Women & Children's
Health Research Institute

2012/2013 Annual Report

UNIVERSITY OF ALBERTA

Alberta Health Services

STOLLERY CHILDREN'S HOSPITAL FOUNDATION

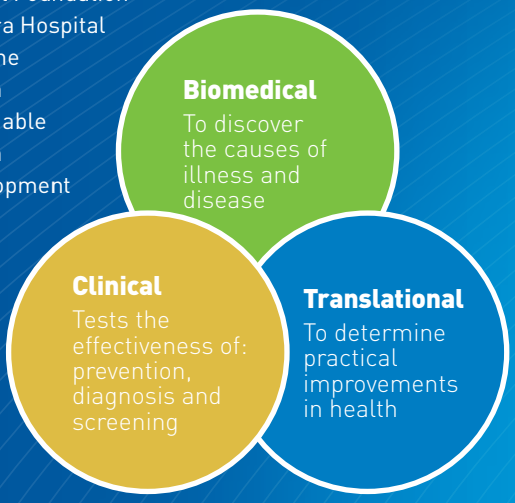
Royal Alexandra HOSPITAL FOUNDATION

WCHRI Overview

Research saves and improves lives. Many disorders of both women and children affect multiple organ systems and require complex care and collaborative research. Many researchers and clinicians of the Women & Children's Health Research Institute (WCHRI) are focusing on more effective ways to improve the care and health of these patients. Moreover, research focused on women and children's health can lead to prevention and reduction of long-term health complications as adults. Research leading to healthier children creates a positive cycle of human development that includes pregnancy, birth, growth and development through childhood and adolescence to adulthood. Our researchers investigate fundamental aspects of this cycle and direct the translation of new information into clinical knowledge, improved health care and a healthier population in general.

WCHRI supports this groundbreaking multidisciplinary and transdisciplinary research through grant competitions, ongoing research funding, professional development and expert resources. Our academic membership is made up of approximately 300 leading researchers, clinician-scientists, academics, health care professionals and service providers from academic and community settings.

WCHRI was founded in 2006 as the shared vision of the University of Alberta (U of A) and Alberta Health Services (AHS), with core funding from the Stollery Children's Hospital Foundation (SCHF) and the Royal Alexandra Hospital Foundation (RAHF). Through the generous contributions of both Foundations, WCHRI has been able to support the hiring, research excellence, training and development activities of investigators from a wide range of clinical and academic disciplines, all focusing their efforts on improving health outcomes for women and children in our province.



Vision

Improved outcomes for women and children through health research

Mission

To effect meaningful health outcomes through cutting-edge transdisciplinary research

Goals

- To facilitate basic and applied health research activities focused on women and children's health
- To encourage collaborative and translational research within the university and outside (community, industry, national/international institutions)
- To promote training in health research with a focus on women and children
- To provide a unified team approach for facilitating communication and establishing representation to the public, granting agencies and authorities
- To ultimately translate this knowledge for the purpose of providing the best clinical practice guidelines

Message from the Director

The last year has been a busy and exciting one for WCHRI!

WCHRI's Annual Report highlights a few of the exciting research outcomes and new research programs of our members. Moreover, this past year has been a time of strategic growth as WCHRI developed new initiatives and partnerships, which are also detailed in this report.

Over the next few years, WCHRI will continue to support new initiatives leading to better health outcomes. WCHRI is committed to the belief that research is integral to excellence in care. Members of WCHRI bring their great talents and skills in research and care to benefit all of our patients and the community. Discovery research in WCHRI continues to provide innovative and novel ideas, which form the foundation for advancement in care in our province.

One such strategy is the 'Concept to Completion' approach, which is an idea/project-based workflow process that will allow us to maximize value and impact. The concept will facilitate the development and implementation of a more comprehensive strategy for research priorities, and to plan and conduct health research. Targeted research projects will demonstrate the 'integrated research hospital/clinic' concept, thereby delivering on excellence in care and research.

A second WCHRI initiative is to identify and facilitate team development to tackle important health issues in women and children's health. This initiative is designed to bring both infrastructure support and networking capacity to the development of programs, and to facilitate the establishment and growth of interdisciplinary teams to tackle larger, more complex research questions than can be addressed by individual research laboratories. As a first step towards this initiative, WCHRI has partnered with the Department of Pediatrics to facilitate a program termed 'Connecting Through Research' as a mechanism to bring the research community together.

Over the last year, WCHRI has embraced several provincial initiatives. For instance, WCHRI is playing a key role in the development of the research strategies and directions of the Strategic Clinical Networks (SCNs)* focused on child and maternal health. A national initiative, the Strategy for Patient Oriented Research (SPOR) is being established to advance research in humans through the development of core infrastructure. WCHRI is already a provincial and national leader in providing clinical research infrastructure and is poised to be a key support unit for women and children's health research in Alberta. We will continue to work strategically with our faculty and our provincial partners in the health system for the success of these initiatives.

Importantly, I have had the privilege over the last year to work with an exceptionally talented group of dedicated personnel to support the members of WCHRI. Most recently, Dr. Lawrence Richer joined our executive unit as Associate Director, and he provides outstanding leadership with a clinical perspective. I am thrilled to have him join our team!

The upcoming years are full of promise as we move closer to achieving our goals of further improving health outcomes of women and children through excellence in research.

Dr. Sandy Davidge
Director
Women & Children's Health Research Institute

** SCN's are an AHS initiative for province-wide teams that bring together the experiences and expertise of health care professionals, researchers, government and communities, patients and families to address the delivery of health care to Albertans.*

Demonstrating Excellence

Children's medicine is continuously evolving and improving every day. An important part of the reason why is because of the investment that is being made in research through WCHRI.

Look how far we have come over the past 25 years, the past 10 years, and even the past five years. Innovation and discovery are now part of the integrated approach to ensuring that our children have the best possible chances for outcomes by partnering technology, science, patient care and observation. Our expertise and level of sophistication in children's medicine is growing. And that's a good thing – because as we continue to improve, our children have a better chance to realize the potential they have inside themselves.

The Stollery Children's Hospital Foundation is committed to supporting WCHRI to conduct many forms of research, which in turn leads to new innovative approaches to health care for kids. Our investments are a reflection of the passion our donors have to care for our most vulnerable and important citizens – our children.

Children's medicine is also changing as our world changes. Allergies, obesity, asthma, diabetes and autism were outlying concerns in children's health 50 years ago. Now, they are top-of-mind for parents, grandparents and families who see their children face serious health concerns that could impact their lives into adulthood. By investing in research to improve our knowledge and expertise, WCHRI helps to not only provide better health for kids today, but also creates solutions for adults tomorrow.

