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May 1, 2013

The Honorable Tim Ryan U.S. House of Representatives 1421 Longworth House Office Building Washington, D.C. 20515

Dear Congressman Ryan:

I am pleased to offer the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition's (NASPGHAN) endorsement of the "Gluten in Medicine Disclosure Act."

NASPGHAN is an organization comprised of 1,500 members who have specialized training and expertise in caring for children with disorders of the digestive system, liver and nutrition, including Celiac disease.

NASPGHAN has been active in raising awareness of gluten intolerance, or Celiac disease, through the publication of the first evidence-based guidelines for the diagnosis and management of Celiac disease in children, as well as through a national campaign organized by the NASPGHAN Foundation to educate health care professionals on the subject.

As you know, Celiac disease is one of the most common chronic conditions affecting the general population, and the prevalence in children is thought to be between 3 and 13 per 1000 children. Celiac disease frequently results in a number of serious medical problems including growth failure, chronic diarrhea, abdominal pain, and other problems outside the gastrointestinal tract, such as liver disease. Celiac disease is a lifelong condition for which the only acceptable treatment is complete avoidance of gluten – a protein found in wheat, barley, and rye. Evidence shows that avoiding the ingestion of gluten resolves symptoms common with Celiac disease and reduces other medical consequences, including the risk of gastrointestinal cancer in adulthood.

People with celiac disease must be vigilant to avoid ingestion of gluten-containing products and must often go to extraordinary lengths to confirm a product does not contain gluten. There is marked variability in response to even small amounts of gluten ingestion that occurs in people with Celiac disease, which precludes identification of a minimum safe level for all individuals, particularly children.

It is not known precisely how often gluten is incorporated in the production of prescription and non-prescription medicine. NASPGHAN believes there is an urgent need to help people, especially children with Celiac disease, avoid the risk of inadvertent ingestion of gluten. When it comes to gluten, better medication labeling is needed and is why NASPGHAN endorses your bill, which would require that the label of drugs intended for human use contain a parenthetical statement identifying the sources of any ingredient constituting or derived from a

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NASPGHAN Annual Meeting & Postgraduate Course

October 11-13, 2013 Chicago, IL grain or starch-containing ingredient. If someone with Celiac disease cannot confirm that a medicine is gluten free, he or she may choose not to take it, which can also have adverse health consequences.

I, along with my pediatric gastroenterologist colleagues, thank you on behalf of our patients for your leadership on this very important topic. Please do not hesitate to call upon NASPGHAN if you require additional information or have any questions.

Sincerely,

Athos Bousvaros, M.D.

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President