**Our Mission:** To support innovative, patient-centered organ donation and transplant research that will provide solutions to benefit those whose lives are threatened by organ failure.

**Our Vision:** Leading edge research, new treatments and novel technologies that will ultimately eliminate the waiting list and make transplant a cure.
MESSAGE FROM CO-CHAIR

To say this has been an unprecedented year would be an understatement. At the start of this new decade, just months ago, no one would have been able to predict we would be where we are right now - living through a pandemic. This has meant physically distancing from loved ones, working from home, months out of school, the cancellation of our regular activities and wearing a mask.

For transplant recipients, there is the additional risk of being immunocompromised. At the beginning of the pandemic, there was almost no information about how the virus attacked, who it attacked, and how to treat it. The news coming out of the initial hot spots was terrifying. And those who were thought to be most vulnerable - elderly, infants and young children, anyone with underlying health conditions - were rightfully told to be even more careful than the general population. This meant many of us who either have a transplant, or have a family member with a transplant, were virtually locked down at home.

But there has been a lot of good to come out of this. It has once again reminded me and my family about the importance of living life to the fullest, in whatever capacity we can. That's a lesson my daughter’s heart transplant taught us more than nine years ago. Now, we our finding as much adventure and joy as we can, within the boundaries of COVID-19 restrictions.

At the same time, the Transplant Research Foundation’s efforts to raise money have taken a big hit. With physical distancing measures, our usual fundraising events are delayed indefinitely. We also know many people have been negatively impacted by COVID-19, especially financially. These are difficult times to be asking for donations, regardless of how worthy the cause.

Nevertheless, it is becoming increasingly apparent how vital transplant-specific COVID-19 research is to the health of transplant recipients given their unique immunosuppressive state. In British Columbia alone, more than 5,200 solid organ transplant recipients are navigating the pandemic and living through these uncertain times. To help address the growing need for research that examines the risks, implications, and outcomes of COVID-19 in the transplant population, TRF is proudly funding the peer reviewed project, Comprehensive Immune Profiling of Solid Organ Transplant Recipients with Covid-19 lead by Dr. James Lan. This study seeks to shed light on the complex interplay between infection and immunity, with the goal of informing practical strategies for immunosuppression management for patients who contract COVID-19.

This is why TRF needs your support more than ever. We need specific investigation into COVID-19’s impact on transplant recipients, what treatments are most effective, actual risks of infection, the safety of a new vaccine...just to name a few important topics. This is what is going to help us keep transplant recipients healthy so they can continue to live their lives to the fullest, today, and in the future.

Thank you for helping us make transplant a cure.

THE BOARD OF DIRECTORS

Lori Lothian – Co-Chair
Elaine Yong – Co-Chair
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Dr. Robert McMaster
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Todd Hauptman
VALUE OF TRANSPLANT RESEARCH

TRANSPLANTS SAVE LIVES

Transplantation, once considered a medical marvel saved for the direst of cases, has evolved to become the preferred treatment of choice for a variety of end-stage diseases. Transplant is not a cure but rather a chronic condition requiring ongoing monitoring and indefinite life-supportive drug therapy. The hope for a brighter future lies in research.

- In BC, there were 480 organ transplants in 2019.
- There are more than 700 British Columbians waiting for an organ transplant.
- There are more than 5100 British Columbians living with organ transplants in BC.
- In the last five years, over 200 British Columbians have died waiting for a donor organ.
- There have been more than 8,000 transplants in BC since 1968.
- 120 British Columbians were living kidney donors in 2019.
- For patients under 18, the 10-year survival rate for heart transplants is less than 60 per cent, for lungs it is 44 per cent and livers is 77 per cent.

“Transplantation is not a cure, but I am hopeful that my second transplant will give me time to watch my son graduate, to see him fall in love and get married, and start a family of his own. There is always going to be the lingering fear in the back of my mind of not being able to be here for him. All I can do is live for today and not take any day for granted.

To be able to receive a second chance at life and live without the potent anti-rejection medication and fear of graft failure would be the ultimate goal of transplant research.”

- Miranda, two-time lung transplant recipient

The Venture Grant program provides much needed funding to support transplant related research in BC. As the sole providers of pediatric solid organ transplant (SOT) care in the province, we, as clinical researchers at BC Children’s Hospital, rely on funding like this to allow us to improve outcomes. As survival following SOT continues to improve, we strive to improve the quality of life of our patients. Having received the award twice now, I cannot thank the Transplant Research Foundation of BC enough for their ongoing engagement and support to make the quality of life for our SOT children in BC better.

