

How Community Building Supports Effective Patient-Oriented Research

Anyone who has ever been to a conference—any conference-style learning event—knows that the most memorable moments often occur between the official “sessions.” What stays with you is the surprise reunion in the elevator, the new friend you made at lunch, or the helpful hand you received just when you needed it. The learning part is important, too, of course. But the COVID pandemic has shown us how the context surrounding learning can matter even more.

You probably know what we mean if you attended this year’s National PH Medical Think Tank and Community Conference in person. Perhaps your understanding is even more profound if you could not attend this year’s conference in person. Attending a few sessions on Zoom can be a poor substitute for opportunities such as participating in small group discussions with your peers, questioning a PH expert while sharing a meal, or hugging a friend you’ve only ever seen through a screen. You might be glad you got some answers during the closing plenary about that new drug you keep hearing about, and still feel like you missed out on the most special part of the conference experience.

Events like PHA Canada’s conference and think tank provide opportunities for patients, families, health care providers, researchers, and advocates to co-create the future of pulmonary hypertension in Canada. Some of this “co-creation” occurs during the programmed plenaries and break-out sessions. For instance, Dr. Jason Weatherald

discovered during the opening plenary this year that his co-panellist, Steve Van Wormer from PHaware, is working on an app to remotely test a patient’s six-minute walk. So, Dr. Weatherald invited Steve to collaborate on an upcoming project where the app could help more people from rural and remote communities participate in the clinical trial. What is harder to identify are the countless interactions that occur over a conference that build empathy and social cohesion between patients, caregivers/families, health care providers, and researchers.

Developing Collective Ideas, Vision & Leadership

PHA Canada’s *Research Capacity Building Project*, launched last Fall, aims to advance the role of patients as partners in PH research in Canada. This requires supporting the development of good ideas and good leaders throughout the PH community. Leading up to the conference, the PHA Canada Ambassador team spent months building their knowledge and skills in communications, storytelling, and advocacy, gaining confidence in their abilities to play a meaningful role in health research.

Stakeholders at every level—patients, caregivers, clinicians, scientists, and advocates—learn to advance patient-oriented research by





developing and testing new ways of working together. This work is enhanced when stakeholders feel a sense of camaraderie with one another. The chance to socialize, celebrate shared milestones, and get to know one another personally helps us be more open to new ideas and collaboration.

At a sunset celebration on the roof of the Delta Ottawa Hotel on June 9, the PH community gathered to honour the contributions of leaders such as Loretta Chu, Roberta Massender, and Nicole Dempsey. Their stories reminded us that we are part of a shared journey and inspired us to take up this collective cause each in our own way. The next day, patients were featured as experts alongside their doctors and nurses at the conference. When patients and caregivers share their personal experiences, they are not only supporting other patients and caregivers. They are educating researchers, clinicians, and advocates on the realities of managing daily life with PH and helping to set priorities for future research.

As the *Research Capacity Building Project* continues, there will be more opportunities for the PH community to listen to and learn from one another. While some of those opportunities will come as webinars or workshops, others may happen over dinner conversation or while figuring out how to find the restaurant together! It all matters as we work together to build a research culture that centres on the values and experiences of patients above all else.

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