

# **2016/2017 ANNUAL REPORT**

Embodying our values



The Power of Partnership

















# OVERVIEW

#### Women and Children's Health Research Institute

# **Embodying our values**

# This year, WCHRI has supported 129 projects through expert research staff and awarded 171 research grants that will help improve women's and children's health.

As we celebrate the continued growth and success of this important work, we reflect on the six values that WCHRI is based on. Values that are reflected in every decision, commitment and project we propel forward in our mission to transform the health of women and children by supporting research excellence.

#### EXCELLENCE • TEAMWORK • COLLABORATION • COMMUNITY-FOCUS • ACCOUNTABILITY • INTEGRITY









# **Principles**

#### **OUR VISION**

To harness the power of research innovation for a healthy future for children and women.



#### **OUR MISSION**

WCHRI will foster the brightest minds to discover, innovate and ultimately transform the health of children and women through supporting research excellence.

# MESSAGES

## Women and Children's Health Research Institute

#### What a remarkable year!

This year brought a historic announcement, renewed commitment from our dedicated partners and continued excellence within women's and children's health. In many ways, this growth and our successes over the past year have become a tapestry of our values. Every day, I see how our values — collaboration, integrity, accountability, teamwork, excellence and community focus — continue to ring true; no matter the achievement or challenge.

All of our values particularly came together on June 22, where it was announced that over the next ten years, the Women and Children's Health Research Institute will receive \$14.5 million from the Royal Alexandra Hospital Foundation and \$40 million from the Stollery Children's Hospital Foundation — the largest gift in the University of Alberta's history. I couldn't be more proud of our team and the unwavering support of our partners for bringing this occasion together. "Thank you" just doesn't seem enough.

There were many other reasons to celebrate this year as well, that all demonstrate our shared values. Just a few of these successes are below:

- Record level of attendance at the largest WCHRI Research Day yet 484 registrants.
- Public engagement about the importance of research at 16 community outreach initiatives, including the Stollery Women's Network's "Style for Stollery" event and Lois Hole Hospital for Women's Elevate Aviation Calendar Launch event.
- Support of 53 students through Summer Studentship and Graduate Studentship grants — furthering our commitment to training the next generation of researchers within women's and children's health.
- Recognition through the "Clinical Research Site Award," which was given to the Stollery Children's Hospital, Dr. Loretta Fiorillo and members of our clinical trials team for outstanding efforts on a successful study. (*More detail on page 16.*)



"Every day, I see how our values collaboration, integrity, accountability, teamwork, excellence and community focus — continue to ring true; no matter the achievement or challenge."

We couldn't do what we do without the support of our partners at the University of Alberta, Alberta Health Services, Stollery Children's Hospital Foundation and Royal Alexandra Hospital Foundation. The "power of partnership" has never been clearer and has truly allowed us to harness the power of research for a healthier future for women and children.

#### Dr. Sandra Davidge

Executive Director Women and Children's Health Research Institute



# MESSAGES

## **Royal Alexandra Hospital Foundation**



"We look forward to what the future holds, as the best and brightest in research and clinical care excellence connect in new and exciting ways." The Royal Alexandra Hospital Foundation and the Women and Children's Health Research Institute are aligned in our values and it is the value of innovation that we believe is most intertwined. WCHRI's vision *"To harness the power of research innovation for a healthy future for children and women"* and the vision of our foundation *"Improving the health of Albertans by building passionate community support for the Royal Alexandra Hospital"* is a partnership that is already making an incredible impact on the health of women and children at all ages and stages of life.

The next phase of research integration at the Lois Hole Hospital for Women is on the horizon. Adjacent to the outpatient clinics, on the hospital's ground floor, sits what will soon be the flagship research home of WCHRI. Connecting the physical space of research to the clinical leadership of the Lois Hole Hospital for Women will create synergies of ideas, possibilities and outcomes that will drive women's health excellence to new levels of achievement. The Royal Alexandra Hospital Foundation, through the passionate support of our dedicated donors, is pleased to support this exciting consolidation. We look forward to what the future holds, as the best and brightest in research and clinical care excellence connect in new and exciting ways.

Andrew Otway, MBA, CFRE President and CEO Royal Alexandra Hospital Foundation



# **Stollery Children's Hospital Foundation**

#### Forty million reasons to be grateful for researchers

Our donors are always telling us what's important to them when it comes to children's health. One of those priorities is pediatric research. That's because our supporters understand the importance of not only looking to the future — but investing in it.

Without community support for innovation and discovery, Dr. Lisa Hornberger wouldn't have improved the survival rate of babies with congenital heart defects to 98% from 50 by detecting defects before birth. Dr. Lawrence Richer wouldn't be one of the first pediatric neurologists in Canada to make groundbreaking strides in how doctors treat migraines in children. And Dr. Anita Kozyrskyj wouldn't have discovered that bacteria in the stomach of a newborn can determine childhood asthma.

That's why we value our ongoing investment in the Women and Children's Health Research Institute (WCHRI).

Since 2006, as the primary funder of WCHRI, our Foundation has provided \$39.4 million to fund more than 927 research grants and help dozens of awardwinning researchers in their training and education. And in June of last year, we proudly announced the largest gift ever to the University of Alberta — \$40 million over 10 years — to continue funding pediatric research through WCHRI, creating brighter futures for Stollery kids for generations to come.

On behalf of all of us at the Foundation, congratulations to all of the amazing talent at WCHRI and thank you for pushing the limits of modern science to benefit future generations of children.

Sincerely,

**Mike House, MBA** President and CEO Stollery Children's Hospital Foundation





"Since 2006, as the primary funder of WCHRI, our Foundation has provided \$39.4 million to fund more than 927 research grants and help dozens of award-winning researchers in their training and education."

# MESSAGES

## Faculty of Medicine & Dentistry, University of Alberta



"The unique focus on women's, children's and perinatal health under one research umbrella, positions WCHRI as a leader in Canadian health care research and as a model for others to follow beyond our borders."

On behalf of the Faculty of Medicine & Dentistry at the University of Alberta, I offer our sincerest congratulations to the Women and Children's Health Research Institute (WCHRI) as they celebrate another extraordinary year of success.

WCHRI shares our core values and the vision of our faculty: Working with integrity and accountability, sustaining and facilitating critical research, and advocating for the improvement of health care in our communities. The unique focus on women's, children's and perinatal health under one research umbrella, positions WCHRI as a leader in Canadian health care research and as a model for others to follow beyond our borders.

