

# MOTHER'S STORIES OF ADVOCACY

Following their Child's Substance Passing  
(2017 – 2019)

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Project Summary and Report to Community Partners







Photo courtesy of Moms Stop the Harm



## INTRODUCTION

In 2016 a group of university researchers and parent advocates came together to work together on the first Canadian qualitative research project about parent advocacy following substance use death. Interviews with mothers across the country began in the summer of 2017 and continued throughout the year. Since then we have been analyzing the data, presenting our emerging findings at conferences and talks, and writing up papers for publication in academic journals. In partnership with four parent advocates we also produced a video series, the #SeeTheLives project and website ([see-beyond.ca](http://see-beyond.ca)) to share insights from our research.

We developed this report to share the results of our work with our community partners and stakeholders, as well as our research participants. This report provides the background for the study, a high-level summary of what we found, how we are sharing our research with researchers and the community, and what we plan to do next.

## WHY THIS PROJECT? (STUDY RATIONALE)

The broad aim of our study was to systematically collect, analyze and share the stories of Canadian mothers who have experienced the substance passing of their child, and who have subsequently engaged in advocacy and activism on how substance use impacts families and the need for greater supports and drug policy reforms.<sup>1</sup>

By highlighting parents' lived experiences, this study addressed a knowledge gap that exists between parents' community-based advocacy efforts and health policy scholarship. Through partnering together for this project, we wanted to create greater opportunities for the voices of parent advocates to be heard, by sharing our research findings with a broader academic, policy and community-based audiences. We also wanted to support parents' advocacy for services and policy changes to better support families, by providing research evidence from qualitative interviews that could be shared with decision-makers.

In our project we recognized that the lived experiences of people who use drugs (PWUD, or peers) should be front and center in discussion about drug policy reform (i.e. "nothing about us without us."). But we were also motivated by the fact



Photos courtesy of Moms Stop the Harm

<sup>1</sup> To be inclusive we defined *substance passing* as a death connected to a person's use of substances. This included, but was not limited to, opioid poisoning or 'overdose', substance-related suicide, or a death from other medical complications resulting from substance use. *Advocacy* was defined broadly to include a wide range of formal and informal activities in speaking out or sharing one's story to change attitudes or promote policy change.



*Panelists (from left): Jennifer Woodside (Voice of the Family), Donna May (mumsDU), Petra Schulz (Moms Stop the Harm), Marliss Taylor (Streetworks), Dr. Hakique Virani (MetroCity Medical Clinic). With special guest Jo Ann Saddleback (CRISM–Prairie Node Elder-not pictured).*

*Funding for this event was provided by a Meeting Grant from Campus Alberta Health Outcomes and Public Health.*

*Photo courtesy of University of Alberta, School of Public Health*

that the experiences of parents and families whose children have died had not received much attention prior to the overdose death crisis when bereaved parents began to organize and to speak out about their losses and to share their stories with media and with the public. Therefore, we wanted to provide an opportunity for parents to share their lived experiences of grief, stigma and bereavement but also offer unique insights and expertise about what needs to change to better support people who are using substances and the family members who love, support – and mourn them.

## **WHO ARE WE? (STUDY TEAM)**

The founding parent advocate partners for this project were: Donna May (mumsDU), Petra Schulz (Moms Stop the Harm), and Jennifer Woodside (Voice of the Family). The university researchers for this project were: Rebecca Haines-Saah (University of Calgary), Elaine Hyshka (University of Alberta), and Emily Jenkins (University of British Columbia). Heather Morris (University of Alberta) and Allie Slemon (University of British Columbia) were student researchers who also led data collection (interviews) with parents.<sup>2</sup>

The main funding for the research was provided by a new faculty start-up award from the University of Calgary (Haines-Saah) with contributions from other internal faculty research funds (Hyshka & Jenkins). To support our activities we also received funds from a Campus Alberta Health Outcomes and Public Health meeting grants (Hyshka), the Canadian Research Institute for Substance Misuse (CRISM) Prairie Node (Morris), and the #SeeTheLives project which was funded by the Alberta Ministry of Health, through an Opioid Awareness Grants

<sup>2</sup> Donna, Jennifer and Petra were involved in the critical planning and data collection stages of this project, and Jennifer left the project in the fall of 2017 when she retired from advocacy.

to Community (Haines-Saah). Graduate student funding (Morris) was received from the Social Sciences and Humanities Research Council (SSHRC), the Killam Foundation and the Women and Children’s Health Research Institute through the generosity of the Stollery Children’s Hospital Foundation and supporters of the Lois Hole Hospital for Women.

