AWHF

Finding the Fractures:

THE PANDEMIC, WOMEN'S HEALTH DISPARITIES, AND THE PATH TO EQUITY

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The Alberta Women's Health Foundation respectfully acknowledges that we are on the traditional territories of Alberta of the many First Nations, Métis, and Inuit whose footsteps have marked these lands for centuries, including Treaty 4, Treaty 6, Treaty 7, Treaty 8, and Treaty 10 land. Our main office is located on traditional lands referred to as Treaty 6 Territory, and all the people here and in the surrounding area are beneficiaries of this peace and friendship treaty. Treaty 6 encompasses the traditional territories of numerous western Canada First Nations such as the Cree, Saulteaux, Blackfoot, Metis, Dene and Nakota Sioux. We acknowledge all the many First Nations, Metis and Inuit people who have called these areas home since time immemorial.

Foreword:
A Letter From Our CEO

Without research, doctors are not equipped. Without research, women's health experiences are not validated, and without research, women are unable to live their lives to the fullest, participate in our economy, and lead communities.

But without first understanding what needs to be researched, we cannot make change.

Last year, we set out to make change and expand our collective understanding of what needs to be done in the realm of women's health, thus launching the Alberta Women's Health Foundation (AWHF). Our mission is to foster equity in women's health and women's health research.

We have understood for some time now that there are many gaps and disparities that exist in women's health—a lack of funding for women-specific research, a lack of representation of women in clinical trials, a lack of understanding of women-specific diseases and conditions.

And, more recently, a lack of understanding of how the pandemic has made these disparities all the more evident.

We did not grasp the true extent of the pandemic's disproportionate impact on our province's women, so we sought to understand, and asked.

Our survey reached over 1,650 Albertans, and we are pleased to share with you our findings in the form of our first—but certainly not last—report, *Finding the Fractures*.

Within the pages of this report, we bring together data and evidence of the current disparities in women's health. We uncover stories of women's worsening mental and physical health and of their many challenges juggling medical appointments, childcare, and work commitments.

With this new understanding, we intend to improve the health and lives of women, as we know and understand it is not only good for women, but good for community health, for public health, and for our country's economy.

We are calling upon our community—our thought leaders, policy makers, and all members who have the opportunity to make change—to assist us in amplifying awareness of these issues and facilitate the discussion.

Thank you in advance for reading, for joining your voice to ours, and for helping us bring awareness and attention to these important issues.

Sincerely,

Sharlene Rutherford
President and Chief Executive Officer
Alberta Women's Health Foundation

What Do We Mean By "Women"?

The AWHF acknowledges that sex relates to the physical and biological features of a person at the time of birth, whereas gender is a multidimensional concept influenced by factors including cultural and behavioural norms, and self-identity. As this concept is affected by ongoing societal change, gender is constantly evolving.

The AWHF follows our partners in using the term "women" to refer to all people who identify as women.

Similarly, we use trans and non-binary as umbrella terms to refer to people with a wide range of gender identities that are different from the gender they were assigned at birth.

This is a living definition and we welcome feedback and discussion.

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A History of Health Disparities

Women's health has been sidelined for decades. For many years, it was widely accepted that apart from their reproductive organs, women did not differ medically from men, and thus were excluded from medical research and clinical trials. Instead, data obtained from male subjects were predominantly extrapolated for women until the 1990s.

But, if we consider the differences in biology and physiology of women, in addition to the complex social factors that influence health, we can see the need to understand women's health more clearly. The latest evidence highlights the considerable influence of gender on disease risk, diagnosis, and treatment. And, when we look at some of the consequences of lack of understanding of women's bodies and health outcomes, we emphasize the urgent need for women's health to be prioritized.

While new guidelines by Health Canada acknowledge this bias, the inclusion of women in clinical trials is not mandatory so we have ever-increasing gaps and disparities impacting women's health outcomes. Furthermore, as funding for women's health research is limited and plagued by further gender bias, it is more important than ever to recognize the discrepancies in women's health.

