

# Spotlight on research

## Q&A WITH RESEARCHERS DR. WALSH AND DR. DOWHANIUK

### **Donor-supported research through CCA's James A. Campbell Grants hopes to improve outcomes for children with new management tool**

#### **What is a PROM, and why is it so important when working with celiac disease?**

Patient reported outcome measures (PROMs) are self-completed questionnaires that assess well-being, health status and experiences of healthcare from the view of the child (and caregiver). This is without any interpretation from a healthcare provider. A PROM can be answered by a child and/or a caregiver to help to inform clinical care in line with a patient-centred approach to care. PROMs are developed by following research standards to make them reliable and valid to use in clinical care. Previous research has shown that PROMs can improve patient-provider communication, patient satisfaction, and

help care providers recognize problems that were not previously detected. The PROM we are developing for celiac disease will focus on the symptoms children

with celiac disease experience.

#### **What got you interested in developing this tool (the PROM)?**

A PROM that focuses on the



**Dr. Walsh**



**Dr. Dowhaniuk**

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symptoms and health complaints that children with celiac disease experience will provide healthcare practitioners with a tool to help guide the care of children with celiac disease across Canada. It will help to capture patients' views of their illness experience, support shared decision-making, and guide future research in this field. Most importantly, such a PROM will help make care providers more aware of how their patients with celiac disease function and feel. We decided to undertake this study as no such measures currently exist.

### **How do you hope your research will impact celiac disease management?**

Our study aims to develop a new disease-specific PROM, the Pediatric Celiac Symptom Index (PCSI), designed to reliably assess symptoms in children with celiac disease from the perspective of patients and their families. The PCSI will be the first pediatric-specific celiac disease symptom-related PROM. This is an important step in the care of pediatric patients given the well-established differences in symptoms between children and adults with celiac disease. Engagement of patients and families in the development process will help

to ensure we capture symptoms that are important to them and are aligned with their treatment goals. Once developed, the PCSI can be used for celiac disease symptom assessment both in clinical practice, to capture patients' illness experience and support shared decision-making, and in research. Specifically, it will help to identify changes in the clinical and functional status of a child over time. A change in symptoms can alert healthcare providers to a change in the function of a child and/or their physical, mental or social well-being. For example, in pediatric celiac disease new symptoms could represent a change in how well a child is adhering to the gluten-free diet or signify the development of a complication related to celiac disease, such as arthritis or constipation. The PCSI can also be used to help guide management and interventions provided in clinical care. The PCSI will be

a reliable, valid and feasible tool that can be used to by healthcare providers to follow children with celiac disease over time, help engage children and families in their care, and will identify symptoms that are common and important in the long-term health of children with celiac disease to improve their overall well-being.

### **How does this research fit into the bigger picture of your work with celiac disease?**

We are both dedicated to improving the care and well-being of children with celiac disease. As the shared medical leads of the McMaster Children's Hospital and The Hospital for Sick Children pediatric celiac disease clinics, we diagnose and care for many children with celiac disease and their families. We are passionate about improving the quality of children with celiac disease. We are collaborating with centres Canada and North America on a number of ongoing projects that relate to many aspects of celiac disease, including education around the gluten-free diet, assessing adherence to the gluten-free diet, and how to more effectively detect and manage potential complications of the disease. ♦