During the last year, WCHRI received the single largest health-related donation from the Stollery Children's Hospital Foundation and the Royal Alexandra Hospital Foundation, \$54.5 million. This presents an amazing opportunity for this institute to excel further in its goal of advancing, through research and education, women's, children's and perinatal health.

WCHRI is a driving force for integrating research into clinical care and into our hospitals. We are proud to contribute to the growth of this partnership as it exemplifies the kind of research alliance that builds a front-ranked and high-performing academic health sciences centre in the 21st century at the forefront of Canadian health care innovation.

WCHRI has achieved 11 years of outstanding research accomplishments and provided remarkable service to our communities. We look forward to continuing this amazing partnership, and celebrating future milestones together.

#### Dr. Richard Fedorak Dean

Faculty of Medicine & Dentistry

UNIVERSITY OF ALBERTA FACULTY OF MEDICINE & DENTISTRY

## **Alberta Health Services**

Alberta Health Services (AHS) and the Women and Children's Health Research Institute share many of the same values and goals in their efforts to improve the lives of women, children and babies in the province.

AHS strives to use the best available research evidence to continually improve patient care. The creation of that evidence wouldn't be possible without collaborations between clinicians and researchers at AHS, WCHRI, the Stollery Children's Hospital, the Lois Hole Hospital for Women and the University of Alberta.

Together, Alberta's innovation and research leaders are working hard to help solve health care issues of importance to Alberta's women and children.

Thanks to these partnerships, much has been achieved and many improvements have been made, which you'll read about in the pages ahead. It is a privilege to partner with WCHRI as stewards of children's and women's health in our community.

We look forward to our continued work together in improving health care for Albertans.

#### Dr. Kathryn Todd

Vice President, Research, Innovation and Analytics Alberta Health Services





"Together, Alberta's innovation and research leaders are working hard to help solve health care issues of importance to Alberta's women and children."

# A BRIGHTER FUTURE CELEBRATION

2016/2017 Highlights

## On June 22, we celebrated a historic announcement.

As partners, the University of Alberta and Alberta Health Services hosted an event, where it was announced that over the next ten years, the Women and Children's Health Research Institute will receive \$14.5 million from the Royal Alexandra Hospital Foundation and \$40 million from the Stollery Children's Hospital Foundation — the largest gift in the University of Alberta's history.

Our patients are living longer, healthier lives because of the advances made right here at the Women and Children's Health Research Institute, and we are proud that our members can continue to make a difference to people every day.





Dr. Sandra Davidge thanks the generosity of the donors to the Foundations.



Research that donors make possible is saving and improving the lives of women and children like Geniene Korrall and her son Jake.



David Turpin, president, University of Alberta and Dr. Verna Yiu, president and CEO, Alberta Health Services.



Ennis family and Dr. Lisa Hornberger.



The Ennis triplets show their thanks.



Dr. Richard Fedorak, dean, Faculty of Medicine & Dentistry, University of Alberta.

# EXCELLENCE

We strive to achieve excellence in all our endeavours as a leader in conducting meaningful women's and children's health research.



## Helping adolescents to Breathe again

Dr. Amanda Newton develops online programs to help adolescents manage their anxiety

#### THE ISSUE

Adolescents with mild to moderate anxiety are not getting the help and support they need.

#### THE RESEARCH

An online resource will provide cognitive behavioural therapy treatment to reduce adolescents' levels of anxiety. A teenage boy is brought into the emergency room by his parents. He's experiencing shortness of breath and a slight pain in his chest. The physician assesses his vitals and, after not finding anything physically wrong with him, asks about stressors at home and school. Another teenager, a young woman, has been losing sleep over her applications to university. On the outside, she looks like a confident, happy girl. On the inside, she is overcome by worries about her grades and future.

These two stories are common for adolescents who experience problems with anxiety. Concerned parents may bring their teen to the emergency room if physical complaints cause worry, where they will be assessed by a mental health care provider, and then sent home. Treatment with a specially trained health care provider may be recommended before the teen is discharged from the hospital. Some teens never voice their worries to their parents, and may suffer in silence.

Dr. Amanda Newton, along with her team, has developed a program that adolescents can use to help alleviate their anxiety anywhere, anytime, with just a click of a button. The Breathe program incorporates relaxation, mindfulness and helpful monitoring strategies to deliver cognitive behavioural therapy to adolescents. "The program uses a combination of learning essential skills and tools with the systematic, graduated exposure to the source of anxiety over time," explains Newton. While cognitive behavioural therapy is the recommended treatment for adolescents, it's not always available as health care providers need special training to deliver it. There may also be waitlists to access providers who offer it. "I think kids who need mental health care should get mental health care. If you need it, you should get it - no questions asked," says Newton.

Newton's team has been working since 2013 to develop and evaluate the *Breathe* program for adolescents. Her team recently completed a pilot of the program that revealed a number of lessons learned moving forward; including how adolescents would like the program to be shaped to fit their needs and that social media is a great tool for recruiting participants. "The pilot helped us understand how to reach young people who may not be seeking health care for their anxiety those who are suffering in silence. It also helped us understand what teens are interested in learning and what the program was like for them," explains Newton.

The *Breathe* program would not be possible without the talented team behind Newton and collaborations with the Strongest Families Institute, AnxietyBC and WCHRI. Newton's local team consists of Ashley Radomski, who is Newton's graduate student; Nicole Gehring, the study's project coordinator; and Khristy Rhyason, the communications expert recruiting patients from across Canada through social media.

*"I think kids who need mental health care should get mental health care. If you need it, you should get it — no questions asked."* 

With the necessary pilot work done, Newton is currently recruiting patients to test the effectiveness of the program in reducing anxiety among adolescents with mild-to-moderate levels of anxiety. If the program is effective, the Strongest Families Institute plans to use *Breathe* as a resource for adolescents across Canada. There has also been interest from scholars overseas, and discussions are underway to translate *Breathe* to help adolescents in China, who are known to have high levels of anxiety and depression.

The project could truly help adolescents around the world "breathe a little easier" in the future.



Dr. Amanda Newton and Ashley Radomski's research has been funded by the generous support of the Stollery Children's Hospital Foundation through WCHRI.