The Stollery Children's Hospital Foundation is so proud to provide a long-term commitment to supporting WCHRI's milestone achievements.

Mike House
President and CEO
Stollery Children's Hospital Foundation

STOLLERY CHILDREN'S HOSPITAL FOUNDATION

STOLLERY CHILDREN'S HOSPITAL

The Stollery Children's Hospital Foundation is dedicated to raising funds for specialized equipment, sub-specialty medical education to train the best of the best, research to pave the way to the discovery of new treatments or cures for child health issues and specialized programs that improve patient and family outcomes at the Stollery Children's Hospital.

The Foundation recognizes the tremendous impact that research has on disease prevention, treatment and improved health outcomes, which is why it is providing $30 million over 10 years (2006 to 2016) to support WCHRI's mission to support leading-edge research on children's and women's health.

The Power of Partnerships

This past year has been an exciting time for women's health at the Lois Hole Hospital for Women. As the research home for WCHRI, our hospital is leading the way in women's health on all fronts, and the best part is we're just getting started.

The Royal Alexandra Hospital Foundation along with our Board of Directors and donors recognizes the vital role research plays in the healthcare equation. By integrating research into clinical care, a more comprehensive and shared approach to healthcare is occurring, and as a result our patients are benefiting.

A huge win for research came with the recruitment of Dr. Sandra Davidge as the Director of WCHRI. Sandy is among the pre-eminent researchers in North America and brings incredible knowledge to our city through her leadership and vision. We were delighted to have Sandy as our keynote speaker at The Harvest Celebration in September 2012, our annual gala fundraising event in support of the Lois Hole Hospital for Women.

2012 also marked the recruitment of the Cavarzan Chair in Mature Women's Health Research at the Lois Hole Hospital for Women. As one of the top researchers in Canada, Dr. Sue Ross is working to usher in a new and revelatory focus on women's health research right here in our province. We're very proud.

Collaboration means communication and the governance structure of WCHRI includes foundation representation which allows all partners to be included in the decision making process. This in turn ensures our donor dollars are used in the most meaningful ways for research and education which ultimately impacts our patients. We are thrilled to recognize former RAHF Chair and Campaign Chair for the Lois Hole Hospital for Women, Dale Sheard as our foundation representative on the WCHRI Oversight Board. Dale's passion and commitment to improving healthcare at all levels makes her the ideal ambassador for our organization and a true champion for women's health.

A healthy community starts with healthy women. The Lois Hole Hospital for Women and WCHRI are both emerging as leaders, and together we will continue to work towards a healthier future for women in Alberta and across Canada. Community support does indeed build great hospitals and we are building something truly remarkable through the power of partnerships.

Andrew Otway
President and CEO
Royal Alexandra Hospital Foundation

The Royal Alexandra Hospital Foundation inspires community support for their health-care facilities. The Foundation empowers compassionate, leading-edge patient care through education, research, technology and facility enhancements. They provide support for the Lois Hole Hospital for Women and a growing number of specialized centres of health care located at the Royal Alexandra Campus.

The Foundation places a strong focus on research and innovation and is committed to supporting and promoting the ongoing work of researchers through WCHRI with a commitment of $11 million over ten years (2006 to 2016).

Royal Alexandra HOSPITAL FOUNDATION

LOIS HOLE HOSPITAL FOR WOMEN

Message from Alberta Health Services

As the home of many of WCHRI members' clinical research studies, the Stollery Children's Hospital has a front-row seat to the work of WCHRI-supported researchers. We are able to see firsthand the importance of the Stollery's relationship with the Institute; it is through this relationship that WCHRI members and research coordinators can access patients in real-life situations and in turn gain real-life data, while we benefit from the translation of that data into changes in our own clinical policies and practices.

Patients, clinicians, funders and other stakeholders want and need research that directly addresses the health care decisions they face, and that reflects their values, preferences and goals. That's the kind of research WCHRI funds and sustains. I am confident that, building on the progress made in the past year under the leadership of Dr. Sandy Davidge, with a foundation of significant and ongoing engagement with the communities we serve, we are well on our way.

I am grateful to have had the opportunity to be so closely involved with this dynamic and important Institute. I look forward to following the progress of WCHRI researchers and clinicians as they continue to ensure that our children and their families have improved health outcomes through research and better access to the information they need to make informed choices about their healthcare.

Linda McConnan
Executive Director, Stollery Children's Hospital

Ms. McConnan was the Executive Director of the Stollery Children's Hospital until April 5, 2013, and was a member of WCHRI's Oversight Board. As one of the AHS representatives involved in governing WCHRI, she helped ensure WCHRI's programming continued to support AHS in the delivery of clinical care, wellness and prevention in Alberta, particularly for children's care. Ms. McConnan was a strong and active supporter of WCHRI and a great leader in providing her expertise to the direction of our Institute.

The Lois Hole Hospital for Women, located in the Robbins Pavilion at the Royal Alexandra Hospital, plays a key role in advancing women's health research and innovation through to clinical care. We are thrilled to house WCHRI's Lois Hole Clinical Research Unit and to have WCHRI supporting women's health through research grants and funded research chairs. Having research nurses and coordinators on site is a win-win: researchers have access to the coordinators who know the hospital staff, can obtain necessary consents from patients, and are available to collect samples within the required timelines; our hospital team and patients gain from knowing that we are directly supporting the science of improving women's health.

In the past, many treatments for health issues specific to women came from adopting research done with men. Researchers now understand that it is important to look at women's health separately as women have their own unique challenges. We are very proud to work with the Institute which puts women's health first, through every stage of women's lives.

Dr. Sandy Davidge and the members of WCHRI are tremendously passionate about the work they do and the research they support, I know we can expect many advancements and innovations through WCHRI in the years to come.

Joanna Pawlyshyn
Vice-President, Royal Alexandra Hospital

Ms. Pawlyshyn is the Vice-President of the Royal Alexandra Hospital and sits on the Board of Directors of the Royal Alexandra Hospital Foundation. As a member of WCHRI's Oversight Board, Ms. Pawlyshyn's guidance and support has been invaluable in ensuring that women's health and AHS's standards in the delivery of clinical care, wellness and prevention in Alberta remain a focus of WCHRI's mandate.

Message from Vice-President (Research), University of Alberta

The University of Alberta is renowned for its health research expertise, capacity and partnerships, and its numerous and significant contributions to public health. WCHRI is a prime example of this. WCHRI, a partnership between the university and the Alberta government, facilitates and supports cross-disciplinary collaboration across the biomedical, clinical and translational research spectrum. By tackling crucial and complex health questions, researchers at WCHRI help advance public health knowledge and discovery and improve outcomes.

