

Legislation Details (With Text)

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Title:	Recognizing the month of May as Celiac Disease Awareness Month in Philadelphia and honoring eight-year-old Philadelphian Jax Bari for shining a national light on ABC's World News Tonight with David Muir on the need for increased federal funding for Celiac research and federally mandated labeling of gluten on all packaged foods.				
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Date	Ver.	Action By	Action	Result	Tally
6/10/2021	0	CITY COUNCIL	ADOPTED		
5/27/2021	0	CITY COUNCIL			

Recognizing the month of May as Celiac Disease Awareness Month in Philadelphia and honoring eight-year-old Philadelphian Jax Bari for shining a national light on ABC's World News Tonight with David Muir on the need for increased federal funding for Celiac research and federally mandated labeling of gluten on all packaged foods.

WHEREAS, May is nationally recognized as Celiac Disease Awareness Month. Each May, the Celiac community comes together to advocate for awareness of the disease and to raise funds for research for treatment options and a cure; and

WHEREAS, According to the Celiac Disease Foundation, Celiac Disease is a serious autoimmune disease that occurs in genetically predisposed people where the ingestion of gluten leads to damage in the small intestine. It is estimated to impact 1 in 100 people worldwide, and about 3 million Americans; and

WHEREAS, For Celiac Disease sufferers, gluten, a protein found in wheat, barley and rye, is poison to their bodies. Even a trace amount (a crumb) triggers an immune response leading the body to attack the small intestine. This intestinal damage causes more than 200 debilitating symptoms. Moreover, according to the University of Chicago Celiac Disease Center, gluten ingestion for people with Celiac Disease causes permanent immunological scarring, doubles the risk of heart disease, and acts as a carcinogen, quadrupling the risk of small intestinal cancers; and

WHEREAS, As one of his projects in 2nd Grade at Penn Charter, Jax has been working on persuasive letters. In May of 2021, Jax Bari wrote a letter about his Celiac journey to David Muir, anchor of ABC News' World News Tonight. Jax hoped to bring national attention to the illness and the need for a cure on a national scale; and

WHEREAS, Jax wrote to Mr. Muir, "When I turned 8 in May, I wished for a cure for Celiac Disease for me and

3 Million Americans with Celiac. I watch you every night on World News with my dad... You are a great storyteller and I have learned so much from you, including about the NIH. Eating without fear is our hope. Food insecurity for Celiacs happens everyday. I recently wrote to President Biden asking for help and wanting to meet with him to share my ideas. Can you help tell the Celiac story this May which is Celiac Awareness Month?"; and

WHEREAS, Mr. Muir was moved by Jax's persuasive letter. Jax appeared on World News Tonight to read his letter and raise awareness during the broadcast along with some of Jax's friends from around the country who have Celiac. They were supporting Jax's efforts to: 1) Increase Federal funding for Celiac Disease research to find more treatments (other than a strict gluten free diet) and a cure; and 2) Mandate that gluten be labeled as a top food allergen on all packaged foods in the U.S., just like it is in Europe and Canada; and

WHEREAS, The World News Tonight story included some of Jax's advocacy efforts including when he co-hosted a bipartisan Congressional Briefing on Capitol Hill in January 2020 along with his family, Congressman Dwight Evans, Congresswoman Madeleine Dean, Congressman John Joyce and his treating physician at the Children's Hospital of Philadelphia, Dr. Arun Singh; and

WHEREAS, Jax recently helped start and recruit members for the new bipartisan Congressional Celiac Caucus with Congresswoman Dean, Congresswoman Scanlon and Congressman Joyce; and

WHEREAS, Right now, a strict gluten free diet for life is the only treatment for Celiac Disease, and that is insufficient since gluten is found in 80% of foods and there is a constant risk of cross contamination. Jax and other patients are calling for more funding to help find better treatment options and a cure for Celiac Disease and to require food labeling. The City Council of Philadelphia supports these important efforts to find a cure for people in Philadelphia and around the world who are affected by Celiac Disease; now, therefore, be it

RESOLVED, THAT THE CITY COUNCIL OF PHILADELPHIA, Hereby recognizes the month of May as Celiac Disease Awareness Month in Philadelphia and honors eight-year-old Philadelphian Jax Bari for highlighting the need for greater awareness, research funding and labeling of Gluten on ABC's World News Tonight with David Muir.

FURTHER RESOLVED, That an Engrossed copy of this resolution be presented to Jax Bari as evidence of the sincere admiration of this legislative body.