# EXCELLENCE

# **Understanding the first 1,000 days**

Dr. Maria Ospina "connects the dots" from the lab to the clinic through a lifelong epidemiological approach

#### THE ISSUE

Understanding the first 1,000 days of life is critical for predicting long-term health.

#### THE RESEARCH

Dr. Ospina is strengthening a perinatal epidemiology research program, exploring the history of diseases that originate early in life and evaluating therapies for maternal and perinatal health needs.

As a clinical epidemiologist, Dr. Maria Ospina spends a significant amount of time analyzing large datasets and an array of numbers. But, amid the layers of information, there is one number that has particularly captured her attention: 1,000.

"The first 1,000 days of life is a critical period in development, where many things come together," Ospina says. Quality of prenatal care, maternal, environmental and social influences all collide and ultimately shape the trajectory of a newborn's life. "If something goes wrong during pregnancy, and those first 1,000 days of life, you may see the effects later — such as through chronic diseases."

One of the themes of Ospina's research is understanding what shapes these first 1,000 days and the consequences for future health. In 2016, she was given the opportunity to study the impacts of this critical time period through a recruitment and retention grant, thanks in part to funding generously provided by supporters of the Lois Hole Hospital for Women. In the upcoming years, Ospina will contribute to strengthening a perinatal epidemiology research program within the Department of Obstetrics & Gynecology at the Lois Hole Hospital for Women. "It's a privilege," Ospina notes. "The Lois Hole Hospital for Women is very committed to building a research agenda around perinatal health. More than 7,500 babies are born



the first 1,000 days of a newborn's life.

More than 7,500 babies are born each year at the Lois Hole Hospital for Women; that is like a kindergarten class every day.

each year at the Lois Hole Hospital for Women; that is like a kindergarten class every day. It's very important for me to be there and apply cutting-edge epidemiological methods to understand the natural history of diseases that originate early in life; identify risk and protective factors, and produce evidence to evaluate the value of therapeutic interventions that improve maternal and perinatal health." Research focusing on the developmental origins of health and disease is becoming more prominent in Alberta. Recently, Ospina co-led a meeting with researchers from across the province where priorities for perinatal epidemiology research were discussed, as well as plans to push forward an agenda of epidemiological research focused on the first 1,000 days of life. "I am a firm believer that we are stronger together," Ospina says. "If you bring people from different perspectives around the table, research ideas evolve in ways you wouldn't even imagine."

Ospina's ultimate goal is to influence health policies and improve health outcomes related to maternal and perinatal health: "My proposal was a way to 'connect the dots' between what happens during the perinatal period and later in childhood." Connecting these dots will allow Ospina to identify factors that shape trajectories of health and disease, as well as identify the key moments where interventions would be the most effective. Ospina's research is also personally important due to close family experiences: "One of my nieces, Daniela, was born preterm, very low weight, and admitted to the NICU for weeks. My sister-in-law had all kinds of adverse maternal outcomes listed in a textbook." A year later they were both doing great and 16 years later, they still are. "Working in this field is something that is very close to my heart," Ospina notes. "Sometimes I wonder, what really makes the difference between a good and a bad outcome. I like that this research helps us not only identify what can go wrong, but also how can we intervene early and what can be made better."



Dr. Maria Ospina's recruitment was funded by generous supporters of the Lois Hole Hospital for Women, through WCHRI.

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We have developed a number of new initiatives to catalyze research and improve health outcomes.

• 24 partnerships

Over **20** educational workshops for members

• 4 active Research Capacity Building Programs

**13** investigators supported by our Researcher Recruitment Program

# EXCELLENCE

## Filling the gaps in pediatric dermatology

Dr. Loretta Fiorillo works to transform treatment options for children with psoriasis

#### THE ISSUE

There are no systemic drugs licensed for psoriasis in children.

#### THE RESEARCH

A new oral medication that's already approved for adults with psoriasis is being tested to determine its effectiveness for children as well.

For eight year old Jillian Karst, life is filled with friends' birthday parties and fun days at school. It's a normal life for a little girl from southern Saskatchewan, but it's a big change from where she was only a few short months ago. Jillian has severe psoriasis, which covered her face, scalp and body in very large and painful red, scaly patches. Jillian found it difficult to attend school or see friends, but that quickly changed thanks to a sudden turn of events. "Now it's a night and day difference," says Shirley Karst, Jillian's mom. "She's a social butterfly!"

Eight months ago, the Karst family received what would turn out to be a life-altering phone call from their dermatologist in Saskatchewan. They learned about Dr. Loretta Fiorillo and her first clinical trial for children with psoriasis. A month later, they were in Edmonton meeting with Fiorillo and her WCHRI research coordinator, Heather Rylance.

Today, Jillian has only a single visible patch of psoriasis on her arm and is a bright and bubbly young girl. "It's been a life-changing experience for Jillian," says Shirley. "I would do all of this again in a heartbeat."

Currently, there are no systemic drugs licensed for psoriasis in children, so when a new medication was identified that had been approved for adult psoriasis and administered orally, Fiorillo knew she wanted to study it for her pediatric patients. "I see patients all the time with psoriasis. Psoriasis in children can be very detrimental to their self-image, since it is located in such obvious places," explains Fiorillo. "Having red, scaly patches on their faces really affects their daily lives, experiences with peers, confidence and school performance."

As the study's research coordinator, Heather Rylance has been working with the patients and their parents since the very beginning of the trial. "It's nice to know you are making a difference for these kids physically, mentally and socially," says Rylance. "There was a reason I went into nursing. I wanted to help make someone's life better and I have experienced that with these kids and their parents."

Fiorillo is very pleased with the progress, especially in Jillian's case. "The results seem very promising," she says.

The study has also garnered a lot of unexpected attention — recently winning the Clinical Research Site Award from INC Research in recognition of the group's exceptional study enrolment rate, data integrity and overall quality of work. "It was a big surprise," notes Fiorillo. "I'm very happy because often dermatology is a forgotten specialty." This award is the result of the collaborative efforts between the Stollery Children's Hospital, staff within the Pediatric Clinical Investigation Unit, Fiorillo and Rylance.

"The idea that if there is an unmet need, I can look at helping to meet that need through support from the Stollery Children's Hospital and WCHRI."

This has helped spur Fiorillo forward in considering what's next. "This experience has opened my eyes to the support available for clinical trials, such as having Heather join my team through WCHRI," explains Fiorillo. "The idea that if there is an unmet need, I can look at helping to meet that need through support from the Stollery Children's Hospital and WCHRI."

