

Strategic Planning: 2020-2023
Family Consultations

This report presents a summary of the family consultations conducted as part of the process of developing the 2020-2023 Strategic Plan for the Pregnancy and Infant Loss (PAIL) Network in 2019. The consultations were conducted between April to November 2019 via a series of in-person, telephone, and online survey formats to hear first-hand from families who had experienced pregnancy and infant loss in Ontario.

Each focus group started with a short overview of PAIL Network, including its history and the provincial mandate to expand services for families and education for professionals across Ontario. We also shared a brief update on initiatives and work that had been completed since the creation of our first strategic plan in 2017.

In each of the consultations, participants were asked questions in the following three areas:

1. Family support
2. Healthcare Provider Education
3. Awareness and Advocacy

Participants were asked the following questions:

1. What can PAIL Network do more to support families?
2. Where can PAIL Network do more to raise awareness about pregnancy and infant loss and advocate for better care and understanding of their experiences?
3. Is there anything you want to mention or advice you have for PAIL Network that we haven't covered today?

Consultation Locations:

In person focus groups were held in 3 communities across Ontario in April and September 2019, namely Thunder Bay, Ottawa, and Toronto (participants invited from across the GTA). One telephone consultation was conducted in November 2019 and two online surveys were opened and shared via email and social media in January 2020.

Consultation Participants:

A wide variety of participants attended the focus groups. The families we engaged with had experienced a wide range of loss experiences including first, second, and third trimester loss in addition to medical termination, stillbirth, and death of an infant up to a year old. The losses occurred in a wide range of settings including hospital (Emergency Department and/or Labour and Delivery), doctor's office, and at home.

Summary:

Families discussed how they felt about current and past PAIL Network services and where more work needed to be done in the three areas of family support, healthcare provider education, and awareness and advocacy.

What Families Told Us About Family Support:

- Families were quick to note the rapid response provided by PAIL Network and the support they received throughout the entirety of their bereavement process for example, one family reported they heard back from PAIL within 10mins of seeking support
- Parents would like the opportunity to have pictures taken of their babies at the hospital, some noted they were able to get keepsakes like lock of hair, blanket, memory stones from some hospitals
- Increase online support in many forms – chat lines, PAIL Network online resources and other bereavement organizations – used by many families as a source of information and support
- Families would like the ability to text and/or call someone at unscheduled times to manage grief. Video conferencing could be another avenue for group therapy where vocal participation is not required – video on/muted
- Some families noted phone support should be longer and more frequent
- Families would like more one to one support that is more personalized to each individual seeking support
- More resources needed aimed at family and friends about how to support loved ones at time of loss and care thereafter
- Retreat/conferences for families
- Possibility for spouses/partners to have someone to speak to or text, since their experience may differ {example: male focused groups}
- More resources that target different types of communities like LGBTQIA2S+ and specific losses in more accessible locations
- Connection to mental health services would be beneficial
- Support integration back to routine and defining a new normal
- Set parameters that overcome language barriers and differing cultures

What Families Told Us About Healthcare Provider Support:

- Families would like to be treated with similar empathy and respect from healthcare providers (HCP) as other families who have had live births
- 79% of families in our surveys indicated they would like HCP to communicate with compassion while 71% noted HCP needed more education on specific types of loss (eg. Miscarriage, stillbirth, first trimester loss, etc)
- Offering workshops and webinars in as many different mediums as possible to attract higher attendance at these workshops
- Families would like more resources spent towards emergency and family physician education regarding early pregnancy loss
- Incorporate education and assistance managing loss for private clinics like fertility clinics, ultrasound labs/technicians, funeral parlors, paramedics etc.
- Families would like to see education being provided that goes just HCP training. They would like to see a restructuring of organizations that provides clear/concise standardized care plan around pregnancy and infant loss

- Ability for hospitals to provide access to mental health professionals as soon as possible
- Ensure entire delivery team, including OB/GYN, trained to manage negative outcomes as to provide more compassionate care
- More education for emergency first responders when they attend calls so families are treated with dignity and respect during a difficult time
- Families would like to see improved communication among different HCPs involved in their care so as to avoid burden on families of having to explain their situation multiple times
- Families would like to see more research and stats collected for various types of losses
- More training for medical students and residents – families suggested opportunities for HCP to hear feedback and experiences of families who have experience pregnancy and infant loss

What Families Told Us About Awareness and Advocacy:

- Need to break the silence on pregnancy and infant loss, reach out to different programs offered by province like EarlyOn Centres, prenatal classes etc.
- Families would like focus to be on hospitals so they have the necessary resources to help those who are grieving – attaching credits to workshops, making bereavement training a part of hiring process etc.
- Branding that stands out year-round– making decals for windows and cars
- Adding Mother’s Day/Father’s Day events to other existing commemorative events
- Businesses and franchises need to be educated on what to do when a mother who has experienced loss tries to return items to the store
- Media outreach via interviews, commercials, influential persons would allow for more awareness within the community

We Asked Families What PAIL Network Should Prioritize:

- Create more opportunities for families to come together in a virtual space to celebrate their lost babies and share experiences with others who understand
- Recognize and tailor support to many different types of families, not only the “nuclear” father/mother family model
- Offer groups that will be child-friendly for those families who have children around
- Education for providers about culturally appropriate care of Indigenous families in collaboration with Indigenous care providers and community leaders
- Provide peer support, online support, and written materials to support fathers, partners, siblings, and extended family members
- Advocate for standards of care/improved care in radiology and diagnostic imaging and improve skills training in compassionate care for families experiencing a loss or subsequent pregnancy.
- Continue to “normalize” pregnancy and infant loss by increasing public awareness and addressing the stigma that families face.
- Create a 24-hour telephone helpline for families who have experienced a loss to provide immediate support when needed.

Guided by the family consultations in this strategic plan, PAIL Network will align our mission to meet the goals outlined above in order to support families who have experienced pregnancy and infant loss. We will clearly identify priorities and strive to cultivate a virtual platform that offers integrative initiatives to further our organizational mandate. We will also commit to utilizing resources effectively and efficiently, thereby optimizing performance and achieving the goals set in this plan.

This plan will serve as a guide for the next three years with yearly review as we endeavor to support the success of our strategic vision by providing a more comprehensive substructure for families and healthcare practitioners while raising awareness about pregnancy and infant loss.