In the past year, WCHRI has made substantial progress including:

- Facilitating changes in the way traditional medical research is conducted.
- Developing better ways to ensure research results are communicated and incorporated into clinical practice.

WCHRI is clearly proving itself an excellent enabler and driver of research in women and children's health. I am excited to see what they will accomplish in the future.

Dr. Lorne Babiuk
Vice-President (Research), University of Alberta

The Vice-President (Research) portfolio strives to create and support an environment of research excellence across the university to fuel knowledge advancement, discovery and innovation; all of which provide significant contributions to society provincially, nationally and globally. WCHRI appreciates the university's support and guidance in helping ensure our members become and remain global leaders in groundbreaking research and innovation in women and children's health.

Message from the Dean, FoMD

I appreciate this opportunity to add my voice to those of other friends and families touched by the good works of the Women and Children's Health Research Institute at the University of Alberta. By virtue of its many dedicated members, WCHRI exemplifies the missions of our medical school by 'Advancing Health through Teaching, Research and Patient Care'. For those of us who have dedicated our careers to the health of women and children, it is gratifying to see all this good work changing and saving lives across Alberta.

Dr. Doug Miller
Dean, Faculty of Medicine & Dentistry, University of Alberta

It is through the continued support of the University of Alberta's, Faculty of Medicine & Dentistry (FoMD), that WCHRI can house many of its core groups and its entire administrative staff. FoMD also provides funding for WCHRI's operating expenses; without which, WCHRI would not be able to manage its many grants programs and research support initiatives.

What research can accomplish

What causes premature birth?

Dr. Bryan (Peter) Mitchell - Professor, Department of Obstetrics & Gynecology

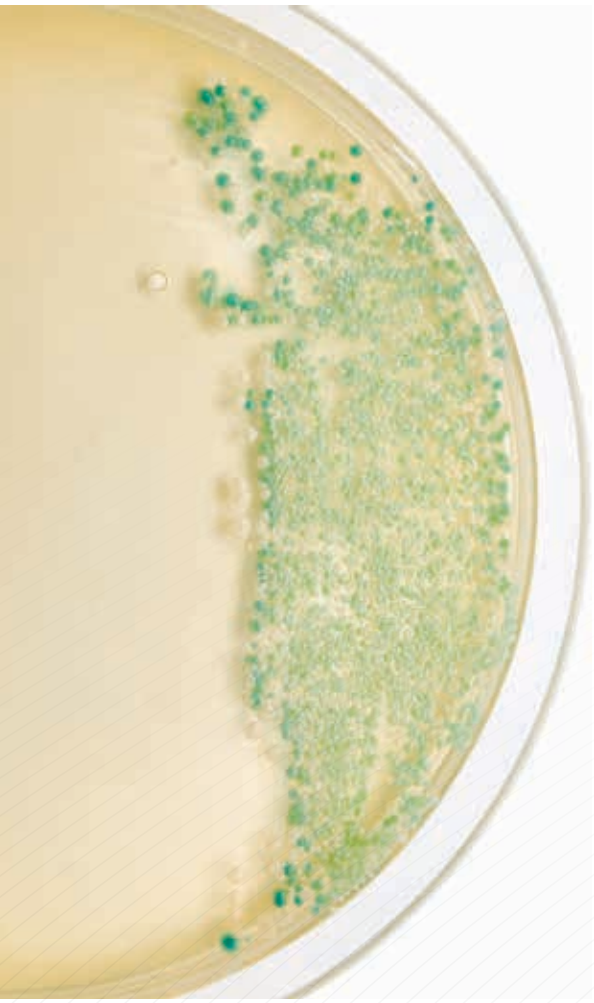
Premature birth continues to be a major complication of pregnancy, particularly in Alberta where the incidence is the highest in Canada. Babies that are born before their organ systems have fully matured are susceptible to a wide range of complications and this remains the major cause of early infant death. The survivors commonly have significant disabilities including life-long neurological impairment, breathing and nutritional complications. In addition, the extra care required for disabled premature babies creates a major burden to the mother, her family and to our health-care budget.

Disappointingly, there has been very little progress in our understanding of what causes premature birth. As a result, we have no proven effective methods to prevent it. One of the major obstacles to progress is that the mechanisms that determine when birth will occur in pregnant women appear to be unique and quite different from other species. Ethical considerations place strict limitations on research in pregnant women.

Supported by a WCHRI Innovation grant, Dr. Peter Mitchell and his team began studies to develop a better model system for premature birth, which will allow researchers to test therapeutic interventions. For instance, the research team is examining potential new drugs that would stop uterine contractions while having minimal side effects on other systems. Dr. Mitchell is optimistic that further studies using this and other model systems will hasten the understanding of human preterm birth. This new knowledge could pave the way for researchers and caregivers to prevent preterm birth and diminish the tremendous strain this can have on the babies and their mothers. In addition it could greatly reduce the social and financial consequences to the families and our healthcare system.

Infant gut microbiota influenced by cesarean section and formula feeding practices

Dr. Anita Kozyrskyj - WCHRI Chair in Maternal-Child Health and the Environment



Over the first year of life everyone acquires bacteria in their gut that play an important role in regulating the bowels, helping digest food and protecting against infection. These bacteria, or microbiota, when disrupted in early childhood have been linked to many diseases and conditions such as asthma, obesity, inflammatory bowel disease, cancer and diabetes.

Dr. Anita Kozyrskyj and her colleagues compared the microbiota at four months of age of babies born vaginally versus by cesarean section (C-section) and those who were exclusively breast versus formula fed after birth.

Using samples from 24 babies participating in the Canadian Healthy Infant Longitudinal Development (CHILD) study, her team discovered babies born by C-section are missing a specific strain of bacteria normally found in babies born through vaginal delivery. The team also discovered differences in the gut bacteria of babies who were exclusively formula fed versus those who received some breast milk.

Dr. Kozyrskyj and her team will now be looking into the impact of this change in microbiota on the infants' health in the future. The next step is to expand the study to 200 babies and then eventually 2,500, which could take two years to analyze. Researchers will focus more on how bacterial differences relate to specific outcomes, such as asthma and allergies, at one and three years of age.

These results were published in the Canadian Medical Association Journal this February. Funded by one of seven Canadian Institutes of Health Research Microbiome Initiatives, they represent the first North American study to look at the gut bacteria of healthy babies.

WCHRI members include leading researchers on lung development, asthma and allergies.