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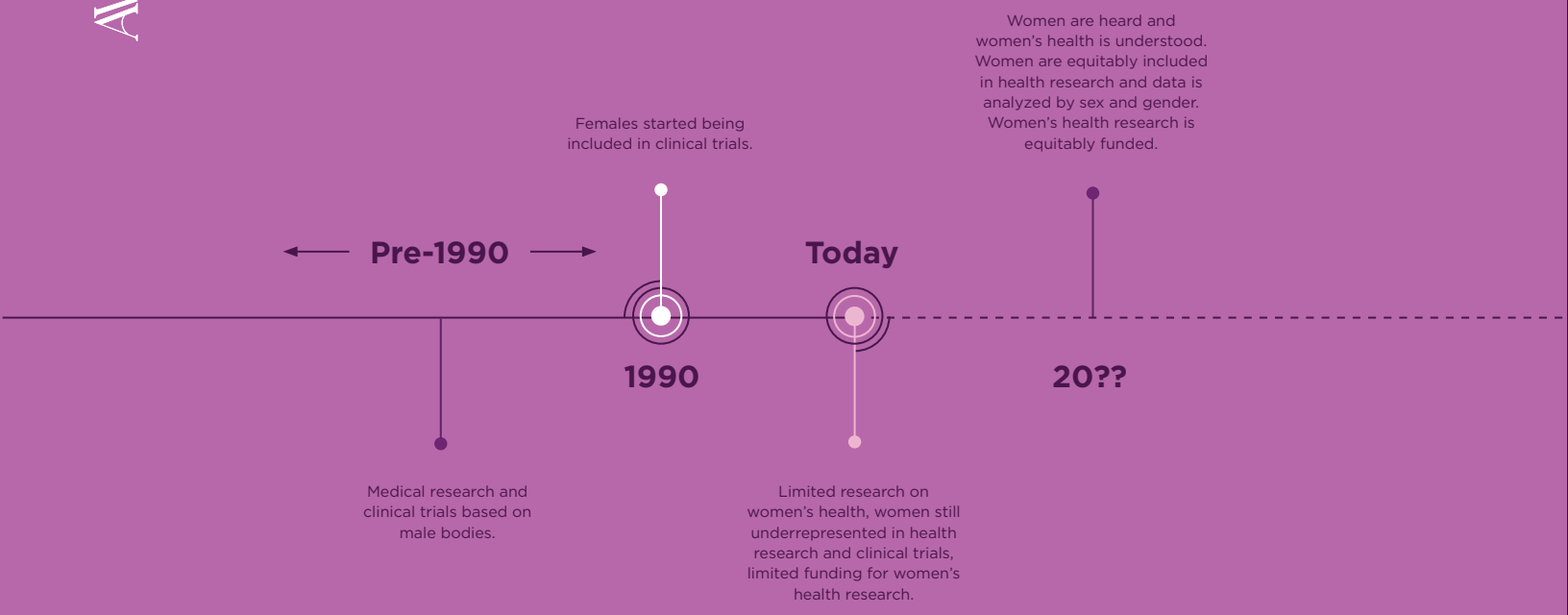

A History of Health Disparities

80%

of all patients diagnosed with autoimmune diseases are women

- Approximately 80% of all patients diagnosed with autoimmune diseases are women (where one's immune system mistakenly attacks healthy cells, tissues, and organs)[1]. These diseases are difficult to diagnose, and tend to affect women during periods of extensive stress, lack of adequate sleep, lack of exercise, or during great hormonal changes such as pregnancy. There are no known cures.

35%

more women die of strokes than men

- 35% more women die of strokes than men, but only 35% of clinical trial subjects in cardiovascular research are women. This means that women may not be receiving care targeted for their needs, especially considering that women often present with 'non-traditional' symptoms[2] of stroke.

- Women were under-represented (38.8%) in the leading research studies of non-sex-specific cancers, yet a non-sex-specific cancer—lung cancer—is the leading cause of cancer deaths in women, killing more women each year than breast cancer, uterine cancer, and ovarian cancer combined.