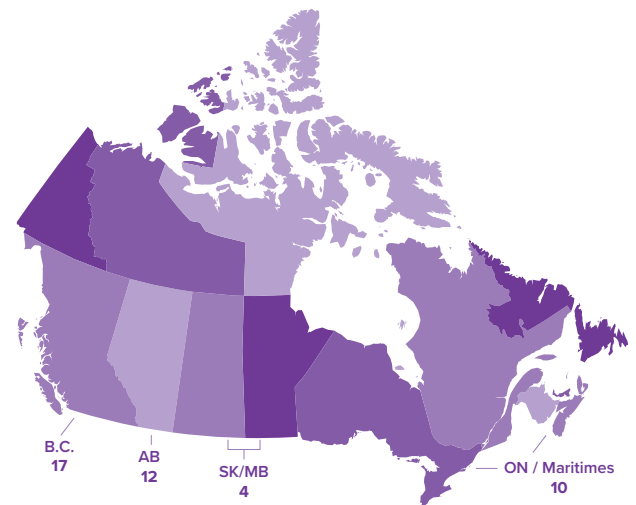
## WHAT DID WE DO? (STUDY METHODS)

The idea for this project came about in the summer of 2016, and we spent several months planning and working together. Our first activity was a public panel and roundtable stakeholder forum on March 9, 2017, hosted in Edmonton at the University of Alberta. This allowed us to plan our project together as a team and to hear from a wide range of Alberta stakeholders and service providers.

The event began with a public forum, “A Family-Centered Approach to Substance Use in Alberta,” attended by 106 community members. An afternoon roundtable discussion workshop was attended by key stakeholders representing over 20 different organizations from both Calgary and Edmonton. We asked participants to discuss and define what a family-centered approach to substance use was and to discuss barriers and facilitators to achieving this. Media coverage of this event included newspaper articles in the *Edmonton Sun*, *Edmonton Journal*, and *Ottawa Citizen* with an accompanying television segment on *Global Edmonton*.

In June 2017 we launched our qualitative research (collecting interviews) project, “Mother’s Stories of Advocacy Following their Child’s Substance Passing.” Recruiting through the networks of parents connected to mumsDU, the Voice of the Family and Moms Stop the Harm, we spoke to 43 parents from across Canada over a period of 6 months: 17 interviews in British Columbia, 12 interviews in Alberta, 4 interviews in Manitoba and Saskatchewan, and 10 in Ontario and the Maritimes.<sup>3</sup>

Interviews ranged in length between 26 minutes to 2 ¼ hours and most interviews (36) took place in person (most in people’s homes), with the remainder (7) being held over the telephone when travel made meeting face-to-face difficult. We asked questions about how and why mothers’ began to share their family story of their child’s death with the public and/or with the media, the different types of advocacy activities they engaged in, the messages they hoped to convey, changes they hoped to see, and also the benefits and challenges of ‘going public’ and choosing to share one’s story. We also discussed how advocacy impacts other family members, its potential relationship to grief and to healing and how speaking out in order to help others was beneficial, but also led to experiences of judgment and stigma. Participants led the interview discussions and while they were not required to share details of their child’s death or other potentially difficult and painful experiences, many chose to do so in retelling the story of their child’s struggles and how substance use had impacted their families.



Distribution of interviews by province or region, 2017

<sup>3</sup> The study was approved by the research ethics boards at the researcher’s universities (University of Calgary, University of Alberta, and the University of British Columbia). Participants signed a consent form detailing how we would protect their data confidentiality and each person was offered a \$50 gift card in recognition of their time.



In addition to interviews, we collected information on a brief survey that asked questions about people's backgrounds, their children, and their advocacy history. For those who shared their age, most stated that they were between 55 to 64 years-old, and about half (51%) were married at the time of the interview. Over half of participants had been involved in some form of advocacy for greater than a year. The children of the people we interviewed ranged in age from 17 to 43 years old at the time of their deaths – most died during their twenties and most were men. Finally, 39 of the 43 mothers we spoke to identified that their child died of a drug overdose or drug poisoning, with many citing fentanyl or use of multiple substances as a cause of their child's death.

Each interview was audio-recorded, typed up, and then checked over for accuracy. We sent a transcript of the interview to each person who was interviewed to make sure that participants had the opportunity to make any changes they thought were necessary. Using a research strategy called Thematic Analysis (Braun & Clarke, 2006), we then read over the interviews, grouped text into different categories and then developed larger themes to describe what we heard during the interviews.