- Dr. Kathryn Armstrong
  pediatric transplant cardiologist, two-time Venture Grant winner
Partnerships have been instrumental in allowing TRF to achieve diversity in the types of research we fund. Through our collaborative efforts with Providence Health Care and Vancouver Coastal Health Research Institute, we have expanded our research funding to allied health care professionals involved in delivering care to patients living with end-stage organ disease and transplant recipients.

2019-2020 was a robust year for our practice-based research, with three projects funded as part of the Research Challenge competition and one Team Grant. Perhaps most exciting is how these projects have given greater attention to actively engaging patients throughout the research process. They are all highly patient-oriented in nature. This year we also extended our funding program to include a team at BC Children’s Hospital Research Institute, ensuring valuable pediatric transplant research is embraced and encouraged.

Research Challenge Program

Vancouver Coastal Health Care – Cindy Luo
Voriconazole associated adverse drug events in lung transplant recipients

Lung transplant recipients require potent life-long immunosuppressive medications to prevent the immune system from recognizing the transplant lungs as foreign; on the other hand, chronic suppression of the immune system also increases a patient’s risk for development of life-threatening infections including fungal infections such as Aspergillosis. Studies have demonstrated that appropriate fungal prophylaxis and treatment are essential components of lung transplantation, as colonization with Aspergillus increases the risk for chronic lung allograft dysfunction and patient death. Voriconazole is the drug of choice for prophylaxis and treatment of Aspergillus in lung transplant recipients; however, voriconazole has multiple adverse drug events associated with its use.

This study aims to identify:
1) the incidence of adverse drug events associated with voriconazole;
2) the most common toxicities experienced by lung transplant recipients on voriconazole; and
3) the frequency of medication discontinuation due to voriconazole-related adverse drug events.

Principal Investigators: Dr. Cindy Luo
Mentor: Dr. Nilu Partovi
Co-investigators: Dr. Robert Levy, Dr. Roland Nador and Dr. Matthew Kadatz
Research Challenge Program

Providence Health Care – Clare Bannon
**Wound Complications in Kidney Transplant: WONDER**

The kidney transplant recipient of today is vastly different from the recipient of twenty years ago, when higher-risk patients with diabetes, obesity and other co-morbid conditions were excluded from receiving a transplant. As research and practice has progressed, it has been affirmed that despite the risks of transplanting higher-risk recipients, there is still a derived benefit from a quality of life and systems cost perspective.

Wound healing in renal transplant recipients is impaired by the necessary use of immunosuppression and steroid therapy to prevent graft rejection. The common presence of co-morbid conditions further complicate wound management in this patient population. Currently, there is no evidence-based post-operative wound management protocols, and no clear data collection system in place to capture post-operative wound complications. This team seeks to identify risk factors that will allow for early intervention even in the pre-transplant phase, and to develop protocols for better post-operative wound management in kidney transplant recipients.

Principal Investigator: Clare Bannon
Mentor: Dr. Luba Veverysts
Co-investigators: Pamela Turnbull, Jessica Donnan and Joanah Habacon

BC Children’s Hospital – Kat Broad
**Increasing Preparedness: Examining the effect of transition themed workshops for pediatrics solid organ transplant recipients before transfer to adult care**

The transition from pediatric to adult care is challenging for adolescents with medical complexity, including recipients of a solid organ transplant (SOT). It is well known that young adult and adolescent recipients are at higher risk of medical complications before, during and after transition. The goal of this study is to design and pilot a patient-centered, evidence-informed transition workshop to improve readiness for transfer to adult care. The feasibility, acceptability and design of the workshop will be evaluated in order to incorporate this feedback into future workshops.

Principal Investigator: Kat Broad
Mentor: Dr. Tom Blydt-Hansen
Co-investigator(s): Sarah Fay and Jessie Ahuja
Pharmacogenomics is the study of how the variation in an individual’s DNA can affect drug response, which can assist us in predicting how well a drug would work and in determining the potential for drug side-effects. The purpose of this project is to learn whether pharmacogenomics testing can help us tailor medications for lung transplant recipients.

Lung transplant recipients require life-long immunosuppressive medications to prevent organ rejection; however, chronic suppression of the immune system increases the risk of life-threatening fungal infections, such as aspergillosis. The medication of choice for the prevention and treatment of *Aspergillus* infection is voriconazole. Voriconazole requires routine drug monitoring, since low drug concentrations may lead to treatment failure, and high concentrations are associated with significant toxicities. It is anticipated that the use of pharmacogenomics testing to determine genetic variations in lung transplant recipients can assist health professionals to customize medication regimens that will improve drug effectiveness and reduce side-effects. The goal of this project is to improve the overall care of transplant recipients through individualizing their medication therapy.

