



TRANSPLANT
RESEARCH
FOUNDATION
of British Columbia





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MESSAGE FROM BOARD CHAIR



I have been on TRF's board since 2008, the year following my husband Tom's liver transplant. Through that time, we have had many wonderful, talented people serve on the Board, all with the vision of supporting research that will make transplant a cure.

Amanda (Poch) Lapierre was one of these individuals. She served on the Board from 2010 to 2014 and then stepped in for a time as Interim ED.

Amanda died on July 22, 2018, after undergoing a liver transplant. She was only 39 years old and this was her second transplant. Amanda was a lovely, spirited woman and a fierce advocate for transplant patients and organ donation. The tragedy of her death is a stark reminder of the importance of all work that advances knowledge of organ failure, organ donation and health after transplant.

At TRF, we are all working hard to contribute to this knowledge and improve the lives of recipients through research. TRF has recently expanded its research grants to include the Research Challenge Grants. These small (\$5,000) grants target nursing and allied health professionals who work with transplant patients (you'll read about the exciting projects that were funded later in this report). This year we had a chance to meet with the pre-transplant (liver) group, and their enthusiasm for programs that would allow them to realize their ideas was palpable.

We're also moving forward in partnerships with Providence Healthcare and Vancouver Coastal Health to offer Team Grants. These grants provide substantial funding to practitioners for great ideas in transplant care. What is most exciting about these grants is that they address patient identified research priorities and actively engage patients in the research process.

As always, our Venture Grants, which support innovative research in transplantation, continue to receive many outstanding applications than we are able to fund.

We ask for your help in joining us in support of TRF's mission. You can start by signing up for our excellent blog which shares stories of transplant research through its beneficiaries. You can also help by supporting the work of TRF with your donations and, if you have time and talent to offer, we would be happy to talk about your potential future on our Board.

Serving on the TRF Board provides a unique lens with which to view the work being done in transplantation. We know there are many talented researchers and practitioners out there who are looking for answers, and as long as we are able to support their work to build knowledge in transplantation, I'm confident that tragedies such as the death of Amanda will happen less and less often.

THE BOARD OF DIRECTORS

Lori Lothian – Chair
Elaine Yong
Ed Ferre

John Wiens
Niko Lambrinoudis
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Sandra Fairey
Carmen McKenna
Dr. Robert McMaster

Dr. Alice Mui
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VALUE OF TRANSPLANT RESEARCH



- In BC, there were 479 organ transplants in 2017.
- There are more than 600 British Columbians waiting for an organ transplant.
- There are more than 4800 British Columbians living with organ transplants in BC.
- In the last five years, 162 British Columbians have died waiting for a donor organ.
- Between 2004-2013, more than 1250 children in Canada have undergone a life-saving organ transplant.
- There have been more than 8,000 transplants in BC since 1968.
- 97 British Columbians were living kidney donors in 2017.
- For patients under 18, the 10-year survival rate for heart transplant is less than 60%, for lung it is 44% and liver is 77%



WHY TRANSPLANT RESEARCH?

Transplantation saves lives, but it comes at a cost. Life following transplant presents unique challenges for recipients and health care teams. Post-transplant care of recipients is complex and demanding. Recipients must take daily medication to avoid rejecting their organ(s). This medication is potent and comes with serious side effects. Recipients undergo frequent and painful testing to monitor organ function. Graft survival is an ongoing threat. No one knows the importance of transplant research more than the patients who live with this reality.



"I've always wanted to be a dad, a great dad! But I wonder, will I be here for her? Or will my disease take me before I get to see her grow up? The reality is very real and very scary. However, I wouldn't trade this time with my beautiful daughter for anything in the world. I want people to know transplant is not a cure. It's a Band-Aid. Transplant offers me more time, time I'm so grateful for, but it doesn't guarantee me any more time than just today."