- Multiple papers and reports have been published on the subject of the disparities in health and wellness of Indigenous women, such as "Aboriginal Women in Canada: Gender, Socio-Economic Determinants of health and Initiatives to Close the Wellness Gap," authored by Regine Halseth from the National Collaborating Centre For Aboriginal Health (NCCAH). Most recently, several Indigenous women have reported instances of experiencing systemic racism in healthcare settings—including Marissa Smoke's experience at a southern Alberta hospital, and Joyce Echaquan's death in a Quebec hospital, which sparked outrage and protests around systemic racism.

- Only recently, evidence has arisen on female-specific factors and medication on health outcomes, such as the influence of hormonal fluctuations during specific life stages on stroke risk.

This impact is not just felt elsewhere. **This is impacting women in our province**. In Alberta, women face a 20% higher risk than men of dying or having heart failure during the five years following a heart attack. Women are also less likely to receive the needed care, from receiving a diagnostic angiogram, seeing a heart specialist, or being prescribed medications.

1. All data comes from existing academic studies referenced in hyperlinks.

2. Due to the exclusion of women from clinical trials, 'non-traditional' symptoms often refer to those not identified in research focused on male participants.

Uncovering Realities:
Underlying Mental Health Issues

Leading Canadian women's health researcher, Dr. Dawn Kingston[3] and her team in Alberta, have found that women are already less likely than men to report health issues or discuss taboo topics with their doctors.

When it comes to mental health concerns, 70% of women do not mention these to their doctor out of fear of judgment[4]. And the level of routine screening for mental health concerns is severely lacking. Other barriers to speaking about their issues include a woman's tendency to focus on physical health instead of mental health, a fear of judgment, incorrect assumptions that symptoms are due to hormones, and time constraints of doctor-patient appointment times.

Dr. Kingston's team posed a very simple question to a group of female subjects: If asked by a healthcare provider, would you be willing to talk about these issues?

97% said yes.

Combining this with the knowledge that three out of four women wish to self-manage their mental health[5], Dr. Kingston and her team have launched a digital mental health platform for women called the Hope Platform, providing women and their families with access to support, information, and compassionate healthcare.

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"The bottom line is all about overcoming barriers to mental health care,"
said Dr. Kingston.
"No country anywhere in the world has been able to offer accessible, affordable mental healthcare for all, and it has always been an ambition of ours to do that."

3. Dr. Dawn Kingston is a renowned AWHF-backed and Women and Children's Health Research Institute-supported researcher and expert in perinatal mental health. Along with being a professor and certified coach, she holds the prestigious national New Investigator Award from CIHR and is the chairholder of the Lois Hole Hospital for Women Cross-Provincial Chair in Women's Mental Health—Canada's only endowed Research Chair in the area of perinatal mental health.

4. These findings are from a cross-sectional study by Kingston et al. Preferences for Mental Health Screening Among Pregnant Women: A Cross-Sectional Study. American Journal of Preventive Medicine, 2015 Oct;49(4):e35-43. Available here.

5. As found in Kingston, et al. Barriers and facilitators of mental health screening in pregnancy. Journal of Affective Disorders, 2015;186:350-357. Available here.

"That's why we built [the HOPE platform]—to be accessible by anyone, any time, and to get the kind of help that they need. Knowing the perinatal period is an area of high risk, it helps give women the chance to start their families the way they want to. But as we've discovered through our journey, so many women come into pregnancy and leave the post-partum period still having mental health problems, so what we've wanted to do is extend the program so that it will be available across the full life course... Helping women helps the broader family." - Dr. Dawn Kingston

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Added Pandemic Health Disparities: Decline in Mental and Physical Health

The COVID-19 pandemic has intensified many disparities in society—women's health was not exempt. Using survey data and stories from 1657 Albertans, 75% of which were women, we uncover the depth and breadth of impact on women's health.