Fiorillo and Rylance hope that this medication will be approved to treat pediatric psoriasis and then would like to start working on helping other children with dermatologic conditions. This was Fiorillo's first clinical trial but it will not be her last — she's looking forward to starting more trials to help children, like Jillian, who have limited solutions or medications available. "I see this study as a stepping stone to more research that will help fill the gap in pediatric dermatology treatments," concludes Fiorillo.



Dr. Loretta Fiorillo's research was supported by the generosity of the Stollery Children's Hospital Foundation, through WCHRI.



# TEAMWORK

Our members work together to address questions relevant to the needs of the community and to advance the goal of improved health outcomes for women and children.

# Working together to find the "why" in clinical research

Dr. Aisha Bruce and WCHRI bridge the divide between research and clinical practice to help young patients with sickle cell disease

#### THE ISSUE

Parents of children with sickle cell disease can feel isolated and may need educational resources to share with members of their community.

#### THE RESEARCH

Exploring how clinical practices can be improved and creating resources to increase awareness of sickle cell disease.

Dr. Aisha Bruce meets many new immigrants and their families through the Stollery Children's Comprehensive Sickle Cell Clinic. After finding that many parents were struggling to accept their child's diagnosis with sickle cell disease — an inherited blood cell disorder — Bruce began to ask what was missing in their child's medical care. The response, she soon found, was surprising.

Bruce is a pediatric hematologist who works with children and their families affected by the disease. Over the years, she's found that the increase in immigrants from Africa and other nations affected by malaria has led to a corresponding increase in sickle cell disease in the patients she sees. Bruce decided to explore how clinical practices can be improved for these patients and their families, so she reached out to the WCHRI qualitative research platform for assistance in developing the study.



Sickle cell disease causes hemoglobin, which carries oxygen in red blood cells, to change from a normal "doughnut" shape to a crescent shape. Sickle-shaped red blood cells can cause a buildup in blood vessels, which may lead to severe pain attacks and organ damage. Sickle cell disease takes a heavy physical and emotional toll on the patients and their families.

"In their home countries, the parents we interviewed witnessed children affected by sickle cell disease in their neighbourhood or extended family who often did not receive the medical care they needed due to the massive cost to the family," says Tatjana Alvadj, WCHRI research coordinator, who worked with Bruce on the study. "When they learned that their child here has sickle cell disease, all these memories came back and the stigma around it."

"We were originally trying to figure out how we could improve our clinic for patients," says Bruce. "We learned interpretive services were needed in the hospital and, most importantly, allowing parents time to emotionally process the diagnosis and its consequences. However, the biggest gap we found lies outside of the clinical scope, and deals with the social isolation that families experience."

In response, the research team modified the direction of their knowledge sharing process. Together, Bruce's

clinic staff and Alvadj created brochures and other resources that they distributed to the parents' source of support: their child's school or daycare. This will enable teachers and caretakers to understand the complexity of sickle cell disease, including the need for patient confidentiality, the ability to identify symptoms of a crisis and how to respond appropriately.

This project has helped Bruce and her clinic staff understand their patients' fears and adapt their practice to help patients and their families move past the stigma and grief toward a better quality of life.

Bruce hopes to continue asking "why" when it comes to improving treatment for her patients. She wants to bring research to the forefront to improve patient care in Alberta.

"I am really thankful that WCHRI exists," says Bruce. "Without its support, especially as a junior investigator, this wouldn't have been possible. Its support helped me move forward to create high quality research and ultimately improve my practice."



Dr. Aisha Bruce's research was funded by the generous support of the Stollery Children's Hospital Foundation, through WCHRI.

## **Our research platforms**

We support our members through expert research staff who provide project consultation and implementation services.

#### Summary of research services provided:

	Research coordination	Data management	Biostatistics	Totals
Children	61	31	17	109
Maternal	3	3	2	8
Women	2	2	8	12
Totals	66	36	27	129

# TEAMWORK

## A rapid response to devastation

Dr. David Olson quickly mobilizes his team to help pregnant women evacuated from Fort McMurray

#### THE ISSUE

Women who were pregnant during the Fort McMurray fires experienced a high level of stress — potentially putting their children at risk for negative birth outcomes.

#### THE RESEARCH

A writing intervention could help lower the stress levels of pregnant women impacted by natural disasters, such as the Fort McMurray fires.

In May 2016, Albertans experienced the largest wildfire evacuation in the province's history. The wildfire started on May 1, southwest of the community of Fort McMurray. Two days later, all residents were forced to evacuate as the fire drew closer and closer to the city. Close to 90,000 men, women and children fled the area amidst the devastating inferno.

That's when the rest of Alberta stepped up to lend a helping hand; including Dr. David Olson. "I just wanted to do something," says Olson. "I live in Edmonton — Fort McMurray is just in our backyard. Just like everyone else, I wanted to contribute something."

Olson decided to use his skills and knowledge to help the people of Fort McMurray in a way that differed from the volunteer efforts of many concerned Albertans. He knew that a natural disaster as stressful as the wildfires could have serious consequences for the mothers and babies who had been evacuated, so he started a project with the potential of helping the women reduce the negative effects. Instead of a traditional natural disaster study, however, Olson added an intervention element to try to help combat some of the post-traumatic stress the women were experiencing.

Other studies following children born after natural disasters have found that the children have lower

language fluency and are at a higher risk of becoming overweight or obese and developing diabetes. "It is the accumulation of stress that we are pretty sure leads to the poor outcome and poor health of the child throughout their lives," explains Olson.

Women who are taking part in the study are asked to write for 15 minutes each day, four days in a row — a therapy technique called "expressive writing." Expressive writing is typically used to help treat people who are coming back from conflict areas, such as soldiers coming back from Afghanistan. "The ideal outcome would be that the intervention works," says Olson. "That way we can help not only the women of Fort McMurray but the children as well."

Given the nature of this study, a lot of people and resources had to come together quickly in order to respond at the right time. It took many people and long hours to create this study in time to support the women of Fort McMurray. "I think the WCHRI team embraced the spirit of it," says Olson. Not only was WCHRI able to respond rapidly to the call for support so the opportunity to recruit pregnant women would not be lost, but the Wood Buffalo Primary Care Network also helped to push the project forward as it is one of the first natural disaster studies to give something back to the participants involved.

#### "I live in Edmonton — Fort McMurray is just in our backyard. Just like everyone else, I wanted to contribute something."