Intensive motor training after perinatal stroke to enhance walking

Drs. Jaynie Yang, Professor, Department of Physical Therapy, and Monica Gorassini, Professor, Department of Biomedical Engineering

Perinatal (around birth) strokes are devastating especially because the children live with its effects for the rest of their lives. Most often they are diagnosed with cerebral palsy (CP), a group of non-progressive motor conditions that cause physical disability, chiefly in the various areas of body movement. The majority of children with CP have problems walking, yet current treatments are limited. Orthopedic surgeries to correct these problems have been referred to as the 'birthday syndrome', due to the common need to repeat them yearly or bi-yearly. Aside from the huge quality of life impact, it is estimated that the lifetime health care cost for each CP child is around $1 million.

Currently, children with CP in Alberta receive therapy for leg related function about once a month usually starting at about age two. However, based on previous scientific evidence, Drs. Jaynie Yang, Monica Gorassini and their colleagues predict that the critical period for motor pathways to the legs is from shortly after birth to the age of two years.

Therefore, the team, from Edmonton and Calgary, intend to provide intensive motor therapy to children as young as eight months of age. The essence of the research is to intervene with walking training during the critical period for the legs, in order to train the nervous system while the neural pathways are still forming. It is anticipated that the results of this study will: 1) determine if early, intensive training of the legs improves walking more than later training or no training, and 2) determine how age at time of training affects the pathways from the brain to the spinal cord (motor), from the spinal cord to the brain (sensory), and spinal circuits (motor/sensory).

CP results in severe and life-long consequences for the family and the child. Dr. Yang and her colleagues aim to make a difference by applying intensive training when the nervous system is most plastic. By intervening at the ideal time, limited resources for therapy can be applied when the effects are greatest, resulting in 'the biggest bang for the buck'. They predict this will have further economic benefits as the child ages by reducing the need for surgeries, reducing secondary complications, increasing mobility, and leading to greater participation in employment and less dependence on social supports.

Dr. Yang received external Alberta Innovates—Health Solutions (AIHS) Collaborative Research and Innovation Opportunities (CRIO) and Canadian Institutes of Health Research (CIHR) awards in September 2012, based on preliminary data funded by WCHRI Bridge and Innovation grants. The team has also benefited from on-going support from the WCHRI Biostatistics, Knowledge Translation and Grant Support services.

WCHRI researchers who investigate brain/neurodevelopment and adolescent mental health are working towards the development of better diagnosis, treatments and/or interventions for improving child health outcomes.

Children's Brain Development: making a connection

Drs. Lonnie Zwaigenbaum, Jerome Yager, Christian Beaulieu, Carmen Rasmussen and John Andersen - NeuroDevNet Researchers

NeuroDevNet, one of the Canadian Networks of Centres of Excellence (NCE), is a national initiative focusing on childhood brain development from both basic research and clinical perspectives. The Network, also supported by WCHRI and CIHR, is initially researching the impact of genes and/or the environment on three important developmental disabilities in children including:

1) Cerebral Palsy (CP), led by Drs. Michael Shevell of McGill University and Jerome Yager of the U of A.

2) Autism Spectrum Disorder (ASD), led by U of A researcher Dr. Lonnie Zwaigenbaum, Stollery Children's Hospital Foundation Chair in Autism Research.

3) Fetal Alcohol Spectrum Disorder (FASD), led by Dr. James Reynolds of Queen's University and Dr. Joanne Weinberg of the University of British Columbia.

The U of A has the largest active investigator involvement in all three projects among the academic institutions across Canada. Drs. John Andersen and Helly Goez are directing the CP Registry. Drs. Christian Beaulieu, Carmen Rasmussen and Gail Andrew are leading the FASD component in neuroimaging studies, and Drs. Joanne Volden and David Nicholas are involved in various facets of the ASD project. In each project, the teams are researching common themes that are affected by genetic and environmental influences. They are also interested in determining if there are commonalities among the three disorders that may provide clues to the underlying causes of disease, or perhaps common intervention strategies.

Currently in its third year, NeuroDevNet has made tremendous gains which could have significant health impacts for a large number of children in Canada. The CP project created one of the largest patient registries in Canada and leveraged

this to successfully obtain funding from several additional partnering sources including the AIHS CRIO grants initiative, CIHR and others. The ASD project has successfully leveraged WCHRI and NeuroDevNet support with substantial funding from Genome Canada, Autism Speaks (Canada and US) and the Simons Foundation. Progress has been made in identifying genes underlying vulnerability to ASD, which combined with early behavioral markers, could lead to earlier detection of infants at risk of the disorder. Finally, the FASD project has shown widespread structural anomalies in the brain of children diagnosed with this disorder. Current studies aim to link these changes with specific cognitive dysfunctions and genetics to understand the range of disability. Progress has also been made to help guide the development and assessment of promising treatments or interventions to address areas of difficulty in FASD. The Alberta Center for Child, Family and Community Research is a partner in supporting this research.

The WCHRI funds remain in Edmonton to fund local research under each of the three projects. WCHRI's Clinical Research Informatics Core and it's software, REDCap, were also utilized in the development and maintenance of the CP Registry.

"WCHRI's support allowed Edmonton to more fully participate, and become a major player, in this network," says Dr. Yager. "WCHRI and the U of A site in Edmonton is perhaps the only group across the country holding major leadership positions in all three of the demonstration projects."

Can diet help manage Prader-Willi Syndrome?

Dr. Andrea Haqq - Associate Professor, Department of Pediatrics

Childhood obesity is identified as a priority by our health care professionals. Our members are conducting research to address this complex issue from a variety of perspectives.

Prader-Willi Syndrome (PWS) is a genetic condition characterized by failure to thrive and low muscle tone during infancy, followed by severe obesity in childhood. Children with PWS experience constant hunger that can negatively affect their health and behaviour. Food-seeking behaviour can include food hoarding, foraging, stealing and consumption of inedible items. Obesity in children with PWS is associated with decreased quality of life, breathing difficulties and poor self-esteem.

Using a WCHRI Recruitment & Retention grant and an Innovation award, Dr. Andrea Haqq and her team wanted to investigate the mechanism by which alteration of protein in the diet may affect neuroendocrine (connection between the nervous and endocrine systems) mediators of hunger and satiety in obese children with and without PWS. One such mediator is active Ghrelin. Ghrelin, often known as "the hunger hormone", is the chemical that triggers the feeling of hunger. In children with PWS, the ghrelin level does not decrease as much when eating as it would normally and the levels rebound faster than is typical. Dr. Haqq's team wanted to determine if a diet high in protein could help regulate these levels.

Dr. Haqq's team studied the ghrelin levels of 12 children with PWS. They tested both 'active' and 'inactive' ghrelin and found that the PWS children had higher levels of both.