Photo courtesy of Moms Stop the Harm

## WHAT DID WE LEARN? (SUMMARY OF STUDY FINDINGS)

*The following overview represents a short summary of some of the insights from our interviews related to the topic of advocacy. It does not summarize all the themes we are developing from the interview data. Please note that we have used pseudonyms or fictitious names in this report as well as removing other potentially identifying information.*

### Advocacy Purpose

The purpose of bereaved mother's advocacy is multifaceted. A primary objective for many we spoke to was simple: **to save lives**. In addition, a few of the women we interviewed spoke of an aim to decrease people's use of substances. Many expressed that they wanted to **enhance kindness, empathy and greater public support and understanding** of people who use drugs. An important element in doing this was working to erase the shame, stigma and silence surrounding substance use. Changing harmful or unhelpful policies and programs for substance use was also seen as an important goal. Finally, many women spoke of the importance of **providing support** either by helping oneself (healing from grief, remembering or honouring one's child, being part of a community with shared experience) or helping other individuals and families.

*"... the bottom line is let's all try to save someone else's child...I can really get behind that because there is absolutely no pain in this world like losing a child, and it's something you just don't want to see anybody else go through..." (Emma)*

## Advocacy Actions

Mothers in our study engaged in a wide variety of actions in spreading their messages about substance use and overdose including **use of social media and news media**; informal **discussions in their communities**; formal **community presentations** and **meetings with or writing letters to politicians**.

**Social media** was a tool used extensively by those who chose to advocate publicly. Working in partnership with the **news media** was deemed to be essential in getting their message out to the public, with the aim of also reaching policymakers. Speaking to media was described as a springboard for invitations to speak and to other advocacy opportunities.

*“And it really wasn’t until I went to the media that I – I got the health minister to sit down with me because he knew he was going to meet me at a press [conference]” (Sophie)*

*“There are some people in the media who’ve just been amazing in their support. They tell our stories over and over, and give us a voice...” (Hope)*

But engaging with media was not all positive - some participants expressed concern about the use of stigmatizing language in the media, and that posts and comments on articles they appeared in could be extremely negative and hurtful.

## What types of activities were participants engaged in?

- Discussions with family and friends
- Community presentations & education
- Providing mutual support
- Engaging on social media
- Sharing photos of their child
- Being interviewed by news media
- Writing letters and op-eds to media
- Attending a rally
- Meeting with or writing to politicians
- Meeting with community stakeholders
- Meeting and writing to bureaucrats, health professionals, professional organizations
- Creating posters, shirts and stickers
- Appearing in videos produced by government
- Consultation to government, NGOs
- Working in harm reduction and supporting people who use drugs
- Fundraising for foundations addressing substance use
- Attending conferences and meetings
- Participating in research projects
- Writing a book
- Connecting with other advocacy groups
- Leading petitions
- Presenting to government hearings and meetings

## What were some of the main advocacy messages and priorities?

- Challenging Stigma
- It could be “anyone’s child”
- Sharing the story of their child and their love for their child
- Greater awareness about substance use
- Prioritizing the family experience and impact on the family
- Compassion, kindness and empathy for PWUD
- Drug law reform
- Harm reduction advocacy
- Health care and substance use treatment reforms
- Supporting families dealing with substance use and mental health
- Understanding the social determinants of substance use beyond addiction

Mothers also advocated and connected through informal **discussions with family, friends and members of the community** and by providing mutual support to one another online and in person. Formal **community presentations** included giving talks to students and schools, university groups, community events (i.e. International Overdose Awareness Day), their workplaces, and at public forums, rallies, professional conferences, and to various levels of government.

*“... I talk to people in parking lots, or getting my car repaired, I talk to young men ... my biggest thing is that young men between the ages of 20 and 30 often don't want to talk to Mom type figures, you know? ... But I make a point of getting in their face ... I talked to a young man at ... the hardware store who was loading insulation into my car, and he... said he has saved several people's lives in his own social circle with naloxone”. (Ava)*

Advocacy strategies also targeted elected officials from various levels of government, through letter writing campaigns. However, several people we interviewed recognized that some of the most important discussions were the face-to-face **meetings with politicians**. Some of the participant we interviewed had had opportunities to meet with mayors, Premiers, federal and provincial health ministers, the Canadian Senate and Prime Minister.

### Advocacy Messages

We wanted to know what mothers were advocating for: what their key messages or ‘asks’ were in their advocacy. There were nearly as many different types of messages as there were mothers interviewed. Those mentioned most often were around **anti-stigma; health care and substance use treatment reform; drug law reform; harm reduction services; and wanting to share stories about their child and the love they have for their child**.

Mothers targeted their messages towards many different people but the most prominent message centered around challenging the prevailing **stigma** around substance use - the blame and the shame that is so pervasive and expressed by members of the public, the media and in the justice and health care system. Many of the participants commented that they often tried to convey that “this could be anyone’s child”. While mothers often shared that they began confronting stigma when their child was alive, some addressed it for the first time after the death of their child.