- Darvy, liver transplant recipient

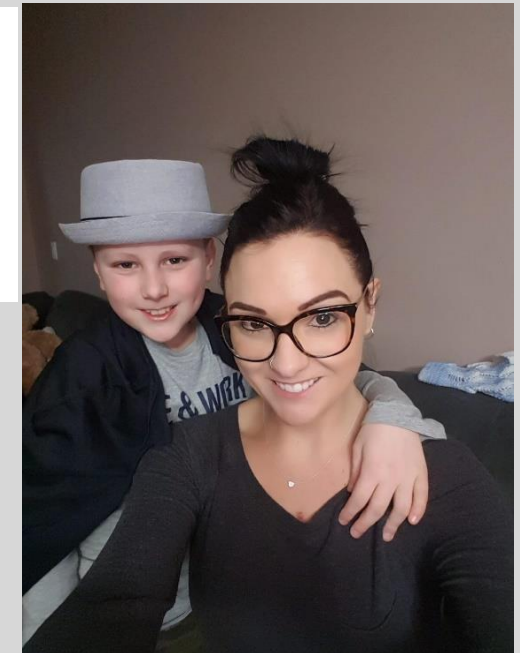
"I am currently in chronic rejection - one of my arteries is 70 per cent clogged. My doctors are exploring other treatments, but if nothing works, another transplant may be in the future. This is very scary as I have not had any major problems until now. I am trying to stay positive and hope for a good outcome. Fingers crossed."

- Lindsay, heart transplant patient



"I would like a simple blood test to check if my heart is okay, rather than having an invasive biopsy done in the cath(eter) lab. It would also be great if I didn't have to take as much medicine as I do now."

- Abby, heart transplant recipient



COLLABORATING FOR SUCCESS: RESEARCH CHALLENGE

In 2016, the Transplant Research Foundation of BC partnered with Vancouver Coastal Health Research Foundation (VCHRI) and Providence Health Care (PHC) to promote the Research Challenge Grant program. This program targets allied health care staff and point-of-care professionals and addresses patient care initiatives related to transplantation. TRF was honored to fund four \$5,000 grants.



Providence Health Care – Wynne Chiu

How do highly sensitized patients describe their experience with being on the heart transplant Waitlist

This project focuses on understanding the highly-sensitized patient experience on the transplant waiting list. Our aim is to understand the patients' lived experience, which would provide an important perspective to the characteristics of this emerging group of transplant patients.

Principal Investigator: Wynne Chiu

Mentor: Annemarie Kaan

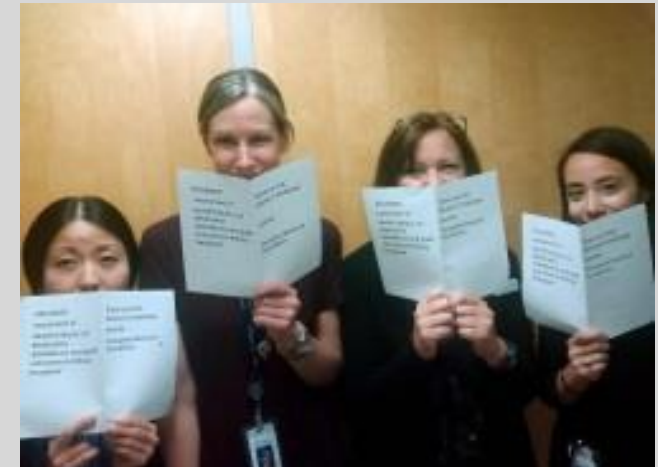
Co-investigator(s): Kim Brownjohn, Erica Johansson

Providence Health Care – Sally Kwan

Assessment of HeALth Literacy on Medication AdheRence and graft outcomes in Kidney transplant recipients (HALLMARK)

This project specifically looks at improving medication adherence and clinical outcomes of kidney transplant recipients by proactively measuring patient's health literacy and addressing any gaps in treatment approach for the individual patient, as well as at the system level in the post-transplant clinic.

Transplant related patient education materials will be amended, and tools developed to tailor transplant recipients with limited health literacy.



