UNIVERSITY OF BRITISH COLUMBIA

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|  | Consent Form UBC Faculty of Medicine317-2194 Health Sciences Mall, Vancouver, BC V6T 1Z3 |
| **A Community-University Partnership to Improve Health Outcomes of Families and Caregivers of Children and Youth Impacted by Self Injurious Behaviours (SIB)** |

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| **Study Team:****Principal Investigator:** Dr. Anamaria Richardson, Department of Pediatrics, Faculty of Medicine, University of British Columbia. Ph: 604-423-4803; email: Anamaria.richardson@cw.bc.ca **Co-Investigator(s):** Dr. Robin Friedlander, Department of Psychiatry, Faculty of Medicine, University of British Columbia. Email: rfriedlander@cw.bc.ca Dr. Suzanne Lewis, Department of Medical Genetics, Faculty of Medicine, University of British Columbia. Email: Suzanne.lewis@ubc.ca Erika Ono, School of Social Work, Faculty of Arts, University of British Columbia. Email: erikaono@alumni.ubc.ca**Research Assistant(s):** Rachel Horng, Undergraduate Student, University of British Columbia Natalie Cavallin, Faculty of Medicine, University of British ColumbiaAlison Fong, Faculty of Medicine, University of British ColumbiaAmanda Percival, Faculty of Medicine, University of British ColumbiaChiara Piccolo, Faculty of Medicine, University of British ColumbiaDanielle Pietramala, Undergraduate Student, University of British ColumbiaMatthew Tester, Faculty of Medicine, University of British ColumbiaVanessa Wong, Faculty of Medicine, University of British Columbia |

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| **Sponsor:**This project is funded by the University of British Columbia Community-University Engagement Support Fund (CUES).  |

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| **Purpose:**The purpose of this project is to better understand and foster community among caregivers of children and youth with self injurious behaviours (SIB) and intellectual impairment. We anticipate that this research will help support a SIB Community while increasing education and advocacy around SIB.  |

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| **About the Study:**1. ***Web-Based Sessions***

You will be invited to attend 6 monthly web-based sessions lasting 2 hours each. You are not required to attend each session. The sessions will be divided into a 1-hour information session, a 45-minute question and answer period (Q&A), and a 15-minute sharing period. You will be able to attend the information session on your own time as it will be recorded as a video. The Q&A and sharing period will take place the following week in real-time using the platform Zoom.1. ***Surveys***

In addition, you will be asked to complete an online survey both before and after each session. This survey will ask for information about your current knowledge of a SIB-related topic as well as the amount of support or resources you and your child receive. These surveys will be anonymous, and it will not be possible to know who you are based on your responses. All responses to the survey will be submitted electronically and stored confidentially.1. ***Program Evaluation***

This project includes a qualitative program evaluation, which will include observation during the web-based group sessions Q&A and sharing period. This provides descriptive information about questions and answers, interactions, processes, and outcomes. For a new web-based group for parents/caregivers of children with SIB, observation will provide more insight on what is beneficial for families. Research assistants will take notes during the sessions. No identifying information will be included in the notes.**Use of Zoom:**The Q&A and sharing period will occur in real-time over Zoom. If you are not comfortable using your real name, you may choose to use a nickname or a substitute name when logging in. In addition, you will not be required to turn on your camera and your microphone can be muted unless you choose to speak. If you feel uncomfortable speaking, you may also choose to use the chat function to ask questions or share your thoughts. **Potential Conflict of Interest:** The Principal Investigator (PI) and the Co-Investigators (Co-I) will moderate and answer questions during the real-time Zoom sessions. It is possible that the PI or the Co-I’s may be your child’s clinician; however, you may refuse to participate or to withdraw from this study at any time, and this will not impact the clinical care your child receives**Project Outcomes:**After each session, you will be provided with an infographic summarizing the content discussed in the session. These infographics will be made available online. Possible other research products include journal articles, books, or conference presentations. The results will also be used to improve future web-based support groups for parents/caregivers of children with SIB. After 5 years, the data will be destroyed.  |

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| **Potential Risks:** As the sessions and the surveys deal with topics that are sensitive or personal, it is possible that they may raise issues or feelings that you find uncomfortable. If these feelings arise during the sessions, you may choose to not participate at any time. For the survey, you may choose to not answer any questions if you do not want to. Survey responses will not be recorded if you do not submit. **Potential Benefits:** |
| This study may help you as you will be able to increase your education around severe SIB and you may be able to find resources and a supportive community through the discussion sessions.  |

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| **Confidentiality:**We encourage participants to be respectful of each other by not discussing the content of the sessions to people outside of the group; however, we have no control over what participants do with the information discussed. All survey results received will be anonymous and will be identifiable only by code number. Electronic copies of the survey will be kept on the local hard drives of team members’ computers – all of which are password protected. You will not be asked to share your name or the name of children you care for when you complete the survey. It will not be possible to identify any individual participant by name.  |

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| **Limits of Confidentiality:** At any point in the study, if the researcher becomes aware that there has been abuse and/or neglect of a child (or that there is a risk of such occurring in the future) please be advised that the researcher must, by law, report this information to the appropriate authorities.  |

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| **Compensation:**We will not be able to pay you for your participation in this study. However, we will reimburse you for the cost of childcare to attend the session, if needed.  |

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| **Contact for Information About the Study:** If you have any questions or desire further information with respect to this study, you may contact Rachel Horng (Email: rhorng@student.ubc.ca). If you prefer to contact us by phone, you may call Dr. Richardson’s office at 604-423-4803.  |

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| **Contact for Complaints:**  |
| If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598. The Ethics ID number for this study is H21-00774.**Participation Consent and Signature:**Your participation in this study is completely voluntary and you may refuse to participate at any time. If you have partially completed the surveys and decide to withdraw, you may do so as long as the data has not been submitted. However, once you confirm your submission of the survey, withdrawal of the data will not be possible. If you decide to withdraw from the study, there will be no negative impact on the clinical care your child receives.Your signature below indicates that you consent to participate in this study and that you have received a copy of this consent form for your own records. |

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