*“... the message that we try and project is just that... addiction isn't a moral failing... it isn't because they were bad people, it isn't because they were lazy ... just to educate people on addiction, and by doing so, reducing the stigma, and by reducing the stigma, having the legislatures and the politicians ... understand that they need to have the courage.” (Olivia)*

We heard numerous stories of how the **health care system** and **justice system** had failed their children – as a result, many mothers had a lot to say about the need for health care reform access to services and treatment.

*“I just needed to let everybody know how beautiful my son was and that ... he didn't deserve this ending, and I knew that our province did not have adequate services and resources and treatment. I don't think they had any frankly.” (Mandy)*

The need for greater access to **harm reduction services** was conveyed by many of the mothers we spoke to, as a number were directly involved in bringing about policy changes such as establishing supervised consumption sites and expanding community access to naloxone. Mothers also took enormous pride in **sharing stories about their child** – in other words, they did not only describe their child's struggles with substance use to others but also what their child was like when they were still alive - their personal interests, what their child valued and how much they are loved by family and friends.

*“I want them to know that it can happen to anyone, that these kids are loved and they're special... and they try really hard.” (Rose)*



Images courtesy of Moms Stop the Harm

## Community Impact

Most of those we spoke to felt that their advocacy efforts had made some impact in their community. **Ending the silence and opening conversations** about substance use was seen by almost everyone as being significant:

*“... when I saw how that impacted people, and I saw that it helps people feel that they are part of a community, that they're not isolated, that they're not on their own with these challenges as parents, I really saw the value of telling one's story.” (Alison)*

Impact was also seen through raising **increased awareness and understanding of substance use** – many spoke about receiving positive comments and words of encouragement and that others have learned from them. Mothers, however, also spoke of instances where they experienced **negative community responses** (e.g. hurtful comments in the media). While many said that they felt **politicians were listening** and saw signs that changes to the system were underway, there was also frustration that progress was too slow and that not enough resources were being put forward to address drug use and overdose. Overall, participants were positive about using their experiences to **reform policies** and to change how the health care system treats people using substances.

*“... naloxone and the Good Samaritan Act and Suboxone. First responders carrying Naloxone now... So those changes happened because we spoke ... I'm absolutely positive we made those changes as a group of mums.” (Mandy)*

## Personal Impact

Nearly all participants described their advocacy as a double-edged sword in that speaking out came with a personal benefit but also with a cost. While they found advocacy to be **emotionally difficult, painful, or tiring**, advocacy also **contributed to healing** for nearly everyone, through a variety of ways: from a sense of helping others, having an opportunity to speak their child's name and share their story, providing mutual support, and the sense of 'turning something negative into something positive'.



Photo courtesy of Moms Stop the Harm



*“I think that its’ kind of flip sides of the coin... on one hand, the advocacy can be cathartic and healing ... and then I think on the other side, ... it’s the right thing to do, but it just hurts. You know, it’s just painful.”*  
(Norma)

Mothers described how advocacy brought with it a **connection** with other advocating mothers and members of the community. Nearly half of mothers spoke about how advocacy contributed to enhancing their feelings of connectedness with their child who had passed away.

Most participants described feeling **empowered** through their advocacy through: experiencing personal learning or growth, feelings of strength, resilience, confidence; a feeling that one is ‘making a difference’; a sense of meaning or purpose; personal pride; taking comfort or freedom from being open about their family story, and also hope.

*“...I’m learning a lot about myself, what I’m capable of and where I’m strong and where I need to change and what I need to improve. So, it’s meaningful in that way.”*  
(Alison)

### Opportunities or Facilitators of Advocacy

The opportunity to engage in advocacy was influenced by several factors. **Personal facilitators** were described by nearly every person we spoke to. Those mentioned most often included: personal traits that lend themselves to advocacy (e.g. strength, passion, honesty), support from others, advocacy skills (e.g. communication skills), timing or ‘readiness’ to engage, having a history of being involved with advocacy, and advocacy as tied to motherhood (e.g. the role of a mother in fighting for their child).

*“I think it’s going to be hard for us to be ignored, because I really don’t think that there’s anything much stronger in the world than the force of mums with a cause. I don’t mean that as a – we’re so almighty or anything. We’re very tenacious. We don’t give up, and our voices, we get louder instead of quieter.”* (Ingvild)

In terms of the **advocacy groups** they were affiliated with, many participants spoke of the importance of respecting the skills and roles of all members. Ensuring that advocacy was informed by research evidence was mentioned by participants as was the importance of approaching a wide variety of issues (‘scattergun approach’) rather than just working on one at a time. Interviewees also shared that their advocacy groups also benefited from being ‘grassroots’ and community-based, and that this created a context where taking the time to grieve and honour the children who have died was a priority, in addition to organizing and speaking out.



