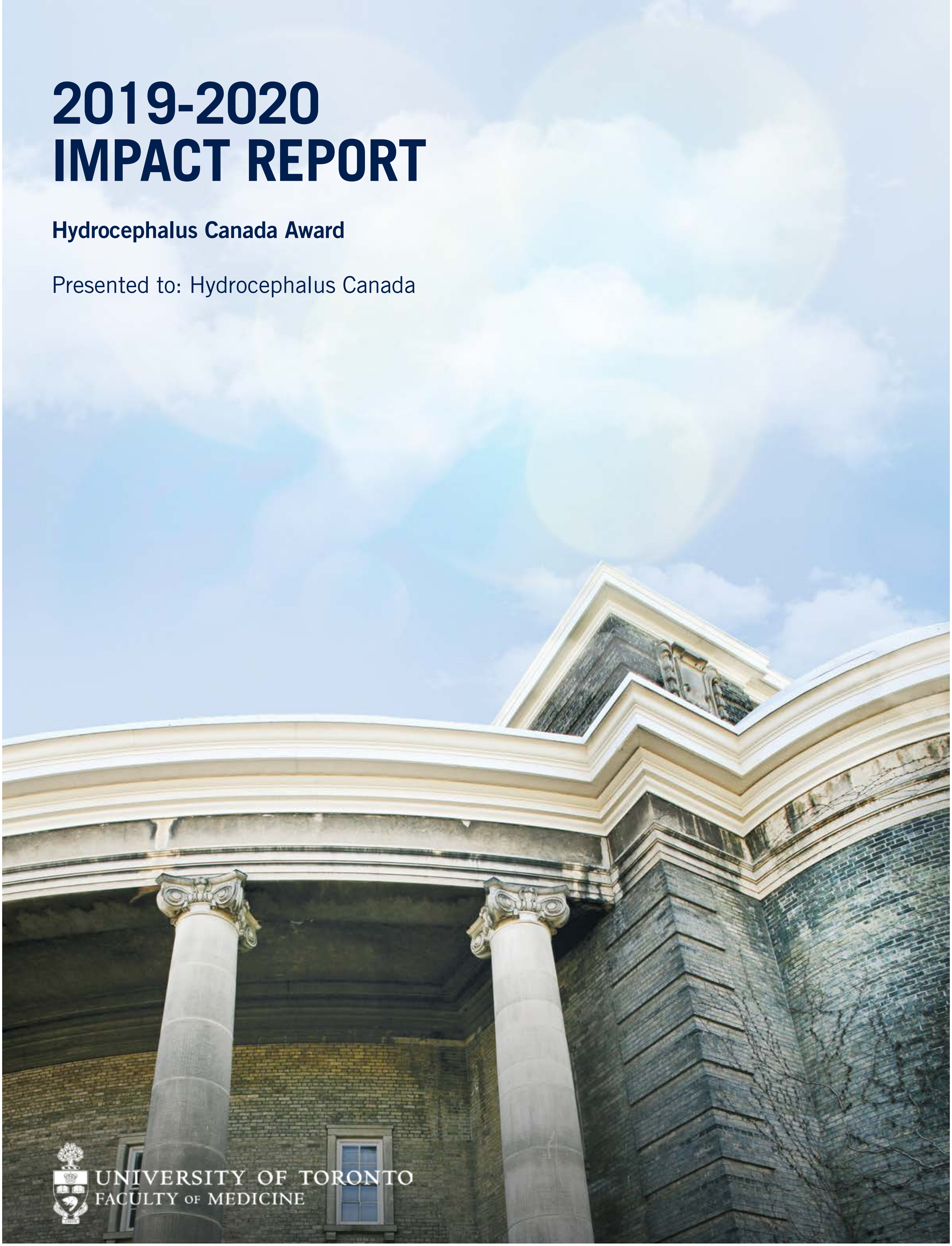
2019-2020
IMPACT REPORT

Hydrocephalus Canada Award

Presented to: Hydrocephalus Canada



UNIVERSITY OF TORONTO
FACULTY OF MEDICINE

HYDROCEPHALUS CANADA AWARD

AT THE FACULTY OF MEDICINE

ASIA VAN BUUREN

MD Candidate, Year 3

Faculty of Medicine,
University of Toronto

Thank you for your generous gift to the Faculty of Medicine. Your donation facilitated the opportunity for me to participate in research this past summer as an undergraduate medical student. This experience has had a significant impact on my medical education and will continue to influence my career moving forward.