This team believes that having patients engaged in their own care is crucial for improving outcomes. Patient partners will play an integral role throughout this project, from the development of patient-specific education materials on pharmacogenomics to the creation of surveys that will describe the patient’s perspectives on using pharmacogenomics in their transplant care.

Principal Investigators: Dr. Cindy Luo
Mentor: Dr. Nilu Partovi
Co-investigators: Dr. Robert Levy, Dr. Roland Nador and Dr. Matthew Kadatz
In 2013, the Addison Fund of the Transplant Research Foundation of BC was created by Elaine Yong and Aaron McArthur with the goal of advancing pediatric transplant research. Their daughter Addison was the first infant to receive a heart transplant at BC Children’s Hospital.

Children are not little adults and have distinct needs and health considerations related to their transplant status. Research focused exclusively on pediatric transplantation is instrumental to ensure these children have the best chance possible.

The Addison Fund is pleased to partner once again with the Canadian Donation and Transplantation Research Program in the 2019 Research Innovation Grant Competition. Through the power of partnership, the Addison Fund is proudly co-funding this highly rated peer reviewed project. This research has great potential to transform the care of pediatric transplant recipients and lead to new knowledge that can dramatically improve the quality of life for young patients.

Megan Levings - Development and validation of a novel assay to quantify alloantigen specific T cells

Following transplantation, immune cells in the recipient recognize the new organ as a foreign invader and subsequently launch an attack to destroy it. To stop this immune response, transplant recipients are placed on immune-suppressing drugs that severely reduce the immune system's normal ability to fight off infections and cancers. It is therefore critical to prescribe just enough immune-suppressing drugs to prevent organ rejection, but not so much that patients suffer from the numerous side effects of these medications. Currently, there are no tools available to measure how well immune suppression is working in each transplant patient. Although tissue biopsies are often performed to assess whether rejection is happening or not, they are often done too late, after immune cells have already caused irreversible transplant damage. We need a way to measure immune responses to transplants so that changes in immune suppression can be made pro-actively, rather than reactively. This team aims to develop a new test that will rapidly measure immune responses to a transplant using a small amount of blood. The test is based on a fascinating immunological phenomenon whereby immune cells from the recipient that want to kill the transplanted cells pick up proteins that are exclusively expressed on the very cells they are trying to attack, allowing us to quantify the number of these killer immune cells. By quantifying these dangerous immune cells, the theory is that doctors will be able to determine the risk of transplant rejection and provide the information they need to prevent transplant rejection and individualize immune-suppressive drug regimens to enhance transplant and patient health.

“"A project that could mean less biopsies and medication if it works? Yeah! I hate biopsies!” – Addison McArthur, heart transplant recipient and the inspiration behind the Addison Fund.
The primary goal of the Transplant Research Foundation of BC (TRF) is to fund innovative research in transplantation through our Venture Grant Program. This annual program is 100 per cent supported through donations and provides $25,000 in funding per project to support research that will improve the outcomes and quality of life for transplant recipients and patients living with end-stage organ failure.

In the ten years since the program’s inception, TRF has awarded $650,000 to local researchers. Many of these projects have had a transformational impact on transplant medicine and our funds have been leveraged into over 10 million dollars of external peer reviewed funding.

The projects listed below, from our 2019 cohort, seek to optimize individual immune responses by tailoring therapies to prevent rejection.

**Jonathan Choy - The role of IL-17 receptor A in transplant rejection**

Organ transplantation is the only treatment for end-stage organ failure. As such, it is a potentially curative procedure for devastating conditions such as kidney, heart and liver disease. The success of organ transplantation is limited by the rejection of grafts by the immune system of recipients. Activation of the immune response that causes rejection depends on the actions of proteins that signal between cells, termed cytokines. IL-17 is a cytokine that has been implicated in transplant rejection but little is known about how it does this. Also, one of the main types of rejection that is particularly difficult to manage is caused by the production of antibodies that target transplanted organs. Dr. Choy’s laboratory has preliminary evidence that IL-17 may contribute to immune-mediated rejection of transplanted organs by supporting the development of antibodies that target the graft. The proposed studies will examine how IL-17 contributes to transplant rejection through supporting the production of antibodies. The findings have the potential to identify new therapeutic targets for the prevention of rejection.

**Tom Blydt-Hansen Investigating serum immunometabolomic profiles associated with kidney transplant alloimmune outcomes**

Transplantation is the leading treatment for people with end-stage kidney failure. But beyond the first year after transplant, we know some people will develop chronic forms of rejection that limits transplant survival. We know that some people’s immune systems adapt better or become more “tolerant” to the transplant, but we don’t know all of the reasons why. While medications are an important part, we also know a person’s metabolism can play a role. That includes things like nutrition and disease, which can influence how a person’s immune system will respond.

