

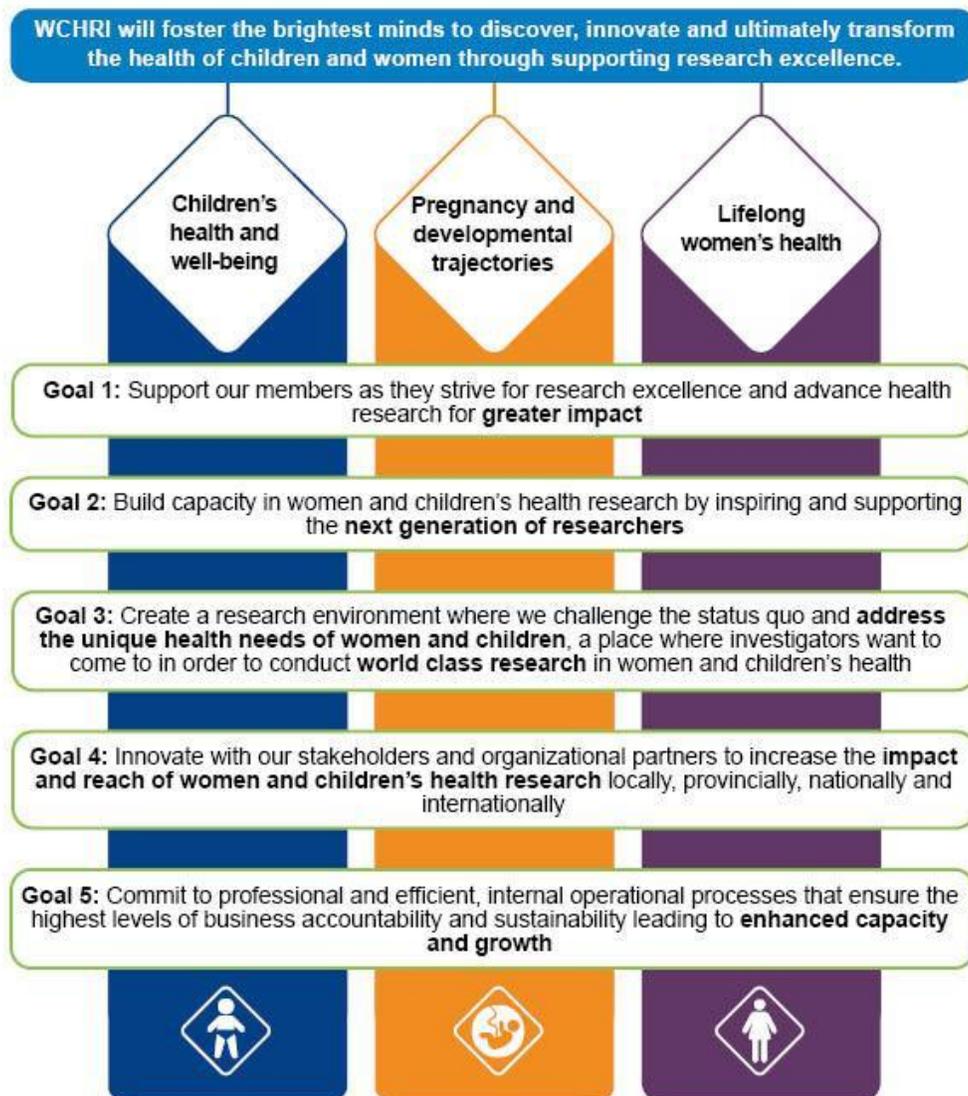
Executive Director Progress Report

Presented to: Oversight Board

Date: December 7, 2022

Reporting Period: October to December 2022

Strategic Plan Overview



Goal 1: Our academic members

Support our members as they strive for research excellence and advance health research for **greater impact**

- **Objective 1.1** Promote research leadership and collaborations in theme areas
- **Objective 1.2** Support our members to advance their research in our changing environment
- **Objective 1.3** Recruit and retain research excellence

Stollery Science Lab Distinguished Researchers

One of our Stollery Science Lab Distinguished Researchers received media mentions in the reporting period:

- Lonnie Zwaigenbaum and Grant Bruno, “Research, services lacking for autistic Indigenous people, say researchers”, in [Folio](#) and amplified by [CFWE FM Radio](#) and [Synaptic Post newsletter](#).

Grant programs

WCHRI is launching its [Grant Review Support Program](#) this month. This program offers WCHRI academic members the opportunity to obtain critical and robust scientific feedback on their proposal prior to submission to the CIHR Project Grant Program. This program seeks to support academic development and engagement in research at all career stages and phases, with the ultimate goal of increasing WCHRI member success in obtaining CIHR grants.