- **Four out of five women feel more stressed during, or as a result of, the pandemic.**
- **Seven out of 10 women report added stress of the pandemic negatively impacting mental health.**
- **8.3% of women diagnosed with mental health disorder during the pandemic.**
- **63% of women report added stress of the pandemic negatively impacting physical health, including comments of poorer diet, weight gain, reduction in exercise, difficulty sleeping, worsening of a chronic health issue, or onset of new health concerns.**
- **11% of women have experienced thoughts of harming themselves[6].**

"Juggling working at home and online learning with kids leaves me little time to prepare healthy meals, and I end up snacking and drinking more to cope. Even when the gyms opened back up, I wasn't able to go because I didn't have reliable and safe childcare anymore."

6. If you need to access urgent support, information and resources specific to mental health, call the Alberta Health Services Mental Health Line at 1-877-303-2642

"Women are very stressed. Everyone I've talked to has admitted to sitting alone in their car or in the shower sobbing for some period of time."

"The emotional and mental load has been a lot... With no separation of work and home life you just feel like you are never fully giving anything or anyone your attention and failing at both, while having constant worry that whatever actions and decisions you make, even just going for a walk or to the grocery store will have a significant negative outcome."

Yet many women reported barriers in accessing mental health supports including financial barriers to afford mental health care, limited mental health benefits, lack of availability of practitioners, and difficulty finding childcare to attend appointments.

"Tried to reach out to multiple resources but the wait times were a minimum of 6 months for an initial appointment."

"My benefits only cover 50% of the cost of accessing mental health providers. When our family lost access to income the cost was too much."

Evidence from The Centre for Addiction and Mental Health, found that women were more likely to experience symptoms of anxiety and depression at this time, and more specifically low-wage workers and those already living in poverty. In addition, increased isolation and social-distancing have increased incidents of gender-based violence[7], with marginalized communities more at risk.

7. To find supports for gender-based violence, visit Alberta Family Violence Supports

Added Pandemic Health Disparities: The Weight of Caregiving Responsibilities

Women in our survey reported detrimental levels of stress related to juggling so many aspects of their work and family lives with little to no support. This was even worse for single mothers and those looking after both children and elderly family members.

Data from before the onset of the COVID-19 pandemic shows that women in Alberta perform an average of 35 hours of unpaid work each week in both their own home and others—a disproportionate responsibility both compared to men in Alberta (17 hours), and to women in other provinces. It is the equivalent of women working a "double day". In one academic study of chronic stress indicators, working mothers with two children were found under pre-pandemic conditions to be 40% more stressed than the average person.

With the closure of schools and daycares during the early months of the pandemic, alongside wider support for elderly family members, the burden fell predominantly on the shoulders of women:[8]

"Stress levels have been higher than usual due to the unprecedented pressure while working at home to manage my job, my children's education, additional household duties, additional support to my elderly parents, additional need to fill social requirements in my children's lives and support/enhance their emotional well-being, with little down time to recuperate."

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8. Note, all quotes in this section were kept verbatim for the sake of impact and authenticity. See Methods section at end regarding approach to quotes used in this report.

"We have lost our community of support and are floundering."

"I am a mom, but as the eldest daughter in my own extended family I am the primary point person for aging parents who have struggled through the pandemic, which has caused my own stress levels to increase as their need for assistance and care, living in a remote location, was considerably increased...While I am glad and grateful to be able to help as much as I possibly can, it is completely exhausting."

"The supports for single mums has not been enough. It is very hard being isolated as a single parent."

"Being a primary caretaker of someone who has been seriously ill with COVID and coping with their long COVID symptoms is very stressful."

"Women have disproportionately had to take on the extra burden of household and childcare, both prior and particularly during, the pandemic. Of the families I know, it has been pretty much exclusively the women who have changed their work schedules to accommodate at-home learning or lack of childcare."

Added Pandemic Health Disparities:
Delays in Accessing Care

With the measures to make space for COVID-19 patients, and the addition of COVID-19 protocols, there have been a suite of barriers and new dimensions to seeking care.

Whether for preventative care, pre-existing health issues, new health issues, or recommended tests and treatment, women in Alberta were significantly more likely than men to have either skipped an appointment, have an appointment postponed, or have an appointment cancelled. Wider evidence shows increased risks of missing screening appointments in older and underserved populations during this time.