I am originally from Vancouver, BC and moved to Nova Scotia after high school to pursue an undergraduate degree in chemistry. After completing my Bachelor of Science, I worked in the non-profit sector for two years with adults with intellectual disabilities. During that time, I became passionate about equitable health care for people with disabilities and hoped that I would be able to continue to contribute to this work as a medical student.

During my second year of medical school, I had the privilege of meeting Dr. Anne Berndl. She is an obstetrician-gynecologist who leads the Accessible Care Clinic at Sunnybrook – a pregnancy clinic designed specifically to be accessible to women with a variety of disabilities. Your funding allowed me to join her research team. The purpose of my project was to use qualitative methodology to understand the reproductive health experiences of women with spina bifida.

After receiving training from Dr. Berndl's incredible team, I had the immense privilege of interviewing women with spina bifida from around the world regarding their reproductive health care experiences. The interviews felt like the most important scholarly work I have engaged in. It was incredibly meaningful allowing women to tell their stories. They were able to share what they wish other women, their health care teams, and the world knew about the reproductive health needs of women with spina bifida. Some of the interviews were emotionally challenging, but it was a true privilege to be a part of this work and collect these narratives from participants.

Afterwards, I completed the data analysis and we are now in the process of sharing our work. Thus far, we have been accepted to three conferences including the Society for Maternal Fetal Medicine's Annual Meeting. We are also working on two manuscripts through which we hope to share our findings more broadly.

I cannot thank you enough for allowing me the opportunity to participate in this work. I now have tangible qualitative research skills that I hope to continue to build on throughout my medical career. I also have a mentor in Dr. Berndl who is an incredible disability advocate and an expert in her field. Before starting my medical degree, I never could have dreamed that research of this nature was happening, let alone think that I would have the opportunity to participate.

Thank you again for your helping make this possible through your generous donation!

Sincerely.

Asia van Buuren

CREMS Summer Program 2019

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REPRODUCTIVE HEALTH, SEXUAL HEALTH, AND PREGNANCY EXPERIENCES OF WOMEN WITH SPINA BIFIDA: A QUALITATIVE STUDY

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BACKGROUND: Despite an increasing number of women with spina bifida reaching reproductive age, there has been a paucity of research into their unique reproductive health care needs.

OBJECTIVE: The primary objective of this study was to begin to understand the sexual and reproductive health experiences of women with spina bifida.

METHODS: A phenomenological study was used to address our objective. Women with spina bifida identified their interest in participating in a semi-structured interview after completing an online reproductive health survey. Open ended questions surrounding sexual education, reproductive health, and pregnancy experiences were recorded and transcribed verbatim. Qualitative analysis of the transcripts was conducted using a phenomenological approach. Transcripts were coded in Dedoose software.

RESULTS: Twelve women with spina bifida participated in our study. Several themes emerged. Lack of information and inadequate education surrounding both sexual health and pregnancy was described by participants, causing women to seek out information online and through other women with spina bifida. Pregnancy often acted as a catalyst to seek out information; however, women described being disappointed by the lack thereof. Support in pregnancy from health care providers was mixed in terms of positive and negative experiences. A number of participants describe being encouraged to have an abortion when revealing a pregnancy. All participants mentioned the need for self-advocacy in shaping their reproductive health experiences.

CONCLUSION: This is the first known study to use a phenomenological approach to understand the sexual health, reproductive health, and pregnancy experiences of women with spina bifida. Women with spina bifida face reproductive health challenges such as discriminatory attitudes and a lack of information. Further research is needed in order to address knowledge gaps.