Nutrition undergraduate students were tasked with studying the children's dietary records. The students discovered that PWS children had a low intake of micronutrients when their caloric intake was restricted. Additionally, they also discovered that the PWS children actually had a higher diet quality than the obese control group.

Currently, no effective treatment options exist to control hunger in children with PWS. Abnormalities in the level of hormones that regulate food intake might contribute to excessive hunger in children with PWS. Specific diets (such as high protein diets) may decrease hunger in children with PWS through alterations in hormone levels. As well, specific diets may be beneficial in reducing the metabolic complications, such as insulin resistance, associated with childhood obesity in general. However, it is not yet fully understood how different types of diets affect hormones involved in the regulation of food intake and metabolism in children with PWS or obesity in general.

This research may lead to diet recommendations for treating obese children as well as children with PWS.

The team used WCHRI's Lipid and Lipid Metabolite Analysis Core for its lipid testing.

Preparing youth for the transition from pediatric to adult congenital heart programs

Dr. Andrew Mackie - Assistant Professor, Department of Pediatrics

Organizing the appointments, treatments and prescriptions involved in managing an adolescent's congenital heart disease (CHD) can seem daunting even when there is a parent to help. What happens when it comes time for a young adult to take care of everything personally?

Dr. Andrew Mackie and his colleagues are now closer to developing a nurse-led protocol that will assist these patients with CHD in their transition from pediatric care to adult care.

The team implemented a single-session, nurse-led intervention for adolescents (ages 15 to 17) with CHD. When patients came into clinic for their regularly scheduled visits, some had the opportunity to also participate in an hour-long, one-on-one session with a nurse who specializes in cardiology. During this session participants created a MyHealth passport, reviewed their cardiac anatomy and discussed common teen issues and potential late heart complications based on their specific CHD diagnosis. Follow-up was performed after the intervention, and included the Transition Readiness Assessment Questionnaire (TRAQ). The group discovered that participants who received the nurse-led intervention scored better on the TRAQ and were more informed of their condition than those who did not receive this nurse-led session.

Dr. Mackie has since leveraged this pilot project into more than $360,000 in national funding for a two-centre study in Toronto, Ontario, and Edmonton, Alberta; with Edmonton as the lead site.

The ultimate goal is to develop a transition program that will enable young adults to enter the adult health care system with sufficient tools to actively and knowledgeably manage their health, along with their cardiologist and cardiac nurses. Ultimately, better-educated patients may suffer fewer and less severe cardiac complications because they better understand their condition and in turn follow up on potential problems earlier than those who do not receive the same education.

This study developed from data collected in Dr. Mackie's previous research that looked at psychosocial maturity, quality of life and autonomy among young adults with CHD. This phase was supported by a WCHRI Recruitment and Retention award.

This work was also supported by WCHRI Innovation grants and by WCHRI's Clinical Research Informatics and Clinical Research Coordination Cores.

Pediatric organ complications and transplants affect children for the rest of their lives. Our researchers want to know how they can improve the health of the child now and as they transition to adulthood.

Ovarian cancer treatment strategies

Dr. YangXin Fu - Assistant Professor, Department of Obstetrics & Gynecology

Ovarian cancer is the fifth leading cause of cancer deaths in women and the leading cause of gynecologic cancer-related death. In Canada, there are approximately 2,600 new cases of ovarian cancer and 1,750 deaths due to this disease each year (Canadian Cancer Statistics). Although an early diagnosis can result in a cure in 90 per cent of all cases, approximately 75 per cent of ovarian cancer patients are diagnosed at advanced stages when tumors have spread beyond the ovaries. Advanced ovarian cancer patients are generally treated by surgery followed by chemotherapy. Carboplatin is the chemotherapy drug most often used in treating ovarian cancers. It is a popular choice of clinical treatment due to its greatly reduced side-effects and works by interfering with DNA repair in tumor cells. Despite an initial positive response to chemotherapy, however, relapse occurs in nearly all ovarian cancer patients and recurrent diseases are resistant to current chemotherapy regimens.

Consequently, the five-year survival rate for advanced ovarian cancer patients is only 15 to 25 per cent. Thus, we need to study this deadly disease at the molecular level to better understand how ovarian cancer cells become resistant to chemotherapeutic drugs such as carboplatin. This will help us develop new and more effective therapeutic strategies and improve the management of ovarian cancer.

Funded by two WCHRI Recruitment and Retention grants, and a WCHRI Innovation grant, Dr. YangXin Fu and his team began studying ovarian cancer at the molecular level, "we need to understand how normal cells become ovarian cancer cells and how ovarian cancer cells become resistant to the current chemotherapy so that we can find more effective ways to treat this devastating, high-mortality disease."

The team has made several important discoveries. First, they found two growth factors that together induce more invasive characteristics in ovarian cancer, suggesting that simultaneously targeting both could be a more effective way to treat ovarian cancer. Second, the inactivation of a gene called GUCY1B3 makes ovarian cancer cells more sensitive to carboplatin. Finally, the team learned that activation of Notch3, a molecule that transmits signals in cells, makes ovarian cancer cells more resistant to carboplatin. This means that targeting this molecule could make ovarian cancer cells more susceptible to chemotherapy drugs, hopefully leading to more effective treatments for this disease.

"Taken together, we have identified a few potential therapeutic targets for ovarian cancer. We will further test these potentials in both cell culture and other models. Meanwhile we will continue searching for critical molecules that are involved in chemoresistance of ovarian cancer in order to develop novel and more effective ways to treat this deadly disease," says Dr. Fu.

Mature Women's Health Research

Dr. Sue Ross - Cavarzan Chair in Mature Women's Health Research & Innovation

On July 1, 2012, Dr. Ross was appointed the Cavarzan Chair in Mature Women's Health Research & Innovation supported by the Royal Alexandra Hospital Foundation. Dr. Ross will be working primarily from the Lois Hole Hospital for Women.

Dr. Sue Ross has 20 years experience in clinical research. As a health services researcher, Dr. Ross has spent most of that time conducting clinical trials, mainly surgical in nature. Her goal is to improve clinical and patient outcomes; though the main theme of her research is providing evidence to support clinician and patient decision making, or studying "real decisions in real clinical situations."

Under the umbrella of research evidence, Dr. Ross has a number of different interests. Her multi-disciplinary team (which includes clinicians, researchers and economists) has evaluated a number of surgical treatments for stress urinary incontinence and pelvic organ prolapse; both of which are conditions that affect a woman's pelvic muscles, usually caused through childbirth or surgery. She has ongoing CIHR funding to perform a five-year follow-up study and economic evaluation of her research of two surgical devices for treating stress incontinence.

