



EMPOWER

Empowering Patient Objectives With
Engagement in Research

*The Canadian Heart Function Alliance (CHFA) Network
Patient-Focused Newsletter*

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A Message From Your Platform Leads



Davina Banner-Lukaris
Scientific Lead

Hello and thank you for your continued interest and support. First and foremost, welcome to our first Patient Engagement and Empowerment Platform Newsletter. Called E-Power – this newsletter will share news from the Alliance and will provide updates on key initiatives. In this newsletter, we look forward to sharing the power of patient/person with lived experience partnership in research. The name of our newsletter was chosen and voted on by our patient leads, representing our passion and dedication to patient-driven and patient-led initiatives in healthcare and research. Finally, thank you also for your patience as we work to develop the platform.



Sylvain Bédard
Patient Lead

Over the past two months, our team have been working hard to prepare the platform and build the structures to help support the ongoing engagement and involvement of people with lived experience.

We are making good progress and are pleased to provide a few updates:

Demographic survey: We have drafted a survey to help us collect information about our Platform members and to identify preferences and experiences that can help us match patient partners with research and theme teams. We are hoping to send this out after our next Platform meeting.

Patient/Persons with lived experience engagement toolkit: We have been working on a new toolkit to support the Alliance researchers when planning their research studies. In particular, we have developed a document that help researchers to think about what types of engagement they may need and what resources are available to support patient partners. This is currently under review by our planning team.

Compensation guidelines and processes: We have been drafting a policy to support the appropriate and timely compensation and remuneration of patient partners. This includes developing the financial policies and claim forms. This is also under review and will be finalized shortly.

A few updates on our outreach activities:

Launch videos: We have shared these previously, but we are pleased to note that these have been shared across the platform team and members.

Platform support: We are in the process of planning the Platform support and will be hiring an engagement and research coordinator to provide support to Platform members and to support regular communication.

Canadian Cardiovascular Congress: Alliance leaders Dr. Jean Rouleau and Marc Bains, along with other Alliance members gave a presentation at the recently Canadian Cardiovascular Congress. The team provided an overview of the Alliance goals, including the Patient Engagement and Empowerment Platform. We had great interest and enthusiasm from the audience!

Getting together:

As per our recent email, we have delayed the Think Tank meeting until we have had the opportunity to share more information about the Platform projects and themes. We did this on the advice of our existing patient partners and network leaders. We are planning a number of Platform meetings and will be inviting our project and theme leads to join us and share their work. We hope that this will whet your appetite and will help you think about where you might want to be involved.

We look forward to reconnecting soon and invite you all to reach out at any time.

Best wishes,
Davina



Platform Meetings

Our next Patient Engagement and Empowerment Platform meetings are:

November 23rd at 12-3pm PST

December 14th at 12-3pm PST

Please mark your calendars. Invites to follow shortly.



Alliance Member Spotlight



Marc Bains

CHFT Alliance Scientific Co-director
Heart transplant recipient and VP of HeartLife

Tell me about yourself?

I was born and raised in Vancouver, BC. I love my city and still remain in Vancouver.

What do you like to do in your free time?

I enjoy traveling, I have been to over 40 countries now. While in Vancouver I enjoy eating and trying new restaurants, taking my '69 firebird for a drive, being by the water, and spending time with family and friends.

Tell me a bit about your experience of heart failure

I was diagnosed with HF in 2008 - I was 23 at the time and it was a shock. The doctor told me I had an ejection fraction of ~10%. I had no idea what that meant - but I knew it wasn't good. Of course, throughout my diagnosis, I had ups and downs. During the ups, I was able to work, travel, and enjoy a new normal. During the downs, there were times my family thought they lost me.

Ultimately, my heart was failing to the extent that I needed a transplant. I received that on June 6th, 2018. It was a tough journey. However, it brought upon opportunities I could not imagine. I got involved in community activities, joined fantastic research groups with folks like the amazing Dr. Davina Banner, co-founded the HF Foundation with Dr. Jillianne Code and Dr. Sean Virani in 2016, developed Canadian and Global documents to improve care, and now have the honor and privilege to work with the CHFA Alliance and the world-renowned Dr. Jean Rouleau.

People always ask me if I would change anything. I say no. I had the resources, care, and support to live well with HF and now I want the same for all Canadians.

What was some of the best advice you have ever been given related to heart failure?

Talk to others who have been through the experience. You have to advocate for yourself. Do not be afraid to ask questions. Listen to your body.

Tell me about your experience of being a patient partner and leader in research. Why is this important to you?

To be frank, it was challenging at first. There is an added responsibility of changing the way care is delivered. However, I have had the opportunity to work with researchers that want to understand the patient's needs and include people with lived experience as they understand the value of our experience and knowledge. I have now been involved in regional, provincial, and national research programs as a reviewer, author, and co-investigator.



What surprised you most about being engaged in research?

The impact people with lived experience can make. I actually knew this. I think it surprises researchers.

What do you think people need to know most about heart failure?

Although it is an invisible disease it is physically and mentally challenging. HF greatly impacts the quality of life and day-to-day lives of folks living with it.

Where do you see the CHFA in five years? What are some of your biggest hopes and dreams for the Alliance?

I know the alliance can and will make great strides in how we talk about heart failure, deliver care in the community and hospital settings, and work with patients and caregivers to improve the quality of life of Canadians with HF.



Dr. Jean Rouleau

CHFT Alliance Scientific Co-director
Senior Cardiologist

Tell me about your work as a cardiologist and how you are engaged in heart failure care.

I got involved in HF research and care when a young mother dissected (a tear) one of her LAD coronary arteries after delivering, had refractory heart failure and eventually died 3 months later. I felt we needed to do better and that was the start for me.

What is the one thing you wished all patients and caregivers knew about heart failure?

The importance of diet and exercise, even just getting out of a chair and circling the room.

What is it like partnering with patients in research and how did this change the way you have worked?

I learnt that each individual with HF has their goals in life and we need to get on board with that, rather than extrapolating our vision of what should be done.

What has surprised you most about patient engagement in research?

Cannot say that there is one thing in particular as I just keep on learning and having to re-adjust my objectives to align with those of individuals with lived experience.

Tell us about your hobbies.

I am an avid gardener, and I am a beekeeper.



The Heart Failure Policy Network (HFPN) is proud to present the second annual **Heart Failure Policy Summit**, which will be held online from Wednesday, October 26th to Wednesday, November 16th, 2022.

With new clinical guidelines, evidence and innovation offering the hope of improving the lives of people with heart failure, now is the time to demand access to the best possible care for everyone living with the condition. The 2022 Summit provides the opportunity for heart failure advocates to come together to focus on the essential topics that will define the future of heart failure care.

Registration is FREE

<https://www.eventbrite.com/e/heart-failure-policy-summit-2022-tickets-407858484707>