

THE UNIVERSITY OF BRITISH COLUMBIA



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Dear Parent,

I write to invite you and your child to take part in a study of cognitive and emotional development in children who may be at risk of mood disorder because of their family history. We wish to understand aspects of self-control, rule-learning, mental flexibility, memory and other cognitive (thinking) processes that might be different in children whose mothers have bipolar I disorder. Eventually this research may help us detect and intervene early with other children at similarly increased risk.



If you give your permission to participate, you and your child would visit our lab at the UBC, Vancouver, for the assessment sessions. All our cognitive tests are presented as games to play and fun problems to solve, either on the computer or with cards. Our games last between 5 and 15 minutes.

We will do our very best to make sure that your child understands how to play a game before we start. We never rush or criticize anyone. All children experience some success in our games, but your child may get bored during easy portions and may get a bit frus-

trated during difficult portions; that is perfectly normal. We will explain to your child that he or she should not be concerned about mistakes because we have constructed our games so that everyone makes some mistakes: it is from their mistakes that we learn. We try to keep each child engaged so that he or she performs well; most children enjoy the individual attention.

In addition to assessing cognitive (thinking) processes, we would like to measure your child's circadian rhythm (the 24-hour cycle of sleep and level of activity). Your child would wear an actiwatch, a wrist-worn motion-sensitive device, similar to a wrist-watch, for 7 days. The actiwatch would not cause significant interference with your child's daily functioning as it is light weight and water-resistant.

We will ask you questions about your own health history and your child's development so that we have a fuller understanding of the factors that might affect your child's performance on our tests and your child's future development. You and your child will be interviewed to look for symptoms of mood, anxiety and behavioral difficulties. Your child's father is also

invited to participate in the child's assessment, if you wish. We will also ask some questions about his medical history. Feedback will be given to you. If there are any concerns regarding your child, Dr Jane Garland who is a Child Psychiatrist will offer guidance regarding the provision of any necessary support.

In order to assess genes associated with cognitive and emotional functioning, we would like to take a sample of saliva from the inside of your child's cheek. Your child would simply wipe the inside of his or her mouth with a cotton swab. Your child is under no obligation to supply a genetic sample. The genes we wish to study are COMT, DRD4, NET, GABA, NR2E1, SLC6A4, MAO-A and BDNF. By studying these genes, we might be able to help explain why some children of parents with bipolar disorder develop difficulties with certain thought processes while others do not. We might be able to help explain why some children with difficulties in certain aspects of thinking develop mood disorders while others do not. No one outside our study staff can get access to any of this material or our results. Even if someone did it would be impossible for that person to know whom any data or tissue belonged. Confidentiality is strenuously guarded.

Our studies are conducted for research purposes only: there will not be any direct, immediate benefit to your child. After the entire study is finished, if you wish, we will send you a report of the study's general findings.

During the psychiatric assessment, both you and your child will be asked personal questions which may lead to some distress due to their personal nature. You and your child are free to decline to answer any question you would prefer not to answer. If at any time you or your child become unhappy during a session and you would rather not participate, we will discontinue immediately. No one will be asked to do anything he or she does not want to do. The participation of everyone in this study is completely voluntary.

We record our sessions on videotape in order to make sure that our staff administer the measures properly and in order to better understand why children at different ages respond as they do. Watching some children at each age teaches us much more than just looking at the computer records. Only those children whose parents give their permission, and who agree themselves, will be videotaped.

The study will be conducted on 2 separate days and may take up to a total of 7 hours. Your child's participation will be conducted on only the second of these days. You and your child may be invited to come back at yearly intervals for follow-up sessions until your child's 18th birthday, but of course you are free to decline this invitation if you wish.

All information will be kept confidential. Research records and videotapes are stored in locked cabinets and in password-protected computer files. All gene samples are kept frozen in a locked freezer. No names or other identifying information are kept with the videos, gene samples, or data files; only subject numbers appear there. No one except the researchers involved in this study will know the names of the subjects and they are the only ones to have access to keys and passwords.

In this study we do not want to include children who might have particular difficulties with the tests because of seeing or hearing problems, a serious head injury or other health problem, not understanding English well or a diagnosed learning disability. We will need to document any medication that might affect your child's ability to perform our tasks.

If you and your child wish to participate, or if you would just like more information, please contact Holly MacPherson by telephoning 604-827-3074 or by email at bipolar@devcogneuro.com.

We look forward to hearing from you!

Sincerely,



Prof. Adele Diamond

The title of this project is "Development of Cognitive Functions that depend on the Frontal Lobe in Children whose Mothers have Bipolar I Disorder" and it is funded by the UBC Department of Psychiatry, the Canadian Institute of Health Research and the Michael Smith Foundation for Health Research.

PLEASE KEEP THIS LETTER FOR YOUR RECORDS.

If any concerns occur to you now or later, please contact:

Principal Investigators:

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Prof. Allan H. Young at (604) 827-4287; allan.young@ubc.ca

Co-Investigator:

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Research Assistants:

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Annie Kuan at (604) 822-7784; anniek@interchange.ubc.ca

If you have any concerns now or later about you and/or your child's treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.