

CELIAC FOCUS

QUARTERLY NEWSLETTER OF CELIAC SUPPORT ORGANISATION

Announcing Celiac Day 2014

It is with great pleasure that we are announcing the celebration of celiac day 2014. It will be observed on Saturday, 3rd May 2014 at MAMC auditorium between 2 pm to 5 pm. The theme this year is **Wholesome Nutrition for Celiacs.**

We are also having a painting competition for children under 10 and essay competition for people over 10 years of age. There would also be a recipe competition for dieticians. All are cordially invited. Entry is free. To register yourself just email your contact details to csoindia@gmail.com. For program see page 5



A report on CELIAC DAY 2013

DMA hall, Darya Ganj New Delhi

Celiac Support Organisation observed celiac day in collaboration with Delhi Medical Association on 11th of May 2013 at 2pm at DMA Hall, Darya Ganj Delhi.

The President of DMA, Dr Anil Agarwal, Dr KK Kohli, Hon. Secretary DMA and Dr Ravi Malik(DMA) extended whole

hearted cooperation to make the programme a huge success.

Prof. SK Mittal (President CSO) was at the helm of the organising committee. The other members included Dr Ravi Malik (DMA), Dr Sushma Narayan, secy general CSO, Dr Shinjini Bhatnagar (Vice president CSO) and Dr Raghvendra Singh,



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FROM THE EDITOR

This new edition of celiac focus is being brought in a new and an informal format. We hope that the readers find this format refreshing and continue to give their support to both the organisation and the editorial team by sending both their bouquets and brickbats.

Dr Vidyut Bhatia



DR Shinjini Bhatnagar answering a question from the audience



A view of the audience



Dr S K Mittal being felicitated by DMA president

CSO AND DMA continued...

ABOUT CSO

Patrons:

Dr. M K Bhan

Dr. S K Mittal

Mr. Naresh Dayal

Mentors and Guides:

Dr. N K Arora

Dr B R Thapa

Dr S K Yachha

Dr. A K Patwari

Dr. John Matthai

Advisors:

Dr. U C Mouli

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Jt. Secretary

Ms. Anuja Agarwala

Treasurer

Dr. Vidyut Bhatia

Jt. Treasurer

Dr. Praveen Kumar



Pediatric Gastroenterologist, Chacha Nehru hospital Geeta Colony, Delhi. The event was very well attended. There were more than 100 patients; nearly 150 parents/carers along with more than 49 doctors from various hospitals across Delhi attended the program.

The program began with a welcome address by Prof SK Mittal, President CSO who welcomed all the participants.

This was followed by an inspiring talk by Dr Naaz, a medical student (4th Year) at AIIMS, suffering from Celiac Disease herself. She described her journey of fighting with the disease since early childhood, delay in diagnosis and all her trials and tribulations while struggling with the disease and how she has found finally the road to perfect health. Dr Naaz's talk was followed by a brief talk by Dr Shinjini Bhatnagar regarding the activities of CSO in the previous year and future plans regarding follow up with FSSAI on gluten testing.

Dr Ravi Malik promised all support from DMA in spreading awareness on Celiac Disease and need for extensive awareness programs.

The function was also attended by Mr Naresh Dayal, Former Health Secretary (Govt of India) and also a patron of CSO.

The interactive session between the expert panel and the patients was in two parts. Frequently asked questions were directed to expert panel by Dr Sushma Narayan, the anchor of discussion. The questions were relating to diet, other associated conditions, necessity for biopsy, the role of alternate therapy such as homeopathy, possibilities of cure, relation of Celiac Disease to poor learning, need for monitoring siblings etc.

This was followed by open house where the patients came forward with their specific queries.

Celiac Disease- Yesterday, Today and Tomorrow

by Dr. Sarath Gopalan & Mrs. Neelanjana Singh

*Senior Consultant Pediatric Gastroenterologist & Hepatologist, PSRI Hospital, New Delhi

** Senior Consultant Clinical Nutritionist, PSRI Hospital, New Delhi

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Ever since we first saw our first case of adult Celiac Disease, which was over 16 years ago, it has been a journey of learning and discovering new facets of the disease in our population. Gluten sensitivity or Celiac Disease was a relatively unknown entity in our population at that time, but, in recent years, many patients with Celiac Disease are being diagnosed early - largely, due to increasing awareness about the condition in the community. In earlier years, it was believed that a gluten free diet was required to be administered only until remission occurred, in some patients. The concept of giving a 'gluten challenge' was quite rampant in those days. Today, there are clear guidelines (ESPGHAN 2011) which state that the diagnosis of Celiac Disease is confirmed by a positive Celiac serology (antigliadin antibodies, anti-endomysial antibodies or anti-tissue transglutaminase antibody) along with a duodenal mucosal biopsy (obtained endoscopically) which has a histopathological appearance compatible with Celiac Disease, followed by a clinical response to a gluten-free diet over 8 weeks.

At first glance, the treatment of Celiac Disease appears very simple - avoiding the toxic grains which are wheat, rye and barley. However, there are many practical issues encountered while trying to follow such a diet. Quite often, people are confused whether this sensitivity is valid to any specific variety of wheat. At this point, it is imperative to point out that all types and varieties of wheat contain gluten

(bulgar, durum, spelt, kamut) and all of these require to be strictly avoided in a gluten free diet. It is also important to specify the status that oats occupies in a gluten free diet. Oats can be safely consumed in a gluten free diet but the problem arises due to the high risk of contamination of oats with wheat grain. This occurs during the cultivation and harvesting of the grains which are usually grown together. Gluten free oats is available in many western countries and can be safely consumed, but such a product is not yet available in the Indian market.

