

International Symposium on Wheat Related Disorders ISWD 2019



INTRODUCTION

The Celiac Society of India (CSI) organized an **International Symposium on Wheat Related Disorders– ISWD 2019**, in New Delhi on 12th-13th January 2019.

CENTRAL THEME OF ISWD 2019: “Beyond Celiac and Beyond the Gut”

AIM: To draw attention to wheat related health disorders, including celiac disease, one of the most under-diagnosed nutritional and medical conditions.

ABOUT ISWD 2019

- It brought together experts and authorities of diverse backgrounds on wheat related disorders from across the globe to a single platform.
- Experts included researchers, physicians, gastroenterologists, dermatologists, paediatricians, neurologists, nutritionists, allergists, culinary experts and other professionals from USA, Canada, Italy, New Zealand, Germany, Netherlands and Israel, in addition to India.
- Discussions and presentations focused on latest research findings in the development, diagnosis and treatment of wheat related disorders including celiac disease.
- A startled awareness was generated for many in attendance of the depth of science and the significance recognizing wheat related disorders outside of Celiac Disease.

- ISWD attracted the attention of, and participation of influential regulatory bodies of India including FSSAI (Food Safety & Standards Authority of India) and Niti Ayog (National Institution for Transforming India). The symposium helped to better appreciate the issue of wheat-related disorders with its nutritional and health impact on the millions.
- Registrations: 950+ people registered and attended the two day symposium, these included:
 - Nearly 450 practicing medical professionals, nutritionists and culinary experts
 - About 250 patients and their caregivers of those suffering from wheat related disorders including celiac disease
 - Approx. 150 medical and nutrition students
 - Almost 50 renowned experts from across the world brought their valuable perspectives to the symposium
 - About 50 eminent media professionals covered the conference online and offline
 - Nearly 50 gluten free product manufacturers showcased their products at the Gluten Free Expo held during the 2 day symposium
- Eminent personalities who graced the Symposium included:
 - Prof. Vinod Paul, Member, NitiAayog
 - Sh. Pawan Agarwal, CEO, FSSAI
 - Dr. Naresh Trehan, Chairman & M.D., Medanta Hospital
 - Dr. K.K. Aggarwal, Ex-President, Indian Medical Association
 - Dr. B.S. Ramkrishna, Director & Senior Consultant, Medical Gastroenterology, SIMS (SRM Institute For Medical Science)
 - Prof. M.K. Bhan, Patron, Celiac Society of India and Ex-Secretary, Dept. of Biotechnology, Ministry of Health
- The Organising Committee
 - **Chairman:** Dr. Tom O'Bryan, Adjunct Faculty, The Institute for Functional Medicine, U.S
 - **Organising Secretary:** Dr. Sarath Gopalan, Paediatric Gastroenterologist, New Delhi, India
 - **Convener:** Ms. Ishi Khosla, Clinical Nutritionist & Founder President, Celiac Society of India, India

HIGHLIGHTS OF ISWD 2019

Awareness

- Increase awareness about celiac disease and wheat related disorders amongst the public, healthcare professionals and the food industry.

- Catalyze information dissemination on latest research about wheat sensitivity to professionals and public through special events, forums, case study presentations, lectures, workshops, seminars, national and international conferences.

Advocacy

- Advocacy amongst policy makers.
- Inclusion of celiac disease in the 'Rights of Persons with Disabilities Act', drawing from policies of the US and other Western countries.
- Government programs supporting the poor diagnosed with celiac disease and wheat related disorders. For example, In Italy, individuals diagnosed with celiac disease are provided government support to lessen the impact of the price difference of gluten free food.

Timely Diagnosis

- Timely diagnosis of wheat related disorders with newer and cheaper techniques. The sooner a diagnosis can be made, the more likelihood of regeneration of a healthier body
- Mass screening in high risk populations.
- Establish a nationwide support structure to provide timely diagnosis, better management, psychological support to families, caretakers and individuals with wheat related disorders and celiac disease.

Better Management

- Increase availability of alternate gluten-free grains, through the public distribution system.
- Ensure appropriate food labelling and implementation of laws regarding declaration of allergens including wheat and gluten. These must be made mandatory.
- Conduct specialized training courses, in person and online, for doctors, nutritionists, nurses and culinary experts for timely diagnosis and better management.
- Create a task force of food manufacturers to formulate incentives for the industry, which could include tax relief, reduction in cost of ingredients and food testing, to benefit the consumer.
- Sensitize food manufacturers, hotels, restaurants and other food catering institutions to follow good manufacturing practices(GMPs), food labeling, and provide appropriate food alternatives.
- Sensitize parnts, caretakers, educational and professional institutions on 'Gluten-Free' living-a need for those suffering from wheat related disorders and celiac disease.