Impacts of missed appointments and seeking support could be particularly pronounced for those with medical issues or those needing time-specific care.

"Physically, I was due to have a full hysterectomy due to endometriosis right when COVID started. That obviously was delayed. I was lucky, and it was only delayed 6 additional months[9]."

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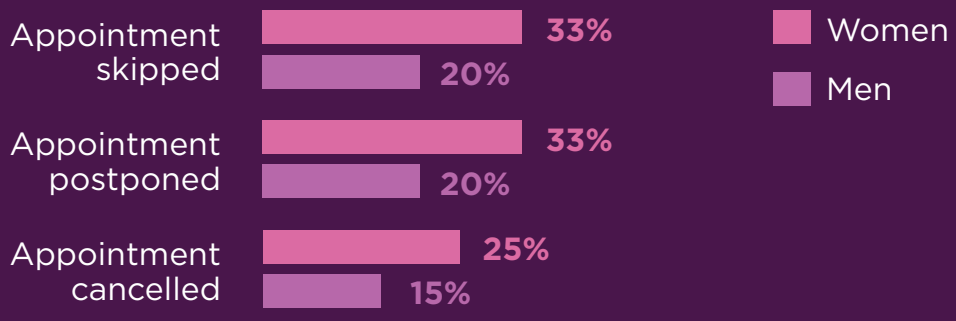
9. Endometriosis affects 1 in 10 women. It is a disorder where tissue similar to the tissue that normally lines the inside of the uterus, grows outside the uterus. Symptoms can be debilitating including abdominal and pelvic pain, and many women experience infertility. Recent research in Canada estimates the average delay in diagnosis of endometriosis is 5.4-years. Further delays in the diagnosis and treatment of endometriosis due to the pandemic means continual deterioration of quality of life linked to the disorder.

In Alberta, based on average testing rates, an estimated 41,180 mammograms, were suspended for two months starting at the end of March to allow the healthcare system to prepare for an influx of COVID-19 patients. Similarly, the estimated number of postponed Pap tests for cervical cancer would be 58,140.

"It was hard to access regular care even before the pandemic because so many GP's in my area aren't taking new patients. Now I struggle to attend medical appointments due to the loss of safe and affordable childcare. A friend in her 20s recently received a cancer diagnosis, and I fear it could have been caught sooner.

For women's health in Alberta, delays in seeking care are concerning and could result in higher numbers of women experiencing more severe health issues after the pandemic resolves. Estimates early in the pandemic for a three-month interruption in breast cancer screening across the Canadian population, were projected to cause an extra 310 diagnoses of advanced stage breast cancer.

Survey results: Medical appointments during the pandemic



Uncovering Realities:
Moms Are Not OK

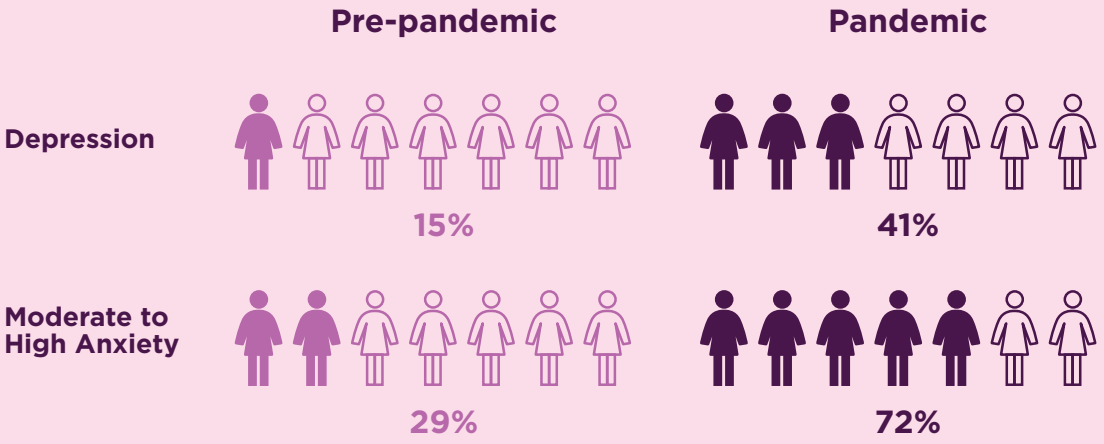
One example of the pandemic's pressure on women is mothers. Leading Albertan women's health researcher Dr. Margie Davenport[10] and colleagues published Moms Are Not OK: COVID-19 and Maternal Mental Health, which focused on the impact of the COVID-19 pandemic and countermeasures on the mental health and physical activity of pregnant and postpartum women.