Photo courtesy of Moms Stop the Harm



Photo courtesy of mumsDU



Photo courtesy of mumsDU

Finally, advocacy facilitated by outside **structural or societal forces** as well, such as shifting political contexts and whether the intended targets of advocacy were open to hearing about the solutions and drug policy reforms parents were advocating for.

*“So, it’s those baby steps into earning enough credibility, and then staying constant with the research and with the information as it comes out through the media that you can take your story and . . . depending on the political environment . . . you marry them with your message so that you can deliver what they’re ready to hear.” (Grace)*

### Challenges or Barriers to Engaging in Advocacy

Mothers we interviewed spoke of several issues that made it more difficult to advocate. Within an **advocacy organization**, personal tensions or differences of opinion within the group were at times challenging. As well, advocacy can be more difficult for people who live in places where groups are smaller (e.g. rural locations) or where there are fewer supports and services. Participants told us that even though **media** coverage of their advocacy was helpful, sometimes working with media was a challenge due to stress and other issues related to working with journalists. In pursuing advocacy, participants also encountered **stakeholders who were resistant or opposed** to their messages about substance use stigma and the need for reforms to drug policies. One participant described the challenges they encountered when they wanted to speak about substance use at a local school:

*“... it drives me crazy; the school districts here don’t believe there’s a problem. So, I’ve caused a few enemies that way because I’ve gone on the radio ... and I’m, like, get your heads out of your ass.” (Nancy)*

**Individual-level barriers** to advocating were raised by almost everyone we interviewed. Participants spoke about how difficult advocacy was due to **stress, grief, fatigue**, and the **emotional labour** involved, as well as the considerable time required, that can detract from work, family and other commitments. More than half of participants expressed that **encountering stigma** when sharing their story was a barrier to advocacy. There were



also participants who felt they lacked some of the skills required to advocate effectively, and some expressed **frustration** with the slow pace of change.

Because of these challenges, there were some participants who were hesitant about being ‘bigger’ in their advocacy, worried about how they would be received by the public and the community, but also by friends and family who might not be supportive. Sometimes mothers were strategic about how and where they shared their story, out of respect for their partner or other children who were reluctant to be public about their family’s story. Others wanted to be more engaged with advocacy but felt they could not. For example, for those who had more than one child who used substances or who was in recovery, there was a need to protect their privacy while sharing the story of their sibling’s drug use and overdose death.

### Media Advocacy Strategies

The majority of mothers we spoke to had some experience interacting directly with the news media with most of these participants stating that they felt that news media accurately represented their story. Over half of the women we spoke to believed that engaging with the news media served as an **important tool** in advocacy work primarily because it allowed them to share their message with a wide audience, potentially influence politicians as well as stimulate conversations and decrease stigma around substance use. The main reasons for not engaging with the media included the **emotional stress** and discomfort that may be involved as well as a feeling of uncertainty about how to best convey the messages to media. A number of mothers commented on the potential difficulties of engaging with media, including the risks of working with journalists who might not portray their story the way they wanted it told (e.g. sensationalizing the story, insensitivity) and the public’s reaction (e.g. negative comments on media stories and on social media). A list of strategies for engaging with the media are shown here.

### WHAT SHOULD FUTURE STUDIES CONSIDER? (STUDY LIMITATIONS)

Our study does have some important limitations. While we were successful in including families from across various regions across Canada, both urban and rural, the people who came forward to be interviewed were primarily women who were white and had some degree of ‘middle-class’ social privilege. Future studies are required to understand the experiences of a range of mothers and families, especially how the social inequity that can be associated with income,

## News Media Strategies

- Reach out to the media outlets directly
- Be strategic in media work
- Focus on one issue per interview
- Prepare talking points ahead of time
- Clear messaging on policy or practice solutions
- Learn to ‘pivot’ back to your message when necessary during the interview
- Negotiate ground rules with journalists in advance
- Educate journalists
- Take the opportunity if it is presented to review the article before it goes to publication
- Hold media accountable for their mistakes
- Take measures to ensure privacy (from members of the public)
- Interview with another advocate (joint interview for support)