This program is offered in addition to our current [Bridge Grant Program](#) that supports WCHRI members whose applications to CIHR have just missed the funding cut-off.

Promoting research leadership and collaboration

WCHRI members Stephanie Montesanti, Richard Oster and Rhonda Bell successfully partnered with Indigenous communities and researchers across Alberta and BC to obtain a \$16M CIHR Indigenous Healthy early Life Trajectories Initiative (I-HeLTI) award. Approximately \$7M is earmarked for work in Alberta. The research program is titled *Hishuk-ish tsawalk (everything is one, everything is connected): Restoring healthy family systems in Indigenous communities*. The program will use traditional Indigenous Knowledge to inform and reclaim positive pathways for promoting and sustaining healthy child development. The program will establish an Indigenous birth cohort (under Indigenous governance) and will initiate research projects to increase our understanding of how social and biological processes and mechanisms along with community-led programs may be optimized for children’s benefit in reducing chronic health conditions such as mental health and cardiometabolic problems, or non-communicable diseases (NCDs). The program takes a lifecycle approach with a focus on healthy supportive environments for parents to be and the early childhood period. WCHRI is partnering with the initiative in several ways, including (but not limited to):

- partnership funding (from both Foundations) and graduate studentship funding to support additional maternal-child health research activities in northern Alberta (Maskwacis and Wood Buffalo communities),
- support from WCHRI Data Coordinating Centre to enable the development of Indigenous-owned research data infrastructure and birth cohort in partnership with the Alberta First Nations Information Governance Centre (AFNIGC),
- support from WCHRI research platforms for other related initiatives that will enhance maternal-child health research capacity in participating Alberta Indigenous communities (guided by communities).

Goal 2: Our in-training members

Build capacity in women and children's health research by inspiring and supporting the **next generation of researchers**

- **Objective 2.1** Attract the best trainees and support their research training

Trainee grant programs

The [WCHRI Patient and Community Engagement Training](#) (PaCET) program has granted awards to five graduate students who are conducting engaged research in the following areas: Examining access to healthcare and support services for Black preterm infants in Alberta; co-designing a high school credit course with Indigenous youth; supporting nêhiyew kinship for fathers raising future generations; improving health care provision at the New Canadians Health Centre for Afghan women refugees in Edmonton; and providing supports for early childhood educators in Alberta. PaCET awardees meet with Bethan Kingsley, WCHRI Research Associate, every month as a community of practice between September and May to develop their experiences and receive support as engaged scholars in the areas of women and children's health.

Trainee Advisory Committee (TAC)

During this reporting period, the WCHRI TAC launched this year's cohort of its mentorship program; mentees participated in an orientation session in October and will be reaching out to schedule their initial meetings with their new mentors.

The WCHRI TAC submitted a grant application to the Gairdner Foundation in order to host a spring 2023 event aimed at engaging young people in research. The proposed program is called "Discovery Day in Women and Children's Health Research" and aims to offer a unique opportunity for high school and undergraduate students to:

1. learn about the diversity of research in the field of women and children's health;
2. interact with "near-peers" (graduate students, postdoctoral fellows) and be inspired by their experiences;
3. gain practical information about entry points into women and children's health research training;
4. explore potential pathways to a career (academic or non-academic) in women and children's health research.

While the proposal was not successful in the funding competition, it forms a basis for future initiatives that TAC may explore in order to further engage with students at multiple levels.

Research Day

On November 2 we hosted our 15th annual Research Day. The day was an outstanding success and we are incredibly proud of each participant who contributed in making this day an unmatched event for our trainee and academic members, partners and stakeholders. This year we once again utilized a virtual event platform to provide interactive presentations and networking opportunities. More than 380 researchers, students and stakeholders actively participated. A full summary of the day is attached.

The Foundations were once again involved in a "Meet & Greet" which offered donors and staff an opportunity to hear directly from a panel of researchers. Katherine Sweet and Lindsay Robertson shared some lovely words during the opening remarks.

Goal 3: Our environment

Create a research environment where we challenge the status quo and address the unique health needs of women and children, a place where investigators want to come to in order to conduct world class research in women and children's health.

- **Objective 3.1** Position WCHRI as a national / international leader in women and children's health research; an institute that supports fundamental / preclinical research through clinical to population health focused on the unique health needs of women and children.
- **Objective 3.2** Position WCHRI as a national leader in interventional research in order to ensure safe and effective treatments for children and women; and to provide patients at our partner hospitals access to novel therapies.

