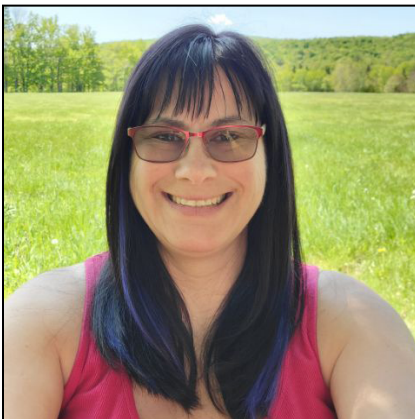




2023 National PH Community Conference

June 9 - 10 | www.phacanada.ca/conference

COMMUNITY CONFERENCE SPEAKERS



Wendy Bedard

My name is Wendy Bedard, I am a caregiver to my stronger half Kendall Tracy!

Kendall was diagnosed with Familial PH in January 2010. His Mother was diagnosed with PH 33 yrs prior at the age of 32 when Kendall was only 3, she survived 6 yrs. So you can imagine how scary it was to get that diagnosis when Kendall was only 36! But we have had angels looking out for us, some unseen and some seen, and here we are 13 years later still able to say he is doing well! I want to add that PH is NOT a disease that affects only the patient but the whole family. I suffered, our children suffered and we still worry everyday wondering what tomorrow will bring. Caregivers are not just wives, husbands, sisters, brothers, moms, or dads. They are everyone that loves that person suffering. I as a caregiver forgot that and took it all on myself only to burn out so if this can help just one of you I will have achieved my goal!

Jennifer Bryson

Jennifer was diagnosed with pulmonary hypertension in September 2012, at the age of 28, while pregnant with her first child. Jennifer has now been living with pulmonary hypertension for over 20 years, and has discovered a lot within that time about herself, health and wellness — what it's like living with an “invisible” chronic disease, and how complete strangers can knock you down or help pick you back up.

Jennifer is passionate about advocating for herself and others living with pulmonary hypertension and chronic disease. She has taken peer support courses, continues to get involved with PHA Canada initiatives when possible, and strives to make a difference in everything that she's involved with.





Dr. Christiansen

David Christiansen is co-Section Head of Respiratory Medicine at the University of Manitoba and is based at St. Boniface Hospital in Winnipeg. He practices in the areas of pulmonary hypertension and general respirology.

He completed training in respirology and pulmonary hypertension at the University of Toronto. He is the Medical Director of the Pulmonary Function Laboratory and enjoys being involved in research and in all levels of medical training, especially in the mentoring of future respirologists.

Anna d'Angela

Anna D'Angela is a Canadian Certified Physician Assistant (CCPA) in Interstitial Lung Disease and Lung Transplant Medicine at St Joseph's Healthcare Hamilton. In this role, she is helping to build a new model for lung transplant care in Ontario that allows patients to access transplant medicine closer to home.

Prior to entering clinical practice, she obtained an MBA in Health Services Management at McMaster University and worked in various organizations in quality improvement and project management roles. She is actively involved in the training of future Physician Assistants at McMaster University.



Nicole Dempsey

Nicole was diagnosed with idiopathic pulmonary arterial hypertension (IPAH) in 2013. She recently transitioned from IV therapy (Caripul) to Upravi. At this time, she benefits from triple therapy to help manage her PH symptoms: Remodulin, Tracleer and Adcirca.

Nicole served as a PHA Canada Ambassador from 2014-16, before being elected to the Board of Directors in 2017 and Board Chair in 2020. She is active on social media where she uses every opportunity to raise awareness and educate others about PH. She is also a passionate advocate for access to PH treatments and has participated in media conferences and meetings with Ontario politicians and decision-makers. Prior to her diagnosis, Nicole worked as an elementary school teacher for 12 years. She resides in Cambridge, Ontario with her husband, Darren, and two young daughters, Carys and Paisley. She enjoys spending time with her family, including her three dogs and 1 bird.