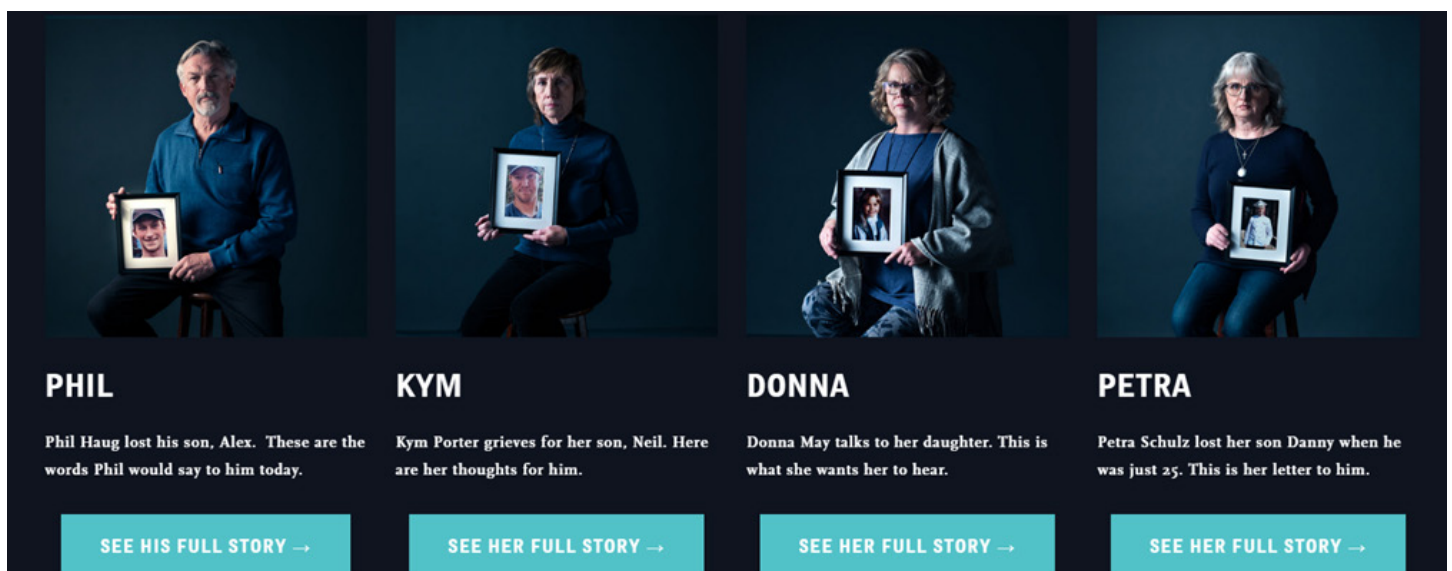
racialization, gender identity and sexuality compounds stigma and can shape how someone who experiences the loss of a child from substance use is able to (or not able to) advocate and to have their voices heard. Particularly needed is research on overdose deaths that is driven by Indigenous families and communities. Meaningful, equitable partnerships with non-Indigenous parent advocacy groups might hold potential to facilitate this. Future studies need to also explore the role of fathers and siblings in advocacy work as many are active 'behind the scenes' in supporting the advocacy work of our parent partners.





Another potential research limitation was that the advocacy groups we partnered with for this study are explicit about their support for harm reduction and drug policy reforms such as drug decriminalization. Although not everyone we interviewed voiced unequivocal support for harm reduction, we recognize that there are other parent advocates who propose much different solutions and supports, and there are some parent groups who express opposition to the solutions the advocates we spoke to endorse.

## HOW HAVE WE SHARED OUR FINDINGS? (KNOWLEDGE TRANSLATION)

In 2018, our team was awarded a \$60,000 Government of Alberta, Ministry of Health: Opioid Response Public Awareness Grant to Communities to produce a series of four, short digital videos that share messages and stories under the theme, 'What families want you to know about opioids, stigma and harm reduction'. This film series was made in partnership with four parents: Kym Porter, Donna May and Petra Schulz, each of whom has a child whose death was attributable to substance use; and Phil Haug, whose son's death was related to suicide and substance use. Each of the parents speak about their emotions related to this loss, what they have learned from it, the stigma they have experienced, and what needs to change to support people who use drugs. The videos end with our 'calls to action' for scaling up harm reduction efforts to provide a safe drug supply and to end the silence and shame that prevents people from speaking out and getting help.