Principal Investigator: Sally Kwan

Mentor: Marianna Leung

Co-investigator(s): Clare Bannon, Anita Ziekiewicz, Nancy Szeto, Linnea Young

COLLABORATING FOR SUCCESS: RESEARCH CHALLENGE



Principle Investigator: Grace Adderly
Co-investigator(s): Rizza S. Angeles,
Alexia L. Jones

Vancouver Coastal Health – Grace Adderly

A Survey of Post Transplant Patients to Assess Correlation between Demographic and Transplant-related Factors with the Incidence of Depression/Low Mood

The goal of this study is to assess the potential correlation between the incidence of depression and the indicator variables. This includes demographics, transplant recovery phases, social support, and clinic/home follow-up. The study expects that the patient population at VGH will show similar characteristics to those described in the literature and the incidence of depression is well-correlated with all these variables.

The specific objectives are defined as follows:

- To determine which literature-identified factors in the study population are associated with incidence of depression.
- To determine if there is a relationship between patient compliance with home monitoring and depression.
- To determine if there is a relationship between the frequency of clinical follow-up and depression.



Providence Health Care – Ruth McCarrell

Assessing the knowledge, attitudes, and beliefs of Kidney Care Clinic staff about kidney transplantation before and after a multi-pronged education program

Kidney transplant is the best renal replacement option for most individuals living with end stage renal disease and pre-emptive kidney donation results in the best prognosis for patients. To increase rates of living kidney donation it is imperative that kidney transplant be discussed with patients early in their chronic kidney disease journey.

In British Columbia, regional Kidney Care Clinic staff are best situated to provide this education and ongoing patient support. A Kidney Care Clinic / BC Transplant pre-emptive transplant working group has been established

to develop a variety of educational materials aimed at increasing staff knowledge and comfort in discussing kidney transplantation with their patients. This study aims to assess the effectiveness of this multi-pronged education approach by testing health care providers' knowledge, attitudes and beliefs at two time points during the implementation of the program.



Principal Investigator: Ruth McCarrell
Mentor: Wayne Fritz
Co-investigator(s): Erin Waters, David Grenkov,
Jody Max, Clare Bannon

YOUR DONATIONS AT WORK

EXCEPTIONAL GROWTH

Between 2009-2018, TRF funded researchers successfully leveraged \$425K of funding directly into \$10 million of external research funding including:

- Dr. Bruce McManus received \$2,054,684 from Genome BC to run clinical trials of non-invasive (biomarker based) diagnostic tests of organ rejection.
- Dr. David Granville received \$1,805,469 from Canadian Institute of Health Research (CIHR)(2015-2022) to study granzymes in injury, inflammation and repair.
- Dr. John Boyd received \$504,900 from Canadian Institute of Health Research (CIHR) (2017-2022) to continue his work with organ donation after cardiac death and optimizing the donor heart.
- Dr. Megan Levings received over \$646,000 to further study the ability of CAR-expressing T regulatory cells to prevent kidney rejection.
- Dr. John Gill received \$1.7 million from the Canadian Institute of Health Research (CIHR) to study strategies to achieve self-sufficiency in kidney transplantation in Canada.
- Dr. Ameer Manges received \$141,692 from Vedanta Biosciences to further her study involving fecal microbiota transplants.
- Dr. Caigan Du received over \$500,000 from CIHR to study a new organ preservation solution in transplantation.



TRF DONOR PROFILE - Dheran Shahi

"We called him DJ V or Master Chef Viraj," recalls Dheran Shahi of his younger brother Viraj, who died waiting for a double lung and kidney transplant. "He was truly the best brother anyone could ask for, I was lucky he was mine," Dheran says sadly. The loss of his brother has had a significant impact on Dheran and ignited his passion for organ donation awareness and transplant research.