Don Downey

Don's wife Kathy started noticing issues with being out of breath in December 2015, although her issues probably date back even further. After over four years of going back and forth for appointments with her GP and specialists with no diagnosis of what the cause was, Kathy had an episode where she ended up in the ER. While there, the ER doctor showed her a lab report that was on her file from September 2017. She sent a copy of it to Don to have a physician friend look at it. Don asked the physician if there were any questions Kathy should ask the ER doctor. He looked at it for less than a minute and said, "Ask him why you have pulmonary hypertension."

This triggered several tests being done and very shortly thereafter, Kathy received a firm diagnosis of severe idiopathic pulmonary arterial hypertension. Don and Kathy can't know if a diagnosis in 2017 would have prevented her case being as severe as it was at diagnosis in March 2020, however, the realization that a lot of doctors don't necessarily know to look for PH as a possible cause of a patient's symptoms made Don want to investigate a way to change it so that, hopefully, others don't go undiagnosed for long periods of time, even when the signs are all there.



Carolyn Doyle-Cox

Carolyn began her career working in Critical Care Units in both New York and Boston. Upon moving to Canada in 1999, she joined the University of Ottawa Heart Institute where she worked in the Cardiac Surgical Unit; she was one of the clinical nurse educators, and worked as an Advanced Practical Nurse (APN) for heart transplant, ventricular assist devices (VAD), and heart failure.

In 2007 Carolyn became the APN for pulmonary hypertension when the Ottawa PH Clinic was founded. Carolyn has since hired and educated new nurses across PH programs in Canada, written articles for PHA Canada's newsletter, and has published three academic articles relating to her work in PH. She is an Executive member of the Canadian PH Professionals Network and a previous Board Member of PHA Canada.

Lyne Ducharme

It was at the age of 39 when I was finally diagnosed with Pulmonary Hypertension, which I had 23 years ago in April. I was twice a member of the HTPAQ Foundation. Now I've retired to take care of myself. But I know what I'm like, and I'll never give up on people with the disease. I'm going to make the same encounters for them. I'll always be there for them, because they're part of me.





Rejean Dupont

My name is Réjean Dupont and I've been suffering from the disease since 2011. First symptoms in June and 4 months later the final diagnosis of Severe pulmonary arterial hypertension stage 4 and the only treatment was Intravenous epoprostenol 24 hours a day, 7 days a week. Gone from successful upholsterer/craftsman to permanently disabled. That's a punch in the face! For my wife Francine and me. Life changed completely, but I've always been an optimist looking at the glass as half full.

Over the past 12 years, research has enabled me to change medication with fewer constraints. I was able to visit and play with my grandchildren in Calgary. As I always say to Francine, I do everything to see tomorrow, every moment is a joy if we look through the right side of the telescope.

Lindsay Forsyth Brochu

After a long two years of waiting to finally confirm a diagnosis of Pulmonary Hypertension in 2018, then receiving a double lung transplant in June of 2020, I decided I was ready to share my knowledge and experience by giving back and helping others. Since my diagnosis, I have made it my mission to raise awareness and be the voice for those who need it most.

I was born and raised in the Niagara region, and moved to Almonte, Ontario, a small town outside of Ottawa in 2013 with my high school sweetheart Husband, Jason and our two dogs, Callie & Toby. I enjoy crafting, being outside, and spending time with our family & friends.

When the opportunity presented itself to become a PHA Ambassador it felt like a natural step forward for me to help support and make positive changes to better the lives of those affected by PH. I am active within the PH and Transplant community and I always look forward to connecting with new patients along the way!



Dr. Fournier

After medical school at the University of Montreal, Dr Fournier trained in pediatrics and Pediatric Cardiology and completed a fellowship in pediatric cardiac electrophysiology. Since 1986, she joined the division of pediatric cardiology at CHU Sainte-Justine as chief of electrophysiology section. She has also developed expertise in the care of pediatric patients with pulmonary hypertension and neuromuscular diseases. Dr Fournier has developed a large network of outreach clinics of pediatric cardiology throughout the province of Quebec, encompassing more than 5,000 visits per year. She participated in numerous clinical research project, is co- author of 20 book chapters, 130 publications and more than 350 scientific presentations.

