

October 25, 2012

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: An Ontario multi-site initiative."

Dear Representatives of the Mach-Gaensslen Foundation,

The Regional Eating Disorder Program at the Children's Hospital of Eastern Ontario would like to thank you for your generous support of our multi-site research trial to study the effectiveness of an online psychoeducational video for parents of youth with eating disorders, and we are pleased to provide a brief update on our progress to date. Since receiving your generous funding, we have been able to accomplish the following tasks:

- We hired a research assistant to help coordinate the project and be the point-person for all participating sites.
- So far, two Ontario Eating Disorder programs (Health Sciences North Hospital in Sudbury and McMaster Children's Hospital in Hamilton) have confirmed their participation in this multi-site initiative.
- We have begun reviewing the most up-to-date literature on the topic of psychoeducation for eating disorders, working with parents and skills-training for parents of youth with eating disorders, learning what other online resources are available for parents of youth with eating disorders, and on the topic of providing online training, in order to learn from other researchers' experiences.
- Based on our previous pilot project and the results of our background research, we have started writing the detailed protocol for the trial, which will be submitted to our hospital Research Ethics Board for approval.
- We have closely analysed the data from our pilot project, in which we provided a workshop to parents from the Ottawa region whose children were waiting for an assessment from our Eating Disorder team. We learned from this data that our workshop was rated very highly on the parent satisfaction evaluation forms, and was effective in increasing parental knowledge of eating disorders and efficacy against the eating disorder. However, the two-hour workshop was not effective in improving patients' symptoms at the time of assessment. We suspect that this may be because our workshop was targeted at parents of youth with anorexia nervosa, while many of the parents who attended the pilot workshop had children with an eating disorder that was more similar to bulimia nervosa. This is likely because only medically stable youth were recruited into the study, and patients with a bulimia nervosa spectrum eating disorder are typically of a higher weight and hence more likely to be medically stable. This information is particularly helpful as we can now more carefully target all spectrums of eating disorders in our psychoeducational video, or possibly create two different online psychoeducational videos for parents, depending on the type of eating disorder that their child suffers from (ie one video for anorexia nervosa and similar eating disorders, and another video for bulimia nervosa spectrum eating disorders).
- Based on our analysis of the data from the pilot project, we have also done further research on psychological questionnaires in order to determine which measures would be best to determine the effectiveness of our online video and resources; for example, to determine how best to measure parental efficacy against the eating disorder, parental report of the severity of their child's eating disorder, and

- severity of symptoms and potential improvements in the patients when they eventually present for assessment of their eating disorder.
- In October 2012, we presented the results from our 'Waitlist' pilot project at the 59th Annual meeting of the American Academy of Child and Adolescent Psychiatry in San Francisco, and received excellent feedback on this presentation. We used this presentation to encourage other programs to consider offering waitlist interventions to parents of youth suffering from other mental illnesses, and we made our pilot protocol available online to those in attendance, so that they could create similar trials to study the effectiveness of waitlist interventions.

Immediate next steps include:

- To invite additional eating disorder treatment sites across the province to collaborate with us on this exciting endeavour
- Once all participating sites are confirmed, we will be able to finalize the protocol and move forward with the CHEO Research Ethics Board approval
- To recruit a medical student or resident to help create the online video and to work on this research project as part of their training in research methodology

We were also fortunate enough to receive a Bell Community Fund grant in support of this project (\$45,000 for one year, starting in October 2012). With the extra funding in place we hope to include additional eating disorder sites in the province, in order to make the psychoeducational video available to an even greater number of families.

We truly appreciate the Mach-Gaensslen Foundation's support in improving the lives of children, youth, and families suffering from the devastating effects of eating disorders. We look forward to keeping you apprised of our progress throughout this project.

Thank you,

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