Patient goals and decision making are also of interest to Dr. Ross. She plans to look into how well informed patients are about their procedures and if they fully understand all the risks. As part of this research, she plans to continue her work in developing and testing decision aids for patients choosing treatment options that best suit their condition.

Dr. Ross will be performing similar research in menopause as part of her new position. She will be looking into patient goals, fears, expectations and the impacts of a variety of treatments chosen by the patients.

"The power of evidence is not as strong as we think," says Dr. Ross. "More needs to be considered about how research is used."

Through our Foundations, WCHRI supports five Research Chairs including Ovarian Cancer Research, Lois Hole Hospital Chair, Cavarzan Chair in Mature Women's Health Research & Innovation, the Stollery Children's Hospital Foundation's Chair in Autism Research and a Chair in Maternal-Child Health & the Environment. These Chairs have acted as an attractor for new talent and provide a stable source of multi-year research support.

A Snapshot of 2012

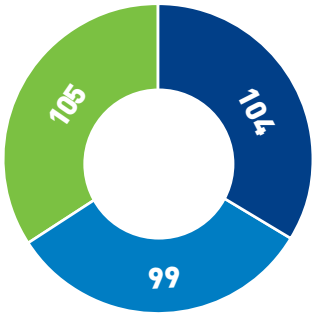
Membership:

Women and children's health research transcends disciplines and departments. Our researchers 'reside' in 14 faculties and over 40 departments at the university, and many of their programs integrate expertise from seemingly disparate areas. The majority of our academic members are from departments in FoMD, notably the Department of Pediatrics, as would be expected.

While many of our academic members are seasoned, international investigators, WCHRI has actively recruited, encouraged, trained and supported many new researchers in fields relevant to our mandate.

As highlighted to the right, **Assistant Professors make up about 34 per cent of our academic researchers, and they represent the next generation of rising stars in the fields of women and children's health research.**

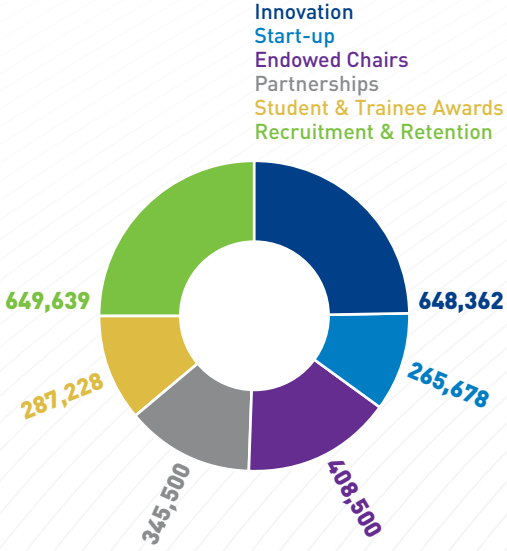
A number of non-academic staff and administrative personnel are also associated with the larger WCHRI family, supporting the various departments that house our academic researchers. WCHRI also claims a number of external stakeholders from community and governmental organizations, who are actively interested in and support women and children's health research and our members.



WCHRI Grants Awarded During 2012:

One of the key ways that WCHRI supports research excellence is through competitive grant funding. Our programs include: operating grants, bridge funding, resident trainee research projects, graduate studentships, summer and science shop studentships, trainee travel funds and scientific knowledge exchange programs (SKEP). All of these programs are competitive with only excellent research proposals receiving funding.

While some of the WCHRI Innovation and other operating grants support projects that have the potential to relatively quickly target a challenging clinical health problem, others generate preliminary data for applications to larger funding institutions. Our competitive grant programs and partnership strategies facilitate the use of our resources in a way that maximizes impact and leverages funds from other partners and agencies.



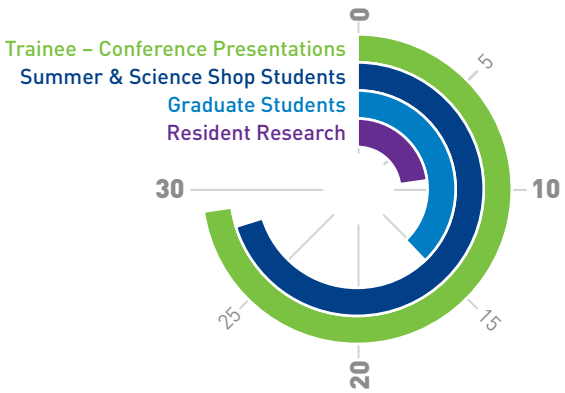
External Funding:

A commonly used indicator of excellence in research is the amount of external grant funding that researchers successfully compete for, both in terms of number of grants and total dollars. For WCHRI, external funding that our researchers receive can be viewed as leveraging our operating grants and other support that we provide to our membership. Based on available data, **WCHRI researchers were awarded over $18 million in external funding last year, with some of these grants awarded for multiple years.** Key external funders included the Canadian Institutes of Health Research (CIHR), Alberta Innovates-Health Solutions (AIHS), NSERC, the Canadian Foundation for Innovation (CFI), the Government of Alberta and many disease-specific foundations.

Capacity Building:

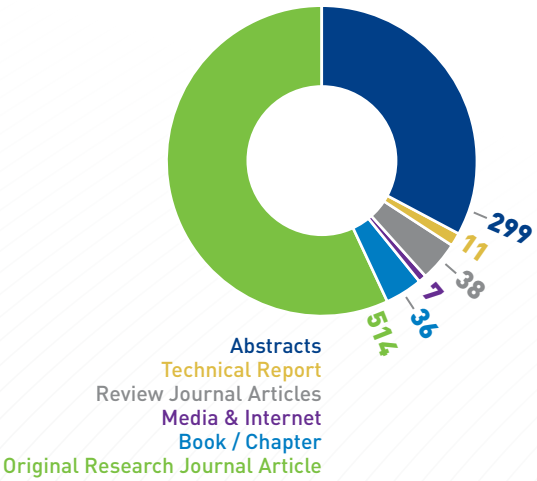
WCHRI has numerous trainee members, who have been supported by funding and educational programs, as well as the benefits of being part of the WCHRI community. These trainees include undergraduate and graduate students, postdoctoral fellows and residents, many of whom have completed their training and are now working in academic and other roles supporting women and children's research around the world.

In 2012, WCHRI grant programs supported 28 summer and Science Shop students, 15 graduate students and 9 resident researchers. In addition, our trainee travel award enabled 29 of our trainees to attend national and international conferences in order to present their original research results.