Andrea Gardner

Andrea began her nursing career in cardiovascular critical care in the U.S and has been dedicated to pulmonary hypertension patient care since 2011. She is currently the nurse and research coordinator for the Pulmonary Hypertension program at St. Joseph's Hospital in Hamilton, ON. She has particular experience in scleroderma associated pulmonary hypertension and the Canadian Pulmonary Hypertension Registry.



Lea George



My name is Lea George and I am 39 years old. Originally from Newfoundland, I moved to Moncton, New Brunswick 13 years ago for work as a Biomedical Engineering Technologist. All my family (including 2 sisters) still reside in Newfoundland and I am fortunate enough to make about 2 trips a year. I was diagnosed with IPAH in 2016 when I was 33. I had never heard of Pulmonary Hypertension before that. I had been feeling unwell for about a year prior and I knew something was wrong. My family doctor couldn't find any issues and combined with that I had very peculiar initial symptoms -such as a hoarse voice, we were lead down a disadvantageous path. I went from being very physically fit (jogging, weight lifting and aerial fitness) to having to sit to get dressed. Once I finally got diagnosed things moved along quickly with tests, specialists and medications. I did well on oral medications and though my life was completely turned upside down - it didn't ever skip a beat for people outside looking in. I am now doing great overall and accomplished my dream of becoming a mom. I have an amazing 3-year-old son. I have also advanced to manager of the Biomedical Engineering Department at the Moncton Hospital.

Joan Gibson

Joan's daughter, Jane, was diagnosed with idiopathic pulmonary arterial hypertension in 2016 when she was 26 years old. Joan is so thankful Jane is supported by the fabulous medical team at the PH Clinic at the Ottawa Heart Institute, her extended family, and the Ottawa PH Support Group. Joan considers herself to be one of Jane's biggest fans!

Having worked in the federal government for 30 years, Joan understands how the political system works. Her professional experience helps her advocate for better and more accessible treatments for people living with PH. She has also benefitted from spending many years volunteering with Parkinson Canada and other non-profit organizations. Joan is a firm believer in not reinventing the wheel, and is always looking to learn from other well-run organizations.



Tina Giroux-Proulx



In 2003, Tina was diagnosed with Chronic Thromboembolic Pulmonary Hypertension (CTEPH), which was caused by old blood clots that had been travelling to her lungs from a large arterial venous malformation (AVM) in her left leg. She received a double lung transplant in 2015 after the disease progressed to an unmanageable state, about 12 years after her diagnosis.

Today, Tina dedicates much of her spare time educating and informing people on the importance of organ and tissue donation. She co-chairs, with her husband Joel, the Ottawa Gift of Life, in which they, and their team of dedicated volunteers work tirelessly in the Ottawa region to increase awareness on the issue and to get more people registered as organ and tissue donors. In 2019, Tina and Joel were recognized for their efforts by the Trillium Gift of Life Network with the Advocates in Action Award, and Tina was named one of CBC Ottawa's 2019 Trailblazers for her continued advocacy work in the region. Her story is the inspiration behind StayWell Charity, a non-profit organization that provides temporary accommodations for out-of-town patients requiring health care services available only in Toronto, and she continues to work closely with them as a patient ambassador. She is currently a member of the CEO Ontario Health Patient and Family Advisory Board, in which she further advocates for patients with invisible disabilities, rare diseases, the immunocompromised and so much more.

Kelly Gould

Born and raised in Moncton, NB, Kelly Gould is a Registered Nurse working for Horizon Healthcare at the Moncton Hospital. Kelly began her nursing career working in the U.S. before returning to her hometown to work at the Moncton Hospital in 2001. In 2004, she received her National Certification in Cardiovascular Nursing, and in 2015 earned a Bachelor of Nursing Degree with honours from Athabasca University. Kelly worked in the Coronary Intensive Care Unit, Cardiac Rehab program and Heart Function. She is currently the Inpatient Cardiac Educator at The Moncton Hospital and Pulmonary Hypertension Clinic Co-ordinator for New Brunswick.