Dale Sheard Centre for Solutions in Women's Health

Maya Henriquez, clinical research coordinator, approached 31 women for research; from those women, 23 consented and 37 samples (e.g. placenta, maternal blood, amniotic fluid) were collected for research. In addition, the centre enrolled 21 pregnant participants in two additional research projects and 12 new participants were recruited into existing urogynecology clinical trials carried out at the Centre. In total, we received over 50 research visits at the Centre during this period.

Our clinical research program lead, Laura Reyes Martinez, focused on:

- Welcoming Dr. Colleen Norris-Cavarzan Chair in Mature Women's Health Research to the Centre and connecting her with divisions and department members
- Supporting Dr. Oana Caluseriu in the Genetics Clinic in Maternal Fetal Medicine space (recent paper submitted detailing the outcomes and utility of antenatal whole exomes)
- Participating in the Women's Health Research Committee meeting, where they reviewed three new studies starting this month: identifying communication gaps between patients and healthcare providers regarding physical activity prescription; determining corticosteroids dose necessary to treat neonates for lung development without affecting their mental/behavioral development; and a chart review of cervical insufficiency with exposed membranes and the use of antibiotics.
- Attending the National Women's Health Research Initiative: Ideas Fair and Learning Circle. CIHR is going to offer grants to create the Pan-Canadian *Women's Health Coalition - Hubs*.
- Supporting the Gynecology-Oncology team submitting their grant with the AWHF to the Cancer Research for Screening and Prevention (CRSP) fund.

Qualitative Research

WCHRI is currently supporting six qualitative projects at varying stages of completion (conceptualization, data collection, analysis and writing). These projects are focused on the following topic areas:

- Maternal-child health services at the Lois Hole Hospital for Women for Indigenous patients and their families
- Migraine treatment for adolescents
- Non-invasive ventilation for children at end-of-life
- Online urogynecological care during the COVID-19 pandemic
- Medical complications in pregnant patients from Nunavut and Northwest Territories during the COVID-19 pandemic
- Co-creating autonomy-supportive environments for autistic children and adults.

Translational Genomics Hub

WCHRI's Translational Genomics Hub (TGH) continues to meet monthly in order to review new patient cases that can benefit from genomic re-analysis and/or further experimentation to understand causes and mechanisms of their disease. During the reporting period the scientific committee reviewed four cases, all of which have moved on to experimentation in the wet lab.

Data Coordinating Centre

Many WCHRI and Maternal Infant Child and Youth Research Network (MICYRN) affiliated investigators conduct clinical trials that require a Health Canada Clinical Trials Agreement (CTA). By law, these studies must comply with Division 5 of Canada's Food and Drug Regulations. As a result of this, any

computerized systems used in these trials must be "validated", where validation is a formal process of testing and documenting a system to demonstrate that it consistently meets its intended purpose. This poses a problem in that validation is a long and cumbersome process and due to a lack of guidance from Health Canada it is poorly understood by researchers and their IT support. In an effort to simplify and harmonize the approach to REDCap validation across Canadian institutions WCHRI's Data Coordinating Centre has formed the Canadian REDCap Validation Group. This is an informal group of REDCap administrators, including staff from Sick Kids, the University of Calgary, London Health Sciences, Women's College Hospital, and the Children's Hospital of Eastern Ontario. We are working to develop a collaborative approach to REDCap validation where the approach is standardized across institutions and where the validation effort can be shared across the participating institutions.

Pediatric Clinical Trials Unit

WCHRI's pediatric clinical trials team is currently supporting 173 active studies (84 cohort studies and 89 clinical trials) with several more in start-up/close-out phases.

Pediatric Clinical Trials Spotlight: Decoding personalized nutritional, microbiome and host patterns impacting clinical and prognostic features in Crohn's disease

The Edmonton Pediatric Inflammatory bowel disease (IBD) Clinic (EPIC), with Dr Eytan Wine, is starting a new trial for children newly diagnosed with Crohn's disease. This is an observational study where families are asked to complete daily diary entries using a specially designed app to describe their diet, activity and symptoms in addition to extensive biological samples collected from the children. The investigators hope to leverage machine learning (artificial intelligence) algorithms to analyze the diary entries and biological samples to provide personalized nutritional recommendations and improve individual patient outcomes. This will be an intense study, with unprecedented amounts of data being collected and analyzed. If effective, the use of artificial intelligence and machine learning will provide children living with Crohn's disease a truly personalized approach to treating their disease.

