

November 20, 2014

Mach-Gaensslen Foundation of Canada 435 Piccadilly Avenue Ottawa, ON K1Y 0H5

RE: "Examining the effectiveness of an online parent psychoeducation intervention for the management of child and adolescent eating disorders"

Dear Representatives of the Mach-Gaensslen Foundation,

The Regional Eating Disorder Program at the Children's Hospital of Eastern Ontario is pleased to provide a brief update on our progress to date of this research project. Thanks to your generous support, we have been able to accomplish the following tasks since our last update in October 2013:

- We developed a research protocol and obtained consent from the CHEO Research Ethics Board (REB) to conduct the current research study. We also developed and modified numerous questionnaires to be administered on our website using an online survey software known as FluidSurveys. These questionnaires will help us to determine how effective the website is at providing knowledge about eating disorders and support to parents and also will provide feedback on any changes we can make to improve the website.
- We contracted a web-development company, Creatrix, to develop our national eating disorders website, www.canped.ca, to support parents of a child with an eating disorder. We created all of the content for the website, which consists of 6 'learning modules' plus a list of helpful resources for parents, and a glossary. The 6 learning modules are: 1) What is an eating disorder?, 2) Medical complications of eating disorders, 3) Understanding eating disorders, 4) Essential Components of Treatment (supporting your child; therapy; and medications), 5) Clinical Pearls: Tips on how to support your child to recovery, and 6) a video showing parents how to support their child at meal times. Creatrix then helped us to design these presentations, 4 of which are animated, voiced-over powerpoint-type slides which range in length from 1 to 10 minutes.
- We also contracted CHEO's Media House to develop the fifth module, a supportive video featuring knowledgeable professionals providing supportive counselling to parents on how to best help a youth with an eating disorder. There is also a separate video on how to support a child at mealtimes.
- We promoted the website at the Eating Disorder Association of Canada's biennial conference in October by distributing handouts at the event. Additionally, we contacted the mental health department at CHEO to mail our study handouts to community physicians so that they could distribute these to parents of children with eating disorder in their offices. We also sent our study handouts to all of the eating disorder programs across Ontario, using the listserve for the Ontario Community Outreach Program for Eating Disorders.
- On Dec.1, 2014, we will officially launch this national website for parents of a child with an eating disorder. While the main purpose of the website is to provide valuable information, support, and encouragement to parents of a child with an eating disorder, it has also been created as a research study in order to measure the effectiveness of providing parents with such knowledge. This

research will help clinicians to understand the effectiveness of partnering with parents and giving them a role to play in their childs' recovery, it will help us to determine what information is most helpful to parents and how to improve the website, and it will provide information to encourage other clinicians around the world to use online information to efficiently share information with parents who might otherwise not have easy access to specialists. While the website is now complete, we encountered a few technical 'glitches' during our trial run which had to be fixed, which is why we are waiting until Dec. 1st to officially open the trial and launch the website. We will then spend the next few months collecting the results of our online surveys, so results of the study are pending. However, you are welcome to visit the website at www.canped.ca.

• Throughout the project, we have hired students to help to work on the content of the website, the website design, and the research questionnaires. To date we have had 3 students working with us on the project: Meaghan (a University of Ottawa medical student), Danijela (a University of Ottawa psychology student), and Jessica (our student research assistant).

Thank you again for your generous support of this project that will improve the lives of children, youth, and families suffering from the devastating effects of eating disorders. Once we have completed our research on the usefulness of the website for parents, we can use this feedback to improve the website, and to encourage others to create websites to help families with other illnesses. We also look forward to making this valuable information available around the world to families with a child suffering from an eating disorder, in order that parents will know how to help their child and to give these young people the best chance of recovery. We look forward to keeping you apprised of our progress throughout this project.

Sincerely,

Dr. Wendy Spettigue

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