Dr. Hosking

DR Hosking is Clinical Professor in Pediatrics (Cardiology) at British Columbia Children's Hospital. After initial medical training in Calgary a pediatric residency in Vancouver was followed by neonatal fellowship in Toronto. A year was spent in Australia as Senior Registrar at Camperdown Hospital in Sydney then returning to the Hospital for Sick Children Toronto for pediatric cardiology and intervention catheterization sub specialty.

At present Dr Hosking practices cardiology at British Columbia Children's Hospital with special interest in intervention cardiology and pulmonary hypertension. Recent research interests include the use of Selexipag and Optical Coherence Tomography for evaluation of pulmonary vasculature in our PHT patients.



Jas James

Jas began her journey living with chronic illness in 1985 when she was diagnosed with Lupus. In August 2001, she was given the diagnosis of PAH.

Jas has connected with patients locally, nationally and internationally and has been a part of this community since 2001. Jas is a support group leader for the Vancouver Island PH Support Group and a former Ambassador for PHA Canada.

Jas currently lives in Cobble Hill, BC with her husband Rick and loves to spend time with her family.



Pat Kelly

Pat is a love-struck grandmother, veteran social justice advocate, Tina Turner fan, and Manager, of the Research Capacity Building Project with the Pulmonary Hypertension Association of Canada.

Pat became involved in advocacy and capacity building when, as a young mother working in immunology research at McMaster University, she was diagnosed with breast cancer. Pat was among a small group of survivors who spearheaded the early development of the breast cancer movement in Canada.

Dr. Kemp

Dr. Krista Kemp is a community respirologist and PH expert who directs and works in the New Brunswick Pulmonary hypertension Clinic in Moncton. She is an assistant professor of medicine at Dalhousie University and Memorial university of Newfoundland.



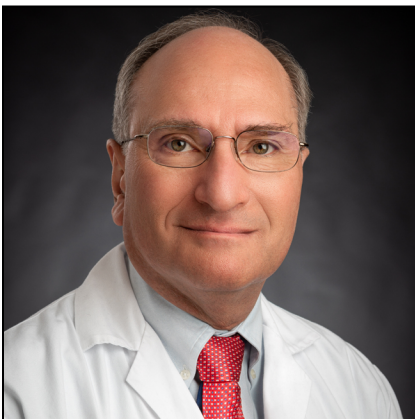


Kelly Kerwin

Kelly has been a Registered Nurse for 33 years. The last 9 years as a coordinator in the Vancouver Pulmonary Hypertension Clinic

Lisa Kolkman

Lisa has been a Nurse Practitioner in the Pulmonary Hypertension Clinic at Vancouver General Hospital since 2012. She has a special interest in prostacyclin therapy, the Canadian Pulmonary Hypertension Registry and the genetics of Pulmonary Hypertension.



Dr. Langleben

Dr. Langleben is a Professor in the McGill University Faculty of Medicine, and former Chief of Cardiology of the Jewish General Hospital. He founded and directs the Center for Pulmonary Vascular Disease, the first pulmonary hypertension clinic in Canada. His research interests include lung vascular metabolism; behaviour and function of lung vascular cells; vascular cell biology; epidemiology of pulmonary hypertension, and the development of new medications for pulmonary hypertension.

Chris Mainwood

My name is Chris Mainwood. I was born in Ottawa and have lived here most of my life. I met my wife Jo-Anne back in grade school and finally got to date her when I was 29. Jo-Anne is my best friend and we have two great kids together, Graham and Kirsten. Jo-Anne and I are also team mates as we navigate PH together with the rest of our family.



Jo-Anne Mainwood

Jo-Anne Mainwood: I am married with two children and I'm a grade 7/8 teacher. I was diagnosed with Idiopathic Pulmonary Arterial Hypertension in the fall of 2009 after several misdiagnoses and after being admitted to the Ottawa Heart Institute for symptoms of cardiopulmonary disease. I have participated in the stem cell SAPHIRE study and advocated for drug coverage in my province. Through the support of the Pulmonary Hypertension clinic, and the excellent care I receive from my respirologist, George Chandy and primary care nurse, Carolyn Cox-Doyle, as well as a very supportive husband, a life altering diagnosis has been manageable.