Goal 4: Our ecosystem

Innovate with our stakeholders and organizational partners to increase the **impact and reach of women and children's health research** locally, provincially, nationally and internationally

- **Objective 4.1** Improve health outcomes for children and women and increase dissemination and implementation of high quality health research evidence by supporting stakeholder* engaged research and research that is embedded at the point of care.
- **Objective 4.2** Ensure research strategies are aligned with and adaptive to our ecosystem

National partnerships

The Partnership for Women's Health Research – Canada (PWHR-Canada) launched its [website!](#)

- The first women's health research seminar was held on September 22 with a panel discussion about "Working with communities to design and implement women's health research". Alison Bourgon, Director of Science Policy for CIHR presented and was the moderator. The inaugural seminar was a success with 56 attendees from across the country who actively participated in the discussion.
- The PWHR Executive Committee met with the Women's Health Collective Canada (WHCC) on November 9 to present the PWHR strategic framework, to discuss synergies and shared objectives, and opportunities for collaboration.

MICYRN's young persons' research advisory group, also known as KidsCan, recently put out a call for new youth members and regional coordinators. Two young people from the Stollery youth council have recently joined this group. The KidsCan group is formed by youth aged 13-19 from all over Canada and meets monthly to work on projects that will help improve research experiences for young patients. This work includes advising on the design of documents about research studies, study websites, research ethics consent forms and other aspects of a study design and its implementation.

Intersectional Research in Women and Children's Health

WCHRI has partnered with Intersections of Gender at the University of Alberta to develop a seminar series titled "Encountering Expertise in Intersectional Health". Through this partnership, three seminars have been offered focused on addressing inequities in women's and children's health; qualitative and quantitative intersectional research design; and framing women's health through a decolonial, intersectional lens. Each seminar has consistently had ~200 registrants, demonstrating the high interest in this area.

Goal 5: Sustainability and growth

Commit to professional and efficient, internal operational processes that ensure the highest levels of business accountability and sustainability leading to **enhanced capacity and growth**

- **Objective 5.1** Prioritize operational and leadership succession planning; optimize internal business processes in order to continuously improve the quality and accessibility of programs/platforms.
- **Objective 5.2** Be accountable and responsive to our funding partners needs

Stewardship activities & Foundation support

- WCHRI released our September 2022 eNewsletter, profiling three SCHF-funded research projects and one AWHF-funded research project.
- On September 17, we celebrated the Royal Alexandra Hospital Foundation by attending the Harvest Celebration.
- The [summer studentship profiles](#) were launched on September 19 and highlighted 15 trainees who were supported by the Stollery Children's Hospital Foundation and eight trainees who were supported by the Alberta Women's Health Foundation. Four summer students ([Julia Craig](#), [Christiane Bilodeau](#), [Zoe Brody](#) and [Kara Terry](#)) created videos explaining their work.
 - WCHRI also created thank you emails and videos for both the [SCHF](#) and [AWHF](#) to share with their donors and boards.
- WCHRI and the Lois Hole Hospital Women's Society partnered on October 27 for an event in a research seminar series offered to monthly donors to the society. This What the Health event was titled "Let's talk about personalized cervical cancer radiation therapy". AWHF-supported researcher Geetha Menon presented.
- On November 2, WCHRI and the SCHF partnered to present a Meet and Greet, an exclusive event offered to SACH staff and donors. SCHF-supported researchers Geoff Ball, Yifeng Wei, Claire Benny, Julia Wolf and Geraldine Huynh presented, with emcee Sandy Davidge.
- On November 2, WCHRI and the AWHF partnered to present the AWHF Solutions Series, an exclusive event offered to RAHF staff and donors. AWHF-supported researchers Colleen Norris, Richard Oster and Bukola Salami presented, with Sandy Davidge providing opening remarks.
- SCHF media mentions / WCHRI stories include:
 - Jacob Jaremko, "Making health care more equitable one ultrasound image at a time" was amplified by [FoMD Connects](#) newsletter.
 - Susan Gilmour, "Clinical trial of new medication for genetic liver condition 'life-changing' for young patient and his family", in [Folio](#) and amplified by [India Education Diary](#) and [FoMD Update](#)
 - Jessica Harasym, "[Communication problems after concussion can cause wide-reaching issues for youth](#)".
 - Ashton James, "[Building consensus on indicators of social and emotional well-being](#)"
 - Samina Ali, "[Research aims to relieve pain children feel in emergency departments](#)"
- AWHF media mentions / WCHRI stories include:
 - Donna Vine, "More awareness, education needed to better treat polycystic ovary syndrome" in [Folio](#) and amplified by [Medical Express](#), [Taproot Edmonton](#), [Troy Media](#), and the [Faculty of Medicine & Dentistry Update](#).
 - Sandra Davidge, Sharlene Rutherford "Reaping a \$650,000 harvest in support of Lois Hole Hospital for Women" in the [Edmonton Journal](#) and amplified by [Taproot Edmonton](#).