Outside the context of the pandemic, Dr. Davenport and team found that depression and anxiety affect one in seven women during their perinatal period. Within the pandemic, mothers appear to bear the heaviest brunt of social isolation. In the group of 900 women studied, the percentages of self-identified depression and anxiety more than doubled from pre-pandemic numbers; scores indicative of depression went from 15% to 40.7%, and moderate to high anxiety was identified in 29% of women before compared to 72% of women during.

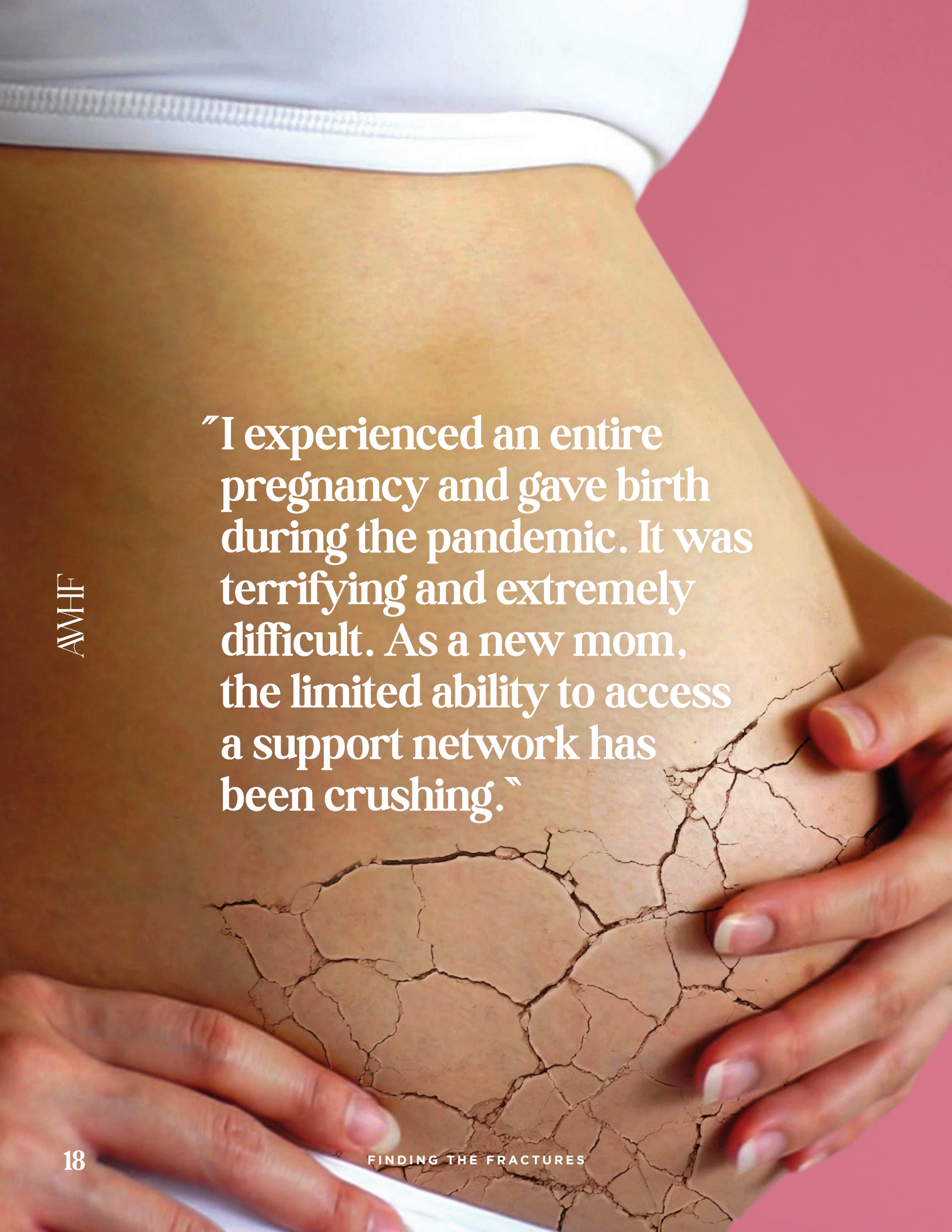
Depression and anxiety in pregnant and postpartum women are associated with increased risk of preterm delivery, reduced mother-infant bonding, and delays in cognitive and/or emotional development of the infant. In addition, the consequences of undiagnosed and untreated depression can be serious, leading to self-harm and in some cases suicide.