Michael Mayville

I am Michael Mayville from Toronto, Ontario. I am the proud husband to my wife, Nicole and father to my son, Vance (10 yrs) and my daughter, Millie (7 yrs). I am a caregiver to Millie who was diagnosed with pulmonary hypertension in November 2020 and Millie is under the care of the amazing team at The Hospital for Sick Children in Toronto.





Vanda McLean

Vanda is a wife, mom and grandma. She has had four careers from ECE, elementary school teacher to PSW and a nurse specializing in gerontology. Her career was stopped in 2017 when walking became difficult because of PH. Vanda was diagnosed in 2016 with Idiopathic Pulmonary Arterial Hypertension, with the investigations into her health beginning a year prior. In 2019 she started on full time oxygen in April and at the beginning of October Vanda was listed for a double transplant. By the end of that year her heart improved with the exercise routine she was on. Vanda is presently on the side-line for a transplant. When things worsen again she will be immediately on the call in list.

After some planning Vanda & her husband travelled to Alberta last year to see their daughter!

Dr. Mehta

Dr. Mehta graduated from McGill Medical School in 1988 and completed further training in Internal Medicine and Respiriology at McGill. He also pursued Respiriology and PH research at McGill and Harvard. His current positions include Professor of Medicine, Consultant Respiriologist with Western University in London, Ontario and Director of the Southwest Ontario PH Clinic, London Health Sciences Center. Dr. Mehta is also a Founding Board Member, Past-Chair of the Board of Directors, and an Eternal PHriend of PHA Canada.

Dr. Mehta has been looking after PH patients for 30 years, since he was a resident at McGill in 1989, and as a PH specialist in London since 1996. He has also participated in many clinical PH research studies and is very active in the education of physicians and healthcare providers about PH, including many Canadian and international PH guidelines.



Gail Nicholson

Coming soon.

Joan Paulin

Joan's daughter Brooke was diagnosed with severe PAH in March 2014 at the age of 24. She has always considered herself to be Brooke's primary caregiver. Because Brooke remains very independent, her support has probably been more emotional than physical - one is no less important than the other!

So, she thinks a better descriptor of her role in Brooke's journey would be as an advocate. In 2017, Joan became a PHA Canada Ambassador and served as an Ambassador until her election to the Board of Directors in December 2021.



Sharon Proudfoot

Sharon was diagnosed with idiopathic pulmonary arterial hypertension (IPAH) in 1999. At this time, she benefits from four therapies to help manage her PH symptoms: calcium channel blocker medication, Adcirca, Optsumit, and Uptravi.

Sharon was one of the founding PHA Canada Board of Directors, and remains on the Board in a non-active position. She is particularly interested in advocating for access to PH treatments and her work was instrumental in getting funding approval of Tracleer in Alberta. Prior to her diagnosis, Sharon worked in senior management at Shell Canada and was on the Board of The Alex, a non-profit health and social services organization in Calgary. She now resides in Vernon BC and enjoys spending time in the outdoors with family, friends and her dog.

Brendan Ritchie

15-year-old Brendan Ritchie was diagnosed with Idiopathic Pulmonary Hypertension on 12/12/12 at the age of 4.5 after suffering a syncope episode while on a short walk with his family. Although Brendan and his family live in the British Columbia Interior, he visits the Pulmonary Hypertension team at the Stollery Children's Hospital in Edmonton, Alberta every few months. He is on triple therapy, including sub cutaneous Remodulin and in 2020 underwent two Potts Shunt surgeries, as well as surgery to remove a 4cm pseudo aneurysm from his aorta. Although Brendan has undergone multiple challenges and complications, he works hard to achieve a straight-A average in high-school and works Saturdays as an Umpire. During the summer, he loves to camp, water-ski and golf while winter brings involvement with the local Junior A Hockey Club. His positive spirit and genuine character inspire many people.