This study will look at samples that have been collected before transplant, to see if there are changes we can measure in metabolism that predict an individual’s response to the transplant. This information will be used to develop a test that could be used before transplant to tell people about their risk of rejection. It may also help to identify why that risk is higher, and ways to reduce the risk.
Funding research that is meaningful, relevant and transparent

It has long been TRF’s goal to ensure the research we fund reflects what matters to patients. In 2019, we achieved some notable milestones towards this work. In collaboration with BC SUPPORT Unit, Vancouver Coastal Health and Providence Health Care, we offered members of our organ donation and transplant community two workshops geared at skill development and knowledge acquisition around patient engagement in research. These workshops were designed for patients, caregivers, policy makers, clinician researchers and scientists. It was inspiring to watch individuals, from all different walks of life, come together in one room to learn from one another and expand their appreciation for the role of patients in research. We also had the pleasure to work directly with our transplant community to facilitate effective partnerships between patient-partners and health care professionals on many of our TRF funded projects, enabling research that is truly responsive to the needs and priorities of patients.

To understand the benefit, it is best to hear from individuals who have been on this journey with us.

_Earl Howell - Diagnosed with primary sclerosing cholangitis in 1982, Earl’s liver disease led to a liver transplant in 1997. A champion for organ donation and patient advocacy, Earl volunteers with BC Transplant, is the local treasurer for the Canadian Transplant Association and a patient partner with TRFBC._

**What has been your experience with research, including before and after you became a patient partner?**

Prior to becoming a patient partner with TRF, I was part of the B.C. Generations project, a project that studied the impact of exercise on transplant recipients. More recently, I have assisted a researcher in setting up her project studying drug compliance protocols with kidney transplant patients. I have also participated as a patient reviewer on the VCHRI Research Challenge peer review panel, offering my feedback and recommendations.

**Why would you recommend becoming involved with research as a patient partner?**

I believe all of us in the transplant community have received the greatest gift of all, the gift of life. We have survived many experiences as part of our transplant journey. Sharing our insight with the research community will most certainly benefit patients, of today and tomorrow.

_Shelby Gielen - Two-time liver transplant recipient embraces every opportunity to help support patients and families navigating the complexities of the transplant journey. She credits her existence today to the many advances in transplant medicine over the years._

**Why do you want to be involved with research?**

I want to put my colourful and diverse 27 years of lived patient experience to work by making the path easier for patients who come after me. It was discovered post-transplant that my donor liver was a carrier of hepatitis B. As a result, I was deemed unfit for another transplant when my liver began to fail. I was given the opportunity to be a part of a clinical trial that would prevent the active virus from transferring to a new liver. Subsequently, I was eligible to receive a second transplant. Since being involved as a patient partner I have been part of a number of grant review panels where I sit alongside scientists, physicians, administrators, and healthcare stakeholders to review applications for funding.

**What has surprised you about being involved in research as a patient?**

I was most surprised at how much fun this has been! I have been happily surprised at how valued my perspective is and how my feedback is incorporated into current research projects. It is incredible how equal a playing field it is when you enter into a great situation of patient-oriented research.
Building relationships one connection at a time

It was a memorable year for TRF! Not only were we able to provide $102,500 to BC scientists and clinicians to advance organ donation and transplant research in our province, but we continue to make great strides in bridging the divide that can often prevent patients and caregivers from being more involved in research. We partnered with BC Transplant for our annual Celebrate Transplant community event, enabling us to share our recent projects and important patient-centered presentations with recipients. We were fortunate to work with local leaders in transplantation to bring our lively, and entertaining, sessions geared at coping with the transplant journey, cannabis use in recipients, and how to stay safe while traveling.

Remembering Eva

We were the fortunate and grateful recipients of the tenth anniversary fundraising event that commemorated the life of the late Eva Markvoort. Organized by film makers, Nimisha Mukerji and Philip Lyall, the event was a chance to celebrate a decade since the release of the film 65-RedRoses, which chronicled the life and transplant journey of Eva, a double-lung recipient. Eva was a dynamic and vibrant woman whose passion for organ donation awareness inspired a movement that brought awareness to the need for organ donors. Despite succumbing to chronic rejection, Eva left a lasting legacy. We share the vision that Eva had for the future – one where no one dies waiting for an organ and ultimately transplantation is a cure.
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, 2020, with comparative information for 2019 and 2018.

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</tbody>
</table>
Contact Us

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