WITH THE EVER PERVAIDING PRESENCE OF PACKAGED FOODS, IT IS IMPERATIVE TO READ LABELS CAREFULLY TO CHECK FOR THE PRESENCE OF GLUTEN.

The encouraging news is that in India we have traditionally used many grains in our diets besides wheat. Rice, corn and the millets (ragi, bajra, jowar) are easily available and are nutritionally superior to many cereals. These can be substituted for wheat and the forbidden grains (rye and barley). The other "safe" grains that can be used as substitutes are amaranth (ramdana), quinoa, buckwheat (kuttu), waterchestnut(singhara), sago (sabudana) and arrowroot (paniphal), to name a few. Many of the lentils can also be used as substitutes and the common ones are soybean and gram flour (besan). It is easy to replace wheat with any of these flours for making chapattis, parathas, puris and pancakes/cheela.

As gluten is the ingredient in flour that gives it elasticity and strength, most of the gluten-free flours do tend to produce flat and crumbly products on baking. Baking with gluten free flours is a challenge but with appropriate binding agents many recipes have been successfully

developed. For example, one cup of maida for baking could be replaced by one cup of corn flour or 14 tablespoons of rice flour. However, beware of the supposedly gluten free cakes and baked products that seem to have very good form and a crown. Such products are likely to contain gluten.

With the ever pervading presence of packaged foods, it is imperative to read labels carefully to check for the presence of gluten. The foods that are most likely to contain gluten amongst the processed foods are cereal beverages (such as malted drink mixes), beer, breaded meats or vegetables, most sauces including soy sauces, processed meats, soups and commercially available cakes and cookies. The presence of dextrin, starch, fillers and malt in any food item should alert the patient that such a food will pose a risk to a gluten sensitive person.

It is also possible to unknowingly imbibe some gluten despite starting out with a gluten free product. At home, one needs to take precautions during preparation to ensure that contact with gluten does not occur. Marinating in sauces that contain gluten in some form, using common toasters, or cooking in oil that has been previously used for cooking gluten containing products are some of the common pitfalls that do occur.

The only treatment for Celiac disease currently known is the strict avoidance of gluten. However, research in the field of genetic engineering is trying to develop a variety of wheat that is gluten-free. Research is being undertaken to develop a gluten digesting enzyme that would break up the toxic gluten before it begins to damage the intestines of those who are sensitive to it.

Diagnostic yield of capsule endoscopy in refractory celiac disease. American Journal of Gastroenterology. October 2012.

by Barret M, Malamut G, Rahmi G, Samaha E, Edery J, Verkarre V, Macintyre E, Lenain E, Chatellier G, Cerf-Bensussan N, Cellier C.

Assistance Publique-Hôpitaux de Paris, Hôpital Européen Georges-Pompidou, Service d'Hépatogastro-entérologie, Paris, France.

Upper endoscopies/enteroscopies have been used to assess celiac disease, but capsule endoscopies, where a small pill-shaped camera is swallowed, are becoming a widely spread practice as well. The capsule endoscopy provides a better, more thorough picture of the intestinal wall compared to traditional endoscopy. According to this study, which looked at close to 50 capsule endoscopies in patients both with and without celiac disease, the improved picture was more effective in diagnosing patients with symptomatic and refractory celiac disease (in which symptoms and small intestinal inflammation persist despite following a gluten-free diet). In addition, the study

found that capsule endoscopy might be helpful for early detection of overt lymphoma, which is a life-threatening condition associated with undiagnosed celiac disease.



WHAT IS CAPSULE ENDOSCOPY?

Capsule endoscopy
A capsule fitted with a disposable mini video camera can examine parts of the small intestine that standard scopes can't reach for diagnosing unexplained bleeding or other abnormalities. The video data is transmitted and stored in a recorder worn on a belt, and is later downloaded to a computer that the doctor can study.

THE PROCEDURE

- 1 Fasting necessary prior to swallowing capsule
- 2 Capsule glides smoothly through digestive tract
- 3 Wireless recorder worn on a belt around waist receives signals transmitted by capsule through sensors placed on patient's body
- 4 Capsule naturally excreted

THE CAPSULE

What it can show: Stomach, Colon, Small intestine disorders, Rectum, Small intestine

Advantages:

- Painless
- No sedation
- Provides 3-D, color images of small intestines without surgery
- Allows doctors to make early, accurate diagnosis of problems so they can recommend most appropriate treatment

Size:

Side: 27 mm (1.2 inches)
Front: 17 mm (0.4 inches)

Components: Batteries, Microchip, LED lights, Transmits and antenna, Camera lens

WILL GREEN/INGRAM

DIETARY TIPS: HOW TO GET ENOUGH FIBER IN YOUR DIET?



amaranth, buckwheat, brown and black/purple rice, millet, and certified gluten-free oats.

The other recommendation regarding adding fiber to your diet is to add them slowly, and drink plenty of liquids to avoid constipation.

Gluten-free, fiber rich foods to include fresh fruits and vegetables, beans and legumes, and whole gluten-free grains including quinoa,

Is yeast considered gluten-free?

Baker's yeast used in most bread products is gluten-free. The same goes for nutritional yeast, which is often used as a flavor enhancer or as a cheese substitute for those on a vegan or dairy-free diet. The (sometimes) exception to yeast being gluten-free, is with true brewer's yeast, which is a by-product of beer and thus not considered gluten-free.

CELIAC DAY

Celiac Support Organisation



2014

Attractions

Recipe competition for Dietitians Painting competition for children under 10 Essay competition and lots more

Program

2 pm	Registration
2: 30 pm- 3:00 pm	Inauguration ceremony
3:00-3:15