Marion Roth

Marion was born and raised in Scotland and immigrated to Canada as a teenager and was diagnosed with Idiopathic Pulmonary Arterial Hypertension in 2011. Marion started on oral meds, then sub-q and is currently on IV Remodulin, Opsumit and Adcira. She has been married to her soulmate Bob for 40 years and has three adult children, Whitney, Courtney, son-in-law Eric, a Golden Retriever fur baby Ryleigh and a grand fur baby Nyomi the boxer. Her hobbies include, quilting, knitting, reading, volunteering in her community, travelling and competitive dog obedience. Marion was one of the founding members of the London PH Support group which started in 2012.

Dr. Thakrar

Dr. Thakrar did his internal medicine and pulmonary training at the University of Calgary. He then completed a lung transplant fellowship at the University of Alberta in Edmonton followed by a pulmonary hypertension fellowship at Newcastle University in Newcastle-upon-Tyne, UK.

He has been member of the University of Calgary, since 2011, and he is currently a clinical associate professor there. He is the current Deputy Medical Director of the Southern Alberta Transplant Program along with the Education Subcommittee Lead at PHA Canada.



Laura Tombolini

Laura Tombolini is the Clinical Nurse Coordinator for the Chronic Thromboembolic Pulmonary Hypertension (CTEPH) program in Toronto, Ontario. She has a bachelors and masters in nursing and has experience in cardiac surgery prior to coming to the thoracic program in Toronto. She is passionate about ensuring the perioperative patient experience is seamless, especially when patients have to fly across the country to have this invasive procedure. In her free time, she enjoys kitesurfing, sailing and skiing.

Janette Reyes

Janette is a Nurse Practitioner in the Pulmonary Hypertension Program at The Hospital for Sick Children in Toronto where she collaborates with the PH Medical Directors and is the primary contact for patients/parents when they are admitted, when they are seen in the PH Clinic and when they have health concerns at home. Thus, reassuring continuity of care.

Janette developed a PH-Specific Transition to Adult Care Workshop and Guidelines which has resulted in positive outcomes over the years. Janette has been a member of PH Association in the U.S. and Canada, and the PH Pediatric Network. Janette was a member on the Board of Directors of PHA Canada from 2018 until 2022. She had contributed in the development of multiple PH Resources for patients and families and continues to be involved in research.



Jane Sernoskie

After receiving a rapid diagnosis of Idiopathic Pulmonary Arterial Hypertension (IPAH), in November 2016, Jane made it her life's mission to pay it forward. Jane enjoys helping to spread awareness about PAH, organizes/participates in PAH fundraisers and takes part in advocacy campaigns to ask for PAH treatments to become publically funded.

Jane lives in Ottawa, Ontario, with her bouncy black Lab dog Penny, handsome husband, Craig and their adorable and full of beans baby Luke. Jane enjoys connecting with her PHellow PHighters and their PHamilies at the Ottawa Support Group, at PHA Canada's Monthly Meet-ups, on the Canadian PHriends Facebook page, during PH Buddy chats, and by reading their updates in The Pulse and Connections magazine. Jane enjoys being an Ambassador with PHA Canada and strives to work as an effective team member to help support the PH community.



Steve Van Wormer

Steve Van Wormer is the Co-Founder and President of phaware global association. He is also the creator of I'm Aware That I'm Rare: the phaware® podcast series. Steve and his wife, Marina, were caregivers to their son, Lucas, who lost his battle with PH in 2021. He resides in Burbank, CA.





Dr. Weatherald

Dr. Jason Weatherald is an Associate Professor at the University of Alberta in the Department of Medicine and Division of Pulmonary Medicine. He completed his education and clinical training at McGill University, the University of Alberta, and the University of Calgary. He then completed a one-year pulmonary hypertension research fellowship in Paris, France at the Université Paris-Sud, Université Paris-Saclay and completed a Master of Science in Clinical Trials from the London School of Hygiene and Tropical Medicine in London, UK. His research interests include risk assessment methods and novel clinical trial endpoints in pulmonary vascular diseases.