It is clear Viraj is missed deeply, but Dheran has turned his family's tragedy into a personal crusade. Now in Grade 10 at Brookes Shawigan Lake School, Dheran was assigned a personal project. He knew he wanted to bring awareness to the importance of organ donation while supporting an organization that works to improve the lives of transplant recipients through research. Dheran knows organ donation saves lives, but he also recognizes that transplantation is not a cure, "I wish recipients had a smoother recovery post-transplant, with fewer complications. I also hope that new medication can be developed so recipients can live healthier lives with their new organs."

He has done a remarkable job fundraising more than \$1,200 for the Transplant Research Foundation of BC. However he does not think what he has done is anything remarkable, "It is our responsibility to find it in ourselves to live life and pass it on."

CONNECTING WITH COMMUNITY

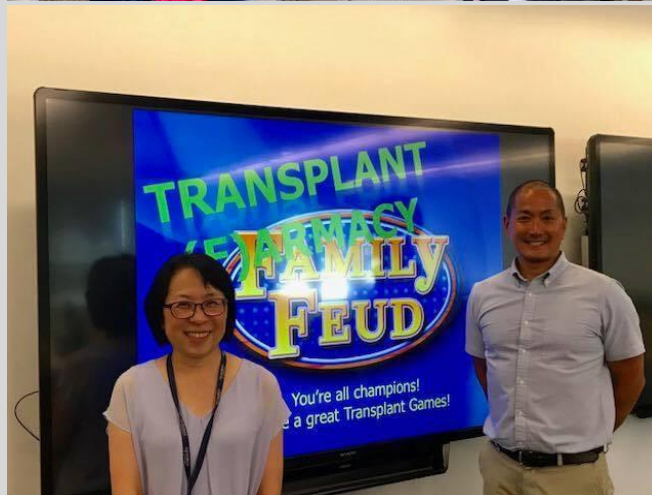


Community is key to transplant research. It is through the support of the transplant community that we are able to fund transplant research in British Columbia.

This past year saw extensive engagement with our transplant community. We worked hard to bring the exciting world of research to our community in a manner that was both understandable and relatable.

We hosted our first annual Celebrate Transplant Research event, where we shared some of the innovative research we have funded over the past year. We held our annual Pig Day at Science World, an educational event that offers the public a chance to learn about research by examining organs from a pig.

Since we take immense pride in helping transplant recipients and their families live their best life post-transplant, we seized the opportunity to become involved in the Canadian Transplant Games when it came to Vancouver this past July. We hosted “Let’s Talk Transplant”, a series of transplant themed presentations. Clinicians, researchers, and recipients came together in one room with the mutual goal of empowerment and education for all those affected by transplant. It was also a time for many of our friends and family members to participate in the Games and show that organ donation and transplantation work!



SUMMARY OF FINANCIAL RESULTS

The Transplant Research Foundation of BC, The Transplant Research Foundation of BC Fund and the Addison Fund

Combined Statement of Operations and Fund Balances.

For the year ended March 31, 2018, with comparative information for 2017 & 2016

	2018	2017	2016
Revenue			
Philanthropy	\$ 153,565	\$ 171,843	\$ 116,250
Gaming Revenue	1,030	4,416	
Investment Income	26,880	38,761	40,265
	181,475	215,020	156,518
Expenses			
Foundation Operations	26,649	22,651	27,757
Fundraising	10,717	14,160	9,236
	37,366	36,811	36,993
Excess of revenue over expenses before disbursements and grants	144,109	178,209	119,525
Community outreach and engagement program delivery	36,210	25,454	28,954
Research grant	20,000	126,716	75,000
	56,210	152,170	103,954
Excess of revenue over expenses, distribution, and grants	87,899	26,039	15,571
Fund balances, beginning of year	780,785	751,319	724,290
Change in fair value of investments	3,521	3,427	11,458
Fund balances, end of year	\$ 865,163	\$ 780,785	\$ 751,319

Our Mission: To support BC based transplantation research that will provide solutions to benefit British Columbians whose lives are threatened by organ failure.

Our Vision: Leading edge research, newly developed treatment strategies, technologies and therapies will ultimately eliminate the need for organ transplantation.