience OR you have too much knowledge/experience. Patient partners find this frustrating.

- 3) Although it is important to have a good understanding of roles and expectations, patient partners should also ask specifically: What do you want me to DO? Goodwill is important but it is not enough to create conditions for success.
- 4) Government commitment to patient-oriented research is always welcome, but there is a responsibility for patients to look critically at what is happening, and what can be improved.

The Masterclass was full of content, much of it presented with PowerPoint slides. The curriculum was rich and varied and the faculty was impressive. This was the third time the Masterclass has been offered, and the second time that CanVECTOR representatives have been invited to attend. This is an opportunity to not only build capacity within CanVECTOR, but also to raise awareness of the existence of the CanVECTOR network and its commitment to its patient partners and to patient-oriented research.

Thanks to CanVECTOR and OSSU/SPOR for the opportunity to attend.

P.S. In a future edition of The Patient Perspective, we will share resources from the Masterclass that may be of interest to patient partners and researchers alike.



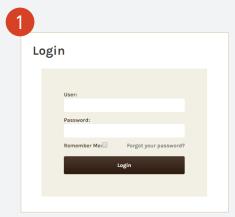
**CAROL WEST** is the CEO of non-profit industry association located in Ottawa, ON. Her academic background in political and policy studies and her work in Canada and internationally reflect her interest in and commitment to the possibilities of government-business partnership. Carol believes that CanVECTOR's engagement of patient partners in a meaningful and institutional way has great potential, and is happy to add value in any way she can.

## Research Coordinators' Corner

Welcome to the Research Coordinators' Corner, this year's new newsletter feature! In this section, we will be highlighting various CanVECTOR resources developed to make research coordination and management easier. In this first edition, we are featuring the Study Start-Up Checklist/Tracker.

With so many steps involved in starting a new clinical research study, a step or two may be overlooked. Download the Start-Up Study Checklist/Tracker to help you stay ahead!

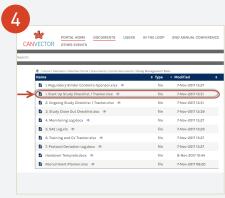
# WHERE CAN I FIND THE STUDY START-UP CHECKLIST/TRACKER?



Log in to the Members Portal.



In the Documents section, select the Study Management Tools folder.



Find the Study Start-Up Checklist/Tracker and download!

# PREFER TO FAST TRACK?



You can skip looking through all of the document repository folders by using the document search on the portal homepage! Simply type in a few key words...



## **Coming Soon**



REMINDER: The deadline to submit abstracts to the ISTH SSC meeting in Dublin, Ireland is February 1st, 2018. Let us all submit our best work!



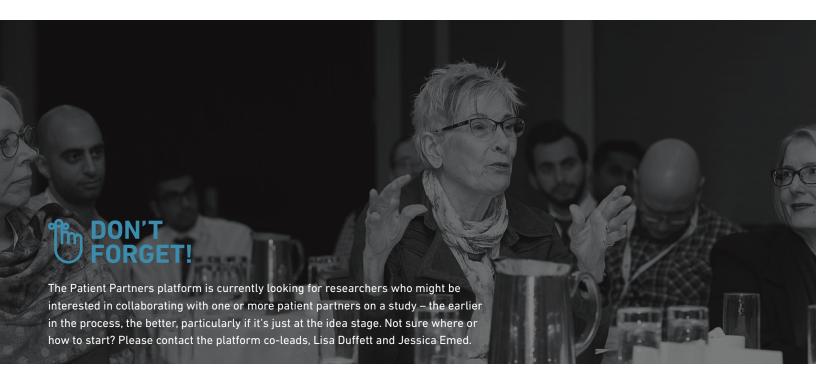
We submitted our first mid-term report to the CIHR-ICRH on Dec 15th. We will share the report with the network in the coming weeks. Stay tuned!



CanVECTOR's social media presence continues to grow. To better reach out to patients and their families, we are now on Instagram. While our content is still being developed, follow us to give us the push we need! Our account is @canvector



The results of the Letter of Intent stage of the Government of Canada Networks of Centres of Excellence grant opportunity will be released in February 2018. Fingers crossed that CanVECTOR is selected to move forward to the next phase!



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