What does this tell us? Davenport said from what she can see, the pandemic isn't getting any easier for pregnant and postpartum women. Mothers now have it even harder in terms of mental health.

Dr. Davenport and her team call for heightened assessment and treatment of maternal mental health. Their work also goes on to highlight the importance and effectiveness of physical activity for pregnant and postpartum women toward reducing the likelihood of anxiety and depression.



10. Dr. Margie Davenport's research program is dedicated to improving the life-long health of pregnant and postpartum women and their children. With support from the Lois Hole Hospital for Women, Margie and her team examine the metabolic and cardiovascular adaptations associated with normal and complicated pregnancies. With a focus on the benefits of exercise prior to, during and following pregnancy for both mother and child, Margie helped prove that exercise has the power to prevent high-risk complications in pregnancy.



"I experienced an entire pregnancy and gave birth during the pandemic. It was terrifying and extremely difficult. As a new mom, the limited ability to access a support network has been crushing."

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Why Should Women's Health Be a Priority in Alberta?

2.1 million women

Alberta is home to approximately 2.1 million women and girls. These women and girls may be your daughters, your sisters, your mothers, your friends, your colleagues, or members in your community. They have unique health needs related to their biology and physiology, and they have a breadth of additional social factors that impact their health, as shown within the pages of this report. Their health should be a priority.

46% of Alberta's labour force

Of Alberta's labour force, 46% are women. Within the health care and social assistance sector, 82% of those employed are women. Within business, finance and administrative occupations, 70% are women, and within education, law, social, community and government services, 69% are women. Women's contribution to the economy is essential. Yet women's health directly contributes to women's ability to participate in the workforce, as demonstrated in research by the BC Women's Health Foundation which showed that investing in women's health could contribute an additional $17.9 billion to the Canadian economy.

Yet women are considering leaving the workforce as a result of the pandemic. Over 40% of women in our survey have considered working fewer hours, 39% have considered changing careers and 24% are considering a permanent exit from the workforce. In Canada, women's workforce participation has hit the lowest levels in three decades.

3.8 billion hours of unpaid caregiving provided per year

In addition to their economic contribution, if women in Alberta do, on average, 35 hours of unpaid caregiving a week, this equates to 3.8 billion hours of unpaid caregiving a year that women contribute to the economy. This caregiving plays an essential role in our society, in supporting elderly populations and new generations, and the functioning of our economy.

In an interview with Global News, Alberta CEO, entrepreneur and author Arlene Dickinson shared her opinion on how COVID-19 has affected women, "We are now the caregivers of both our children and our parents and our homes and trying to balance a career and juggling all that against all of the things that are happening, [which] is virtually impossible, both... mentally and physically... We see a lot of women having to give up their jobs and careers in order to take care of their families."

Where Do We Go from Here?

Faced with compounding threats to women's health, **we need to close the gaps in women's health.**

We need to listen to women's experiences to ensure we understand the realities affecting their health.

We need a clear understanding and appreciation that women's health is unique, women's health has been overlooked, women's health has been negatively impacted by the pandemic, and that we need to address these disparities as a priority.