This project has also been announced as one of seven research projects funded by the Government of Canada, Alberta Innovates and the Canadian Red Cross to help with the long-term effects of the Fort McMurray wildfire.

Although the study specifically focuses on Fort



McMurray, Olson can see how expressive writing therapy could be applied even farther: "Every year tens of thousands of pregnant women are affected by natural disasters globally. My hope is that this intervention will one day be used around the world in any language — to positively affect birth outcomes for all women who have been impacted by disasters."



Dr. David Olson's research has been funded by the Stollery Children's Hospital Foundation and generous supporters of the Lois Hole Hospital for Women through WCHRI.

# TEAMWORK

# **Research Day**

Research Day provides trainees with an opportunity to showcase their research to their peers, research experts in their field, and WCHRI funders and partners.

We have seen growing attendance each year and 2016 was no exception with over 480 researchers, students and stakeholders networking, presenting and learning.

#### WORKSHOPS

Thank you to our workshop presenters who dedicated their time to educating our trainees.

# How to effectively communicate your research to media, funders, the public

- Josie Hammond-Thrasher, Stollery Children's Hospital Foundation
- Janet Harvey, community representative
- Robert Moyles, University of Alberta
- Lindsay Peddle, Lois Hole Hospital for Women

#### Designing audience-specific KT materials

- Dr. Kathy Belton
- Dr. David Johnson
- Dr. Ginetta Salvalaggio

#### Networking and building collaborations

• Dr. Stephen Matthews (who was also our keynote speaker for the day).





#### ORAL AND POSTER PRESENTATIONS

Oral presenters shared diverse and inspiring research to interested attendees and judges.

The poster viewing sessions throughout the day continued to showcase the innovative research by WCHRI undergraduate and graduate students, post-doctoral fellows, professors, residents and subspecialty residents.

#### **RECOGNIZING OUR PARTNERS**

We were honoured to host many representatives from our funding partners – the Stollery Children's Hospital Foundation, the Royal Alexandra Hospital Foundation, the University of Alberta and Alberta Health Services.





#### **CELEBRATING A HISTORIC OCCASION**

This was a very special Research Day for us as we celebrated our 10-year anniversary and a historic year.

Karen Faulkner, VP fundraising operations from the Stollery Children's Hospital Foundation and Andrew Otway, president and CEO from the Royal Alexandra Hospital Foundation, graciously reflected on the last decade.



#### **THE AWARDS**

The day wrapped up with a reception and awards for the presentations.

We are proud of every single participant who contributed in making this day an unparalleled success for all our members, partners and stakeholders.

# COLLABORATION

We are based on a trans-disciplinary model that encompasses a broad range of medical and non-medical disciplines, each of which adds value to the innovative nature of research.

## Creating a gateway to a better life

Sweet Moms' research promotes healthy communities

#### THE ISSUE

High sugar intake during pregnancy can have negative effects on both the mom and baby.

#### THE RESEARCH

Understanding why women increase their sugar intake during pregnancy and educating the public about the effects of sugar.

One of the most exciting times in a woman's life is pregnancy. It can also be a thrilling time for their family and friends, who may bring sweets in a celebratory gesture. After nine months, extra weight gained may be left around mom's middle, but her focus is redirected to the needs of the newborn. The resulting weight retention may not be top of mind, but can contribute to higher maternal weight over the long term.

A team of WCHRI researchers have investigated the causes and consequences of women eating more sugary treats during pregnancy, with the goal of understanding why pregnant women consumed more sugar and how that affected the health of the mother and child. Together the team, led by Dr. Rhonda Bell, with co-leaders Drs. Denise Hemmings, Donna Manca, Arya Sharma, Maria Mayan and Venu Jain, received a partnership grant from the Faculty of Medicine & Dentistry and WCHRI. They called themselves "Sweet Moms" and endeavoured to uncover the not-so-sweet effects of sugar during pregnancy and after.

Sweet Moms was a truly interdisciplinary team. Each investigator is from a different department at the University of Alberta, capitalizing on distinct perspectives and skills that enhanced the three studies that made up Sweet Moms' efforts. "Our studies included an animal study, a study using information from a cohort of pregnant women and a qualitative study," explains Bell. "We were interested in maternal intake of sugar and what it meant for mom and baby." Sweet Moms began in 2012 and has been working to share their findings to fuel the next stage of research. The results of the animal study showed that high sugar intake increased the risk of gestational diabetes and blood vessel constriction in the uterus and the rest of the body. This suggests that excess sugar intake, and particularly purified fructose, could contribute to the development of preeclampsia or other blood pressure-related complications in pregnancy. The qualitative study asked moms why they increased their sugar intake in pregnancy. "The qualitative study really highlighted that women's diets don't change because of just one factor," says Bell. "There are many different factors that influence diet such as ease of access, peer or family pressure, availability of foods, pregnancy-related cravings or aversions the list goes on. If we are going to try to intervene, we have to think about all these different factors."

The data collected during Sweet Moms has been the basis for creating the researchers' next project, ENRICH. ENRICH aims to improve maternal health in pregnancy and postpartum by researching innovative ways to promote healthy weight and healthy eating. "Sweet Moms was very successful and we decided to use the same model for ENRICH," says Bell. "It takes what we learned in Sweet Moms to another level because we are taking our past research and focusing on how to use it to create interventions."

The ENRICH program currently has 12 studies that are all aimed at encouraging women to maintain a healthy weight in pregnancy and postpartum through healthy eating. Different approaches are needed to support the diverse groups of women who live in Alberta. One set of projects has helped develop and release information about healthy pregnancy through new platforms available through Alberta Health Services. Another project worked with the Multicultural Health Brokers Cooperative to create a grocery run program that provides food hampers for pregnant immigrant/refugee women. This encourages



the women to visit the Cooperative to meet their food needs, while accessing other vital assistance or resources. "We are trying to use food as a gateway to providing resources for a better life," says Bell. ENRICH has also helped to establish an Elders Mentoring Program where Elders from the Maskwacis community bridge the cultural gap between health care providers and pregnant Indigenous women who come to the clinic. It's expected that the ENRICH program will continue to work alongside these communities and many more.

Research that started in a lab measuring sugar intake

in animals has slowly translated all the way to helping at-risk communities of women. "It's really exciting to see how a project like Sweet Moms can translate across the research spectrum and interact with the community," notes Bell. "It's incredible to see how so many different people and groups like WCHRI can work together to create positive change."