Launched online in March 2019, promoted ads and posts for the #SeeTheLives videos and website have had 160,500 views on YouTube and 8300 engagements on Twitter. The website has had almost 16,000 unique visitors and 25,000 page views to date. As well, over 70 people completed an anonymous online survey



 <p><b>PHIL</b></p> <p>Phil Haug lost his son, Alex. These are the words Phil would say to him today.</p> <p><a href="#">SEE HIS FULL STORY →</a></p>	 <p><b>KYM</b></p> <p>Kym Porter grieves for her son, Neil. Here are her thoughts for him.</p> <p><a href="#">SEE HER FULL STORY →</a></p>	 <p><b>DONNA</b></p> <p>Donna May talks to her daughter. This is what she wants her to hear.</p> <p><a href="#">SEE HER FULL STORY →</a></p>	 <p><b>PETRA</b></p> <p>Petra Schulz lost her son Danny when he was just 25. This is her letter to him.</p> <p><a href="#">SEE HER FULL STORY →</a></p>
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*Photo courtesy of see-beyond.ca.*



providing feedback on the videos; 93% said viewing the videos had an emotional impact for them and 73% would recommend them to a friend or colleague. The project has been replicated in the UK (“See The Lives: Scotland”) and the videos are currently being used in Alberta Health Services Provincial Primary Health Care, for an education unit on harm reduction. The videos have also had significant uptake nationally in Canada: they were selected by Health Canada for screening at their anti-stigma display at the Commission on Narcotic Drugs (United Nations Office on Drugs and Crime) meeting held in Vienna, Austria in March, 2019. They were also shown at the Harm Reduction International conference in Porto, Portugal in April 2019. Most importantly, the parents and partnering organizations have taken the videos to numerous conference and community presentations, providing them with a powerful tool for disseminating evidence about how death related to substance use impacts families and what needs to change.

Here is a selection of other ways that we have shared our study findings:

## Presentations

Morris, H., Haines-Saah, R., Schulz, P., May, D., Jenkins, E., & Hyhska, E. (April 29, 2019). The personal impact of mother’s advocacy work in drug policy reform. Poster presented at Harm Reduction International Conference, Porto, Portugal.

Morris, H., Porter, K., Schulz, P., Jenkins, E., Hyhska, E. & Haines-Saah, R. (Sept. 26, 2019). Engaging with bereaved parent advocates as partners in substance use research and drug policy reform. Invited presentation to Knowledge Translation Meeting on the Effects of Addiction on Families, College of Nursing, University of Saskatchewan, Prince Albert, Sask.

Thomas, L., Haug, P., Morris, H., Schulz, P., Hyshka, E., Jenkins, E. & Haines-Saah, R. (Oct. 16, 2019). Suicide, substance use deaths and stigma: Call for a unified approach to prevention. Oral presentation at Canadian Association for Suicide Prevention National Conference, Edmonton, AB.

Haines-Saah RJ, Hyshka E, Jenkins EK, May D, Morris H, Schulz P (2018, October 04). What can mothers’ stories do? Storytelling, lived experience, and advocacy for drug policy change. *Stimulus – Drugs, Policy and Practice*. Edmonton, AB.

Haines-Saah RJ, Hyshka E, Jenkins EK, May D, Morris H, Schulz P (2018, May 17). Engaging families and parent advocates in research on substance use and drug policy reform. *The International Society for the Study of Drug Policy, 12th Annual Conference*. Vancouver, BC.

Schulz, P., Morris, H., Haines-Saah, R., Jenkins, E., May, D. & Hyshka, E. (Feb.12, 2018). Working towards a family-centered approach to addressing substance use. *13th Covenant Health Research Day*. Edmonton, AB.

Hyshka E, Morris H, Jenkins EK, Haines-Saah RJ. (2017, November 15). Building a family-centered approach to addressing substance use. *Issues of Substance: Addiction Matters*. The Canadian Centre on Substance Use and Addiction, Calgary, AB.

## Papers

Jenkins E, Slemon A, Morris H, Hyshka E, Schulz P, Haines-Saah R (Accepted for publication, October 2020). Bereaved mothers' engagement in drug policy reform: A multisite qualitative analysis. *International Journal of Drug Policy*.

Morris, H., Hyshka, E., Schulz, P., Jenkins, E. & Haines-Saah, R. (June 2020). 'It's a bit of a double edged sword': How mothers are impacted by their advocacy for drug policy reform. Manuscript under development and to be submitted for publication fall/winter 2020/21.

Morris, H., Haines-Saah, R., Jenkins, E., Schulz, P. & Hyshka, E. (June 2020). The experience of engaging with the news media: Perspectives of bereaved mothers advocating for drug policy reform. Manuscript under development and to be submitted for publication fall/winter 2020/21.

## Podcast

[Crackdown Episode 4: "Blame" \(featured interviews with Petra Schulz & Rebecca Haines-Saah\)](#)

CRACKDOWN is a monthly podcast from Executive Producer Garth Mullins about drugs, drug policy and the drug war led by drug user activists and supported by research.