Research

- O Encourage research on timely diagnosis, incentives to bring newer technology in diagnostic tests from the US, better management and new treatment of wheat related disorders and celiac disease.

BACKGROUND NOTE

The prevalence of wheat related disorders and celiac disease is certainly more common than previously appreciated. It is fairly widespread in the West. The extent and the importance of celiac disease have not been appreciated so far in India. About 1 per cent of the population is estimated to suffer from celiac disease, but it has not received much attention.

The discrepancy between estimated prevalence and diagnosed cases has been linked primarily to the fact that wheat related disorders and celiac disease can be silent or latent, at times. Silent and latent forms of wheat related disorders and celiac disease may go undetected in an individual for years before the person develops symptoms causing him or her to seek medical attention. In addition, wheat related disorders and celiac disease are often mistaken for other gastrointestinal mal-absorption disorders that have similar diarrheal symptoms (e.g., irritable bowel syndrome), which further delays its diagnosis.

The recognition and understanding about wheat related disorders and celiac disease has grown in the last two decades. They manifest in different ways and the spectrum is classified on the basis of the ways they affect the immune system. Wheat related disorders include - Celiac Disease, Non-Celiac Wheat Sensitivity and Wheat Allergy.

Celiac Disease was first recognized by the Greeks in the second century AD. The word celiac is derived from 'koiliaks' a Greek word meaning 'suffering of the bowels'. It is an autoimmune disorder that occurs with ingestion of the family of gluten proteins in wheat, barley and rye. In patients having this condition, gluten is not digested completely and this leads to damage to the villi of the small intestine. Villi form the lining of the small intestine that absorbs food.

Non-Celiac Wheat Sensitivity: The difference between celiac disease and non- celiac wheat sensitivity is in intestinal permeability and genes regulating the immune response in the gut. Intestinal permeability connotes the ability of the mucosal layer of the digestive tract to prevent bacteria, antigens, and undigested food proteins from seeping through the gastrointestinal barrier. When this selective barrier breaks down, the condition is called pathogenic intestinal permeability, or in laymen's terms, the leaky gut. Those who have celiac or wheat sensitivity often have a high degree of permeability. The type of damage to the mucosa in celiac disease is however distinct. In other words the mechanisms of intestinal damage are different but the manifestations & management in both conditions are similar. Data in India is lacking but it is assumed to be affecting nearly 6% of the population in the US.

Wheat Allergy: Listed among the top eight food allergens (others being soy, peanuts, tree nuts, dairy, egg, fish and shellfish), adverse reactions to wheat, apart from celiac disease, can be in the form of an allergy. Most common symptoms for allergies could be respiratory, asthma, atopic dermatitis, urticaria (hives), colic and vomiting or anaphylaxis.

Wheat related disorders and celiac disease are associated with a number of significant health problems and disorders, including iron-deficiency anemia, vitamin deficiencies, protein-calorie malnutrition, weight loss, short stature, growth retardation in children, delayed puberty, infertility, miscarriage, brain dysfunction including depression, anxiety, brain fog, and seizures, and osteoporosis. Individuals with unmanaged wheat related disorders and celiac disease are at an increased risk of developing other serious medical conditions, such as Type I diabetes mellitus, intestinal cancers, and both intestinal and extra intestinal non-Hodgkin's lymphomas. Ironically, India faces a double burden of over and under-nutrition, both presenting with micronutrient malnutrition (hidden hunger).

There is no cure for celiac disease and wheat related disorders, the only way to manage is to avoid eating gluten. Individuals with wheat related disorders and celiac disease require lifelong dietary management. Over time, strictly avoiding consumption of gluten can resolve the symptoms, mitigate and possibly reverse the damage, and reduce the associated health risks of celiac disease and wheat related disorders. For some individuals with wheat related disorders and celiac disease, failure to avoid consumption of gluten can affect multiple organs and lead to life threatening complications and maladies.

Of late the medical community has become more aware of the need to screen for wheat related disorders, wheat allergies and celiac disease.