Sweet Moms' research was funded by generous supporters of the Lois Hole Hospital for Women, through WCHRI.

# COLLABORATION

# Improving patient care, one transport at a time

Graduate student Dr. Atsushi Kawaguchi is developing a decision-making tool that will revolutionize the critical care transport field

Dr. Atsushi Kawaguchi, under the supervision of Dr. Allan de Caen, wants to improve emergency transport in Alberta.

#### THE ISSUE

Around 50% of the patients who use the services of the PICU transport team don't need PICU-level care once they arrive at the hospital.

#### THE RESEARCH

Developing a PICU transport decision-making tool that will help the transport team make informed decisions about the best transport option for each patient.

The phone rings at 1:16 a.m. A six-year-old girl in northeastern Alberta is critically ill and needs to be moved from her rural hospital bed to the Stollery Children's Hospital's Pediatric Intensive Care Unit (PICU). The PICU specialist answers the call and decides to send one of their two transport teams via ground ambulance. Within four hours, the girl is on her way to the Stollery but seems to be steadily improving. By the time she arrives, the specialized care provided by the PICU is no longer needed and she is instead admitted to the Stollery general ward for the night.

About 50% of the pediatric patients who are sent to the Stollery using the services of the PICU transport team do not need PICU-level care within 24 hours. Even though it costs around one million dollars each year to operate the two PICU transport teams in Alberta, that cost is more than offset by the quality care received during transport, which may also result in reduced hospital stays. The need for these specialized teams is growing along with Alberta's population. That is why Dr. Atsushi Kawaguchi, a WCHRI graduate student, decided to use his time and energy to develop a PICU transport decision-making tool that will help physicians remotely assess patients and make stronger informed decisions based on the patient's specific transport needs.

As part of the PICU transport team, Dr. Allan de Caen has been taking calls for over 20 years. "Right now, it all comes down to the gut reaction of the physician taking the call," says de Caen. "We don't have an objective, quantifiable approach that everyone can use when taking a call, so it ends up being a visceral reaction. This tool will provide an objective opinion that may save time, resources and, most importantly, give the patients the specialized treatment they need."

Creating a tool that can assist with making such complicated decisions requires a lot of input from other groups. Kawaguchi has been working with various transport groups across the province including the Referral, Access, Advice, Placement, Information & Destination (RAAPID) team, Advanced Life Support (ALS) flight team, STARS Air Ambulance, emergency physicians and many more to make sure this system will address the needs of each group and be used by everyone in the field of emergency transport. "We are engaging these stakeholders so they understand what we are trying to achieve, and are incorporating their expertise and opinions into the final product," says Kawaguchi.

Kawaguchi has been analyzing all of the PICU transport teams' calls over the last 20 years to create a basis for the tool. The RAAPID team has provided audio records for him to analyze and add to the data to make the tool more comprehensive. Historical data acquired from these transport groups will allow the tool to evaluate transport needs based on each situation and provide recommendations to the physician making the transport decision.

The PICU transport decision-making tool could revolutionize the field of emergency transport here in Canada and across the ocean in Japan. "By helping Atsushi create this tool, WCHRI is advancing not only a provincial initiative for children but actually helping create the foundation for an impact around the world since Atsushi plans to return to Japan and become a national leader in pediatric critical care transport there," says de Caen. "It's visionary!"



Dr. Atsushi Kawaguchi's research has been funded by the generous support of the Stollery Children's Hospital Foundation, through WCHRI.

# COLLABORATION



## Creating a network of change

#### Kids Brain Health Network works with parents to improve treatment for children with neurological disorders

In 2009, a group of researchers from different areas within developmental disabilities and children's brain health met to discuss how they could combine their efforts to create positive change for children with brain-based disabilities. Their discussions evolved and formed a strong multidisciplinary national network of researchers, stakeholders and clinicians, called Kids Brain Health Network (formerly known as NeuroDevNet).

Eight years later, the network is creating early diagnostic tools, learning about new interventions and supporting children and families who are impacted by neurodevelopmental disabilities. They have focused their attention on three main areas of research: fetal alcohol spectrum disorder (FASD), autism spectrum disorder and cerebral palsy. Dr. Christian Beaulieu is in charge of MRI imaging for the fetal alcohol spectrum area. It's his job to determine if there are differences in the brain structures of children with FASD compared to other children. He's discovered that regular brain MRI scans don't show anything obvious but quantitative measurements of brain structure show widespread brain injury in FASD. Beaulieu leveraged the support he received through the Kids Brain Health Network and WCHRI to obtain additional funding from CIHR. This will allow him to continue analyzing structures in the brain and identifying areas that are affected by FASD.

Dr. Lonnie Zwaigenbaum is the team lead for the autism spectrum disorder area. "We've certainly learned a lot about the genetics of autism through collaboration with the Kids Brain Health Network, which may help us better understand the biological mechanisms and potentially develop new treatments," says Zwaigenbaum. "We've also been developing an early detection tool for autism that we are



Dr. Christian Beaulieu studies fetal alcohol spectrum disorder within the Kids Brain Health Network.

hoping to integrate into the community to help with early diagnosis." With the support of the network, Zwaigenbaum's colleague Dr. Jessica Brian has partnered with the Ministry of Children and Youth Services in Ontario to introduce a toddler intervention program into the community.

A similar approach is being taken in the area of cerebral palsy. "One of the best outcomes of the network is that we have brought together all of the cerebral palsy investigators across Canada," says Dr. Jerome Yager, one of the team leads in cerebral palsy. "It's the first time that the researchers are talking to parents and having a bi-directional dialogue about what is a priority for them and new possibilities for patients with cerebral palsy through research." Through this network of investigators within cerebral palsy, an "app" was developed for patients to access nearby facilities, and the team has begun clinical trials in both rehabilitation and prevention. Partnerships with other funders and business have grown as well to better implement solutions the network has found.

WCHRI has recently supported one of the main initiatives of the cerebral palsy area: the Canadian Cerebral Palsy Registry. The registry contains about 1,500 individuals with cerebral palsy across Canada. Dr. John Andersen has been helping to build the registry over the last eight years and is using this new information, such as how cerebral palsy affects individuals in Northern Alberta, to impact how clinical services are delivered and change policies to be centred around best practices for patients and their families. "We've spent a lot of time building a platform that will allow us to jump into 'the next big thing'," says Andersen.