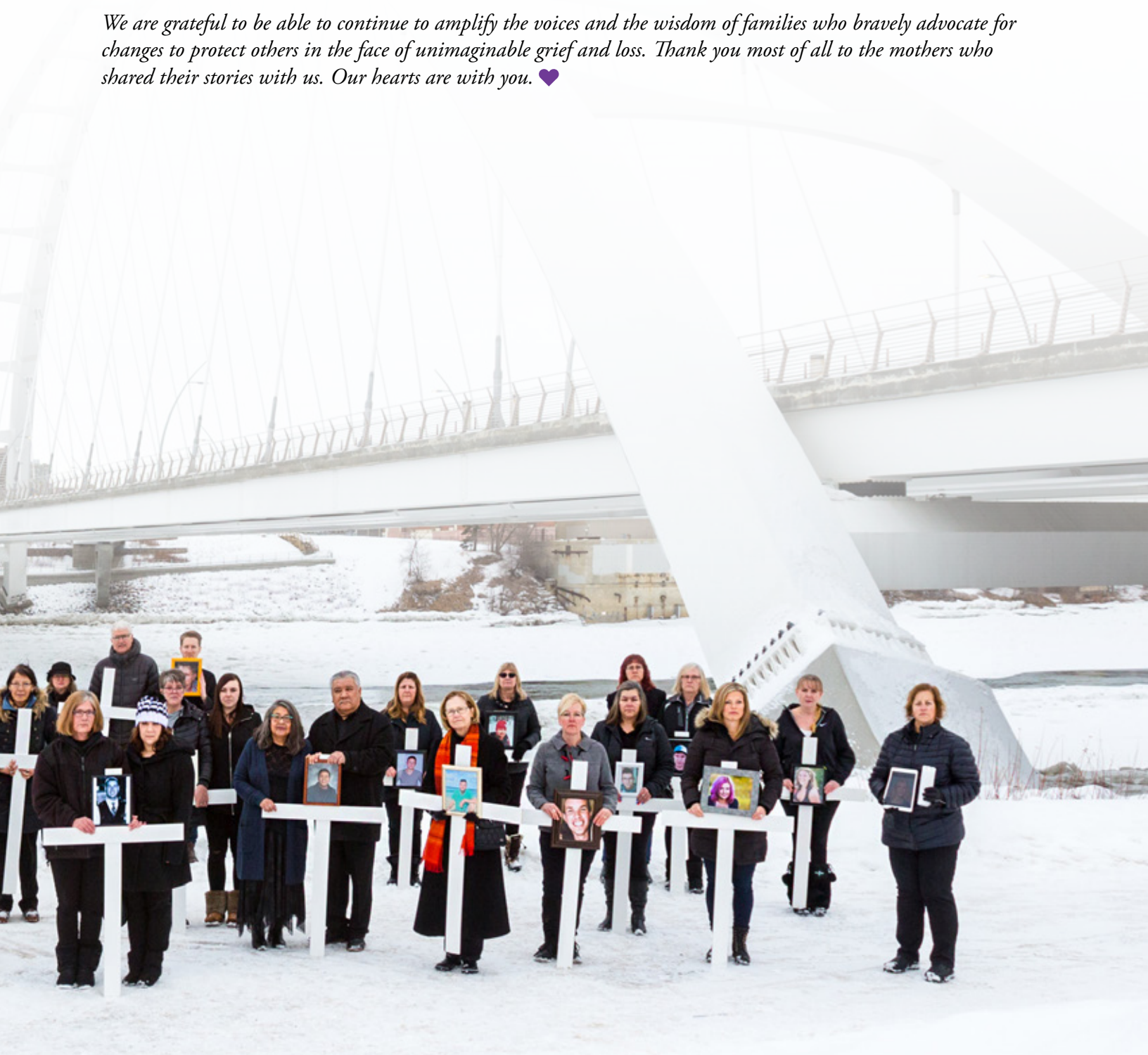




## WHAT'S NEXT?

To our knowledge, this is the first research project in Canada to address the experiences of bereaved mothers advocating for drug policy reform. We continue to analyze, write-up and share these findings in both academic and community settings. It continues to be a priority that every paper or presentation from this project is a collaborative effort between parent advocates and researchers. Our current plan is to submit a Canadian Institutes of Health Research (CIHR) Meeting Grant in an upcoming competition, to secure funds to bring together parents and researchers to map out the next steps in this emerging research program.

*We are grateful to be able to continue to amplify the voices and the wisdom of families who bravely advocate for changes to protect others in the face of unimaginable grief and loss. Thank you most of all to the mothers who shared their stories with us. Our hearts are with you. ♥*

























































For more information about this project, please contact:

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*“I think it’s going to be hard for us to be ignored, because I really don’t think that there’s anything much stronger in the world than the force of mums with a cause. I don’t mean that as a – we’re so almighty or anything. We’re very tenacious. We don’t give up, and our voices, we get louder instead of quieter.” (Project Participant)*