Publications:

We are very proud of the achievements of our members and the impact that their research has had on women and children's health. Peer-reviewed publications are one marker of excellence in research. This is an important means of communicating significant research findings to the rest of the academic world. Based on available data, our academic members' publication output for 2012 has been truly impressive as can be seen from the chart to the right. Of the total number of publications that our academic members reported for last year (about 900), 514 of those were reported as original research articles. The remainder of the publications included abstracts, book chapters, internet publications, review articles and technical reports.



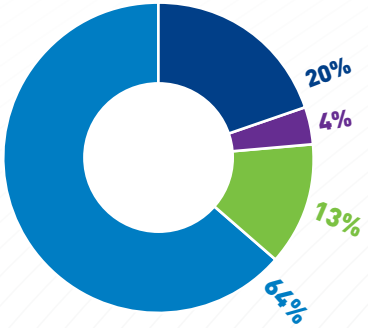
Income Statement for the year ended March 31, 2013

Revenue	
Stollery Children's Hospital Foundation	3,194,138
Royal Alexandra Hospital Foundation	993,861
Faculty of Medicine & Dentistry, University of Alberta	184,106
Cost Recovery	624,762
Total Revenue	**$4,996,867**

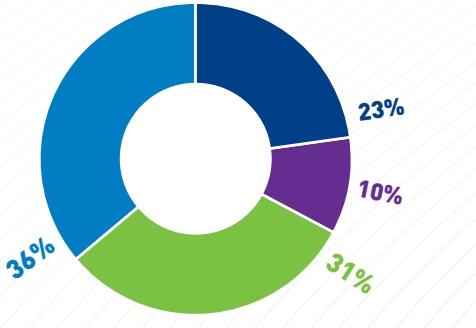
Expenditures	
Research Grants	1,090,720
Research Support	1,737,057
Investigative Core Resources	1,488,035
Administrative Support	503,005
Total Expenditures	**$4,818,817**

2012/13 Revenue Per Cent

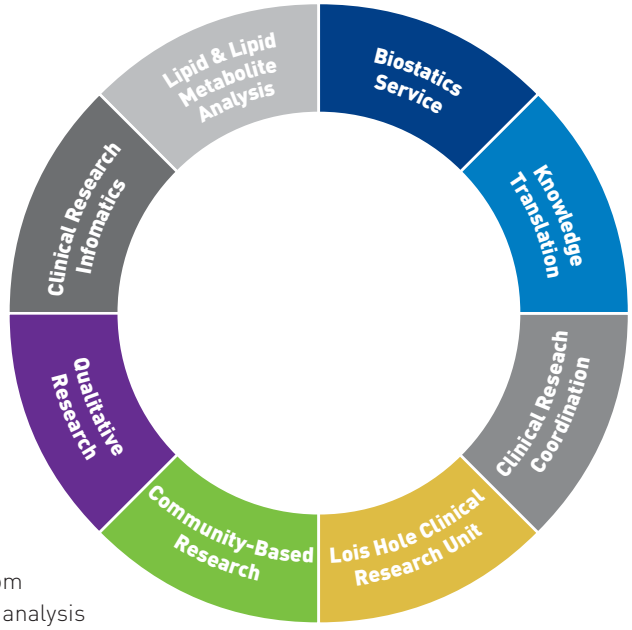
The revenue percentages reflect the ratio of researchers who align with child health compared to women's health, which is approximately 4:1



2012/13 Expenditure Per Cent



Our Team & Core Services



Administrative Team

WCHRI has a dedicated administrative team who has worked to increase efficiency in WCHRI's current processes. The administrative team coordinates the day-to-day functions of WCHRI including membership, core services, financial accountability, communications, research support and grants administration.

Clinical Research Informatics

The Clinical Research Informatics Core offers expertise in advanced electronic data capture and survey solutions to ensure researchers obtain high-quality, statistically sound and verifiable data. This group helps investigators minimize costs by training and supporting research assistants and graduate students in the use of specialized software and offers support through the provision of information technology based services.

Clinical Research Coordination

WCHRI maintains a pool of experienced clinical research staff to meet investigators' needs for skilled, versatile research personnel on a part-time and/or temporary full-time basis. The team collaborates extensively with AHS to offer services at the U of A/Stollery Children's Hospital, Royal Alexandra Hospital, Grey Nuns Community Hospital and Misericordia Community Hospital.

Biostatistics Service

The Biostatistics Service Core works with researchers to produce high quality research based on sound research methods. The Core staff is typically involved from the planning to data analysis stages of projects.

Lois Hole Clinical Research Unit

The Lois Hole Clinical Research Unit provides support, through dedicated research nurses, to researchers who access subjects or resources for their studies from the Lois Hole Hospital for Women, located in the Robbins Pavilion on the Royal Alexandra Hospital Campus.

Lipid & Lipid Metabolite Analysis

The Lipid & Lipid Metabolite Analysis Core assists basic and clinical researchers in measuring lipid-related compounds from a variety of sources. Lipids are of particular importance in many of today's most prevalent health issues: obesity, diabetes, nutrition, neuroscience and cardiovascular disease.

Community-Based Research

The Community-Based Research Core supports a collaborative approach to research that integrates issues of importance to the community with the aim of combining knowledge and action for social change to improve the health and well being of the community members.

Qualitative Research

The Qualitative Research Core assists researchers in studying topics as they occur in nature or the community and make sense of, or interpret, phenomena in terms of the meanings people bring to them.

Knowledge Translation

The Knowledge Translation Core educates researchers on the dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system.

Our Partners

WCHRI collaborates with many other institutes and organizations that share our vision and commitment to improving the health outcomes of women and children through research excellence. We also partner with these institutions to provide our members with a growing variety of research services and support. In this way, we ensure that limited resources are used to the best advantage and that the outcomes and results from our research are widely shared.

Alberta Children's Hospital Research Institute for Child and Maternal Health
Alberta Centre for Child, Family and Community Research

WCHRI has a Memorandum of Understanding (MOU) with the Alberta Children's Hospital Research Institute for Child and Maternal Health (ACHRI) and the Alberta Centre for Child, Family and Community Research (The Centre). One main goal of the MOU is the development of the Child Data Centre (CDC). This facility will house academic research data sets in one central location and increase access of this data to all researchers. WCHRI members are encouraged to both utilize and contribute to this service.

Alberta Research Centre for Health Evidence

One of WCHRI's newest collaborations is a partnership with the Alberta Research Centre for Health Evidence (ARCHE). ARCHE will provide our members with request-specific proposal development services and help in conducting systematic reviews.

Canadian Child Health Clinician Scientist Program

The Canadian Child Health Clinician Scientist Program (CCHCSP) is a transdisciplinary training program for the next generation of clinician-scientists in child and youth health research in Canada. Canadian Child and Youth Health Research Centres recruit, train and provide financial support for trainee researchers and clinician-scientists who have an interest in child and youth health.