"Building a platform" is exactly what Kids Brain Health Network and WCHRI hoped would happen when the network was formed back in 2009. "The goal was to try to bring together these groups of individuals to work together so we could be more than the sum of our parts," says Dr. Dan Goldowitz, the scientific director at Kids Brain Health Network. "I can't put a value on what WCHRI has done, but it's been phenomenal. WCHRI investigators are some of the bedrock of Kids Brain Health Network." All of these projects and investigators supported by WCHRI and the Kids Brain Health Network have created the foundation to spur a change in how researchers interact with families. This collaborative environment will allow researchers to achieve more than one individual ever could.



The research conducted by the Kids Brain Health Network was funded by the generous support of the Stollery Children's Hospital Foundation, through WCHRI.

# Neurological disorder facts:

- The effects of FASD last a lifetime. Behaviour and mood changes such as alcohol and drug abuse, depression, psychosis and aggressive behavior, often begin in the teenage years.
- Autism is the fastest growing and most commonly diagnosed neurological disorder in Canada and is a lifelong spectrum disorder.
- With the right supports and early interventions, all individuals with autism can thrive.
- Cerebral palsy is a long-term chronic medical condition that requires long-term supportive care services.
- The estimated lifetime cost for an individual with cerebral palsy is \$921,000.

# **COMMUNITY FOCUS**

We operate to serve the needs of the community and aim to establish partnerships with health agencies and policy makers with the objective of achieving tangible results.

# Strong hearts and open minds

# Dr. Sue Ross and Indigenous women collaborate to raise community awareness of menopause

Dr. Sue Ross, Cavarzan Chair in Mature Women's Health Research & Innovation, has discovered that surprisingly little research has been undertaken about the experiences of menopausal women in Indigenous communities in Canada. This led Ross and her team (with Maskwacis Health Services) to try to better understand menopausal issues in Indigenous women. As a starting point, the group chose to hold small group discussions with women of the Maskwacis community (located 70 kilometres south of Edmonton).

A community workshop was held to share the small group findings. "After the workshop, several women inquired 'what's next?" says Ross. "They decided they wanted to form a group" to use the findings of the research to support other women in the community.

The women chose the group name "Sohki Teyhew," Cree wording for "Strong Heart," a name that represents the role of a woman at the heart of the family and their place within the community. Members of the group include: Samson Cree Elder, Margaret Montour; Louis Bull Elder, Matilda Roasting; Maskwacis Health Services' Director of Nursing, Bonny Graham; University of Alberta researcher Richard Oster; and other women from the community.

The participants already knew their key goal — they hoped to increase understanding about women's body changes and experiences of menopause, particularly among spouses, children and family members.

"They were very passionate about it," says Ross, "They felt that better understanding would reduce stress within families."

After a year of ongoing collaborative meetings and community workshops, the group developed



"My research program is moving towards wellness research," says Ross. "This project taught me to keep an open mind, to listen to the women participants describing their needs."

informational pamphlets – including culturallysensitive suggestions to help menopausal women and their families. The creation of the pamphlets was honored at a traditional elders' ceremony, after which the pamphlets were distributed through local meetings and Maskwacis Health Services.

"Our group wants to expand this work to support women's experiences of other taboo issues such as incontinence and pelvic organ prolapse," Ross explained. These issues touch many women, but are rarely discussed or researched. Ross and the group recently were awarded a grant for \$150,000 from the Canadian Institutes of Health Research (CIHR) to assist with this expansion and continue this important research. The group will continue to work within the community and hopes to move forward by taking the menopause pamphlets and other knowledge outcomes to other Indigenous communities in Alberta.

This project provided Ross with an opportunity to experience a new way of conducting research as well as opening a lens on how to work collaboratively with Indigenous populations.

"My research program is moving towards wellness research," says Ross. "This project taught me to keep an open mind, to listen to the women participants describing their needs. They brought their culture, wisdom and life experiences to the project. They knew they wanted to increase community understanding about menopause, not to try to 'cure' it."

Ross believes that WCHRI's contribution to the project was fundamental in providing networking and grant opportunities to help her move forward.

"Incidental conversations with other WCHRI members while participating on grant review panels gave me the confidence to undertake this project. The community of WCHRI was invaluable in facilitating the sharing of knowledge and experience."



Dr. Sue Ross' research has been funded by generous supporters of the Lois Hole Hospital for Women through WCHRI.

## WCHRI's community impact this year



# **COMMUNITY FOCUS**



## **Research through a different "lens"**

# PaCET participants facilitate change one project at a time

On the first Friday of March, a group of six women, (four trainees and two program leads) meet on the fifth floor of the Edmonton Clinic Health Academy building. Sitting around the office in plush chairs with coffees in hand, the participants take turns discussing the progress and setbacks in their research projects.

The first to start is Bethan Kingsley who's been working with the Terra Centre and Brentwood Family

Housing Society to facilitate a dialogue with young parents receiving supportive housing to see if there are areas for improvement, such as flexible policies for housing tenants. "I feel like we've built a good rapport with the young mothers, but at some point, we have to ease out," says Kingsley. "I'm struggling with that. So, I am not sure what is going to happen after we're done with the research."

"That's one of the challenges with community-based research: knowing if and when it is ethical to leave," Lisa Tink expresses, nodding in understanding. Tink recently came back to academia to answer some questions she identified while working in the recreation sector.

Interchanges like this are common during these meetings. All of the women bring together different ideas and perspectives to each of their projects, but there is one commonality: participatory research.

Participatory research is a broad-based approach that involves patients, clinicians, community groups and/or the government in a multi-lateral conversation about the research that will affect all parties involved. All the participants have chosen this type of research because, in order to answer the questions they are studying, they need to have a "full picture" understanding of all the people affected. That is why the Patient and Community Engagement Training (PaCET) program was created — to support reaching that full picture lens, which is also strengthened through a partnership between WCHRI and the Community-University Partnership for the Study of Children, Youth and Families (CUP).

Each year, researchers apply to join the program and conduct participatory research focused on improving women's and children's health. The four awardees in 2015-2016 were Bethan Kingsley, Jocelyn Shulhan, Tasneem Siyam and Lisa Tink, who are working to tackle complex questions by engaging in and learning from the communities they are researching. "After this program, people are much better citizens and can participate in a different level of research than traditionally trained researchers," says Dr. Maria Mayan, CUP's assistant director and PaCET program lead. "It allows them to ask questions of themselves and the world that they may have never considered before."