We need to take tangible steps to improve women's health through policy, practice, research, and care.

Our Commitment as the Alberta Women's Health Foundation

We are committed to improving women's health in our province.

Awareness

We are committed to giving a voice to women through public-facing awareness campaigns that bring to light their experiences and barriers that affect their health.

Policy + Practice

We are committed to ensuring policy and practice prioritizes women's health through engagement with decision makers at all levels of government, and stakeholders within the healthcare and social system.

Investment

With the support of our generous donors, we are committed to investing in women's health research that will help us to better understand women's health and improve women's health outcomes.

"I realize that gender inequality exists in our world; some deliberate and some due to ignorance and insensitivity. I believe that it's my responsibility, privilege and legacy to make an effort to eradicate those discrepancies that are based on gender." – Marjorie, AWHF donor

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Closing the Gaps Together

As the impacts on women's health are far-reaching across society, we can all play a role in finding the fractures in women's health research, and closing the knowledge gaps in women's health. We can eliminate barriers...

...in conversation

- By normalizing discussions around mental health.
- By becoming comfortable talking about women-specific health issues.
- By asking questions and talking about women's health experiences.

...at home

- By more evenly sharing unpaid duties such as childrearing or family support.
- By acknowledging a new or expectant mother's increased risk for depression and anxiety.

...in the exam room

- By asking the right questions, listening and not dismissing.
- By promoting improved screening techniques for gender-based trends and concerns.

...in our workplaces

- By implementing and promoting flexible work policies that accommodate caregiving responsibilities and medical appointments.
- By bolstering mental health resources and supports for all.
- By not judging those with employment gaps or entering new careers.

...in policy

- By investing in women's health research.
- By mandating the inclusion and analysis of sex and gender in health research.
- By prioritizing women in pandemic recovery plans.

Let us all find the fractures in women's health and women's health research, and close the gaps together.

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Methods

The survey—focused on the unique challenges in women's health in Alberta during the pandemic—was conducted in May 2021 by Y Station. A total of 1657 respondents completed an online survey, with 72% of survey respondents identifying as female. Additional data available by request at the AWHF's discretion.

All quotes within the report are derived from responses provided by people who participated in the survey. All were kept largely true to form, lightly paraphrased or in some instances combined for the sake of clarity, efficiency and confidentiality, with a small portion kept verbatim.

Supplementary academic and grey literature was obtained to identify additional themes and support the themes identified within the survey results.

Recommended citation: Alberta Women's Health Foundation (2021) *Finding the Fractures: The Pandemic, Women's Health Disparities, and the Path to Equity*

Acknowledgements

The Alberta Women's Health Foundation would like to thank (in no specific order) the following people and organizations for helping make this report possible:

- All respondents that participated in our online survey. Thank you for openly and honestly sharing your experiences.
- Y Station which delivered research insights into the experiences of women throughout the province.
- Researchers and staff at the Women's and Children's Health Research Institute (WCHRI) for their world-leading research that is dedicated to better understanding women's health.
- Consultant Dr. Victoria Gay, for her guidance and expertise in helping the foundation craft a compelling report aimed at building a better world.
- The staff and Board of the Royal Alexandra Hospital Foundation and Alberta Women's Health Foundation, who are unwavering in their dedication to improving women's health in Alberta through fundraising, awareness, and advocacy work.
- The donors and supporters of the Alberta Women's Health Foundation that continue to give generously to support the health of women in our province.

The AWHF
Who We Are

We stand for women and women's health. Disease is not restrained by borders. Fortunately, nor is the knowledge that comes from research.

The new initiative of the Royal Alexandra Hospital Foundation has been created to fill urgent gaps in women's health research, an area historically underfunded and, sometimes, nonexistent.

Excellent health outcomes are the direct result of ongoing investment in health research.

It is our mission to foster equity in women's health, close gaps that exist in research today, connect pathways from lab to life, and advance clinical care at the Lois Hole Hospital for Women, Alberta's only dedicated women's hospital.

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Visit us at

AlbertaWomensHealthFoundation.org

and help us in

#FindingTheFractures

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