Council of Canadian Child Health Research

The Council of Canadian Child Health Research (CCCHR) represents all Canadian academic health science centres across Canada with a focus on child and youth health. The CCCHR and its members help ensure that all children and youth enjoy the benefits of improved health through the application of research findings. The Council promotes networking, collaboration and sharing of resources between hospitals in Canada.

Community-University Partnership for the Study of Children, Youth, and Families

The Community-University Partnership for the Study of Children, Youth, and Families (CUP) is a unique collaboration between the U of A Faculty of Extension, community agencies, and organizations in and around Edmonton and across Alberta. CUP works to develop opportunities for researchers, service providers, and policy-makers to collaborate on research projects that advance knowledge, improve policies and practices and facilitate sharing information about child and family development.

Graduate Program in Maternal and Child Health

In 2012, the Departments of Pediatrics, Medical Genetics, and Obstetrics and Gynecology in partnership with WCHRI were the recipient of a new U of A interdisciplinary graduate student training program in Maternal and Child Health (MatCH). This multidisciplinary program represents a novel approach to the training of graduate students as participating departments are uniquely positioned to provide cross pollination between key areas in the rapidly evolving bench to bedside, personalized medicine and knowledge translation focus of research in Alberta and Canada.

Maternal Infant Child and Youth Research Network

The Maternal Infant Child and Youth Research Network (MICYRN) is a collaborative national initiative to build capacity for high quality clinical research in Canada and links 17 participating academic health centres and hundreds of investigation teams across the country. MICYRN is focusing on improving data management standards and is encouraging the adoption of REDCap, a secure, web-based application for building and managing online surveys and databases. Since WCHRI was the first organization in Canada to adopt REDCap, we have significant experience in this area.

University of Alberta / Faculty of Medicine & Dentistry (FoMD) Canadian Institutes of Health Research (CIHR) Special Project

The U of A/CIHR Special Project provides support for researchers and trainees at the U of A who are submitting applications for funding to CIHR. In support of this initiative, WCHRI contributes bridge funding for CIHR applications with a primary focus on women and/or children's health and will be used to leverage additional funding from AIHS or other institutes and faculties.

WCHRI Research Day

WCHRI's annual Research Day is our time to celebrate our successes and achievements. It brings our membership together to share common interests and research outputs on women and children's health, and is a great venue for our trainees to communicate their recent work, discuss their research and network with colleagues.

This interactive day gives us the opportunity to celebrate our breakthroughs in health research that impact the lives of women and children. By networking with researchers, trainees and community members we can find new opportunities to join together for further research development which will spread our reach to touch more lives.

WCHRI marked the fifth annual Research Day in November 2012. Over 300 WCHRI members, trainees and partners packed into the second floor of the Westin Hotel. Our very full day started with project updates from WCHRI's 2009 Emerging Team Grant recipients and professional development seminars from our guest speakers.

WCHRI Research Day highlighted our trainees, with increased oral presentations and poster viewing time. Approximately 135 undergraduate students, graduate students, post-doctoral fellows, professors, residents and trainees had the opportunity to practice their presentation skills during the oral and poster competitions.

Dr. Susan Ozanne, our keynote speaker, is a British Heart Senior Fellow and Reader in Developmental Endocrinology in the Institute of Metabolic Science Metabolic Research Laboratories at the University of Cambridge. Her research interests are focused on understanding the relationship between suboptimal early nutrition and growth and risk of diseases such as type 2 diabetes, obesity and cardiovascular disease in later life. Her presentation was entitled: Early nutrition and long term health—does mum hold the key?


Categorization of included studies by purpose of intervention
Summary of Included Studies
CCHCSP
PCCCSE

Governance (as of March 31, 2013)

Oversight Board Members

Sandra Davidge	Institute Director (non-voting)
Jane Drummond	Health Sciences Council Representative, U of A (Delegate)
Richard Fedorak	Vice-President (Research), U of A (Delegate)
Murray Gray	Provost & Vice-President (Academic), U of A (Designate)
Mike House	President/CEO, SCHF
Linda McConnan	Executive Director, Stollery Children's Hospital, AHS
Marek Michalak	Vice-Dean of Research, FoMD, U of A
D. Douglas Miller	Dean, FoMD, U of A
Andrew Otway	President/CEO, RAHF
Joanna Pawlyshyn	Vice-President, Royal Alexandra Hospital, AHS
Dale Sheard	Board Representative, RAHF
Zahra Somani	Chair of the Board of Trustees, SCHF
Kathryn Todd	Senior Vice-President Research, AHS
Michael Walter	Head of School, Human Development, U of A

Steering Committee Members

Sandra Davidge	Institute Director (non-voting) and Research Lead, Human Development, U of A
Karen Faulkner	Vice-President, SCHF
Richard Fedorak	Associate Vice-President (Research) U of A
Susan Gilmour	Department Chair, Pediatrics, U of A
Tom Hobman	Vice-Dean of Research, FoMD, U of A (Designate)
Selikke Janes-Kelley	Executive Director, Women's Health, Royal Alexandra Hospital, AHS
Brian Rowe	Associate Dean, Clinical Research, FoMD, U of A
Sharlene Rutherford	Vice-President, RAHF
Margaret Sagle	Department Chair, Obstetrics and Gynecology, U of A
Christine Westerlund	Director, Critical Care and Operative Services, Stollery Children's Hospital, AHS

Scientific Advisory Committee Members (all U of A staff)

Sandra Davidge	Institute Director
David Eisenstat	Division Director, Pediatric Hematology/Oncology/Palliative Care
John Greer	Professor, Physiology
Kathleen Hegadoren	Professor, Nursing
Kaysi Kushner	Associate Dean/Associate Professor, Nursing
Gary Lopaschuk	Professor, Pediatrics and Pharmacology
Maria Mayan	Assistant Director, Community-University Partnership
Linda McCargar	Professor, Agriculture, Food & Nutritional Science
Lawrence Richer	Institute Associate Director, Associate Professor, Pediatric Neurology
Sue Ross	Cavarzan Chair, Professor, Obstetrics & Gynecology

As always, the Women & Children's Health Research Institute greatly appreciates the contributions of our members, reviewers, contributors, committee members and staff to help in WCHRI's vision to make a difference in the health of women and children.

We would also like to thank the Stollery Children's Hospital Foundation, the Royal Alexandra Hospital Foundation and the University of Alberta's Faculty of Medicine & Dentistry for their continued support. If not for the contributions of these partners, the work we do would not be possible.

Thank You!

www.WCHRI.org

Women & Children's
Health Research Institute

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