Shulhan is engaging parents of infants in the neonatal intensive care unit (NICU) to determine the most important outcomes for clinical trials. "Bringing their voices forward at the initial planning stages ensures that future clinical trials will answer problems that are important to families," Shulhan adds.

The trainees have started to celebrate the small

changes spurred by their research. Siyam, who is working to develop a tool to help women make informed decisions regarding early surgical menopause, has already seen some successes from her study. "The women in my study have created two support groups," she says. "It's really wonderful to see them come together and get the support that they need."

"The wonderful thing about WCHRI creating the PaCET program is that it's not only about the quantifiable outcomes, like most research studies," says Tatjana Alvadj, WCHRI research coordinator. "It's really about expanding something in our hearts and our minds as researchers."

After finishing their discussion and coffees, the trainees rise — ready to take on the next steps for their projects. They've all had an opportunity to express their wins and challenges to a group that truly understands the value of their work.

"The wonderful thing about WCHRI creating the PaCET program is that it's not only about the quantifiable outcomes, like most research studies," says Tatjana Alvadj, WCHRI research coordinator. "It's really about expanding something in our hearts and our minds as researchers."



Bethan, Jocelyn and Lisa's research were all funded by the generous support of the Stollery Children's Hospital Foundation, through WCHRI.



Tasneem's research was funded by generous supporters of the Lois Hole Hospital for Women, through WCHRI.

# ACCOUNTABILITY

Financial resources will be managed efficiently, effectively and appropriately to achieve optimal benefits for stakeholders.

## Income statement for year-end March 31, 2017

#### REVENUE

Stollery Children's Hospital Foundation *	5,708,823
Royal Alexandra Hospital Foundation *	1,482,252
Faculty of Medicine & Dentistry, University of Alberta and other	238,197
Cost recovery	651,799
Total revenue	8,081,071

#### **EXPENDITURES**

Research grants	1,734,133
Research catalysts	2,060,827
Research platforms	1,799,634
Donor designated initiatives	1,280,464
Administrative support	671,907
Total expenditure	7,546,965

Surplus (Carry-forward to next fiscal year)	534,106

\* Includes surplus carry-forward from prior year, transfers from closed projects & other donations



# Expenditure percentage



# INTEGRITY

We operate with full transparency following principles of fairness, mutual respect, and trust among staff, members, stakeholders and clients.

## **Our staff**



# Our governing bodies

Oversight Board members				
Richard Fedorak	Dean, Faculty of Medicine & Dentistry, U of A (Chair)			
Steve Dew (Randy Goebel, Designate)	Provost & Vice-President Academic, U of A			
Lorne Babiuk (Randy Goebel, Delegate)	Vice-President (Research), U of A			
Susan Gilmour	Chair, Department of Pediatrics, U of A			
Radha Chari	Chair, Department of Obstetrics and Gynecology, U of A			
David Evans	Vice-Dean (Research), Faculty of Medicine & Dentistry, U of A			
Kue Young	Dean, School of Public Health, U of A			
Lorne Tyrrell	Director, Li Ka Shing Institute of Virology, U of A			
Kathryn Todd	Vice-President Research, Innovation and Analytics, AHS (Vice-chair)			
Christine Westerlund	Senior Operating Officer, Stollery Children's Hospital, AHS			
Judith Hockney	Senior Operating Officer, Royal Alexandra Hospital & Sturgeon Community Hospital, AHS			
Mike House	President/CEO, Stollery Children's Hospital Foundation			
Kelly Blackett	Board of Trustees representative, Stollery Children's Hospital Foundation			
Andrew Otway	President/CEO, Royal Alexandra Hospital Foundation			
Melanie Nakatsui	Board of Directors representative, Royal Alexandra Hospital Foundation			
Ex -officio (non-voting members)	Ex -officio (non-voting members)			
Sandra Davidge	Institute Executive Director			
Lawrence Richer	Institute Associate Director			
Program Advisory Committee Members (	all U of A faculty)			
Todd Alexander	Associate Professor, Pediatrics, Faculty of Medicine & Dentistry			
Geoff Ball	Professor, Pediatrics, Faculty of Medicine & Dentistry			
Margie Davenport	Assistant Professor, Faculty of Physical Education & Recreation			
Sandra Davidge	Executive Director, WCHRI			
David Eisenstat	Professor, Pediatrics, Faculty of Medicine & Dentistry			
Lisa Hornberger	Professor, Pediatrics, Faculty of Medicine & Dentistry			
Gary Lopaschuk	Associate Chair, Research, Department of Pediatrics			
Andrew Mackie	Associate Professor, Pediatrics, Faculty of Medicine & Dentistry			
Maria Mayan	Professor, Faculty of Extension			
Lawrence Richer	Associate Director, WCHRI			
Sue Ross	Professor, Obstetrics and Gynecology, Faculty of Medicine & Dentistry			
Shannon Scott	Professor, Faculty of Nursing			
Lonnie Zwaigenbaum	Professor, Pediatrics, Faculty of Medicine & Dentistry			

# WE'RE JUST GETTING STARTED

# Our five-year strategic roadmap

This has been a particularly historic year for WCHRI and we couldn't be more excited to continue the momentum.

As we look forward to the future, we have developed a five-year (2015-2020) strategic roadmap to focus our support for women's and children's health research for maximum impact.

# WCHRI's strategic roadmap focuses on four areas of research:



**RESEARCH INTEGRATED HOSPITALS AND COMMUNITIES:** 

Improve health outcomes for children and women through research embedded at the point of care.



#### CHILDREN'S HEALTH AND WELL-BEING:

Identify effective treatments to address the unique health needs of children; improve our understanding of rare and complex childhood diseases.



#### **HEALTHY DEVELOPMENT:**

Optimize maternal and infant health outcomes; develop early intervention and prevention strategies to reduce the risk for lifelong chronic disease.



#### LIFELONG WOMEN'S HEALTH:

Support research that addresses mechanisms related to the unique health needs of women; improve reproductive health outcomes.



Because of you — our partners, supporters and stakeholders — WCHRI has become a top research institute in Canada. An institute that works hard to embody our six values in everything we do.



Together, we're drawing attention to areas of health research that are often overlooked and building a healthier future for women and children.

Thank you.



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## www.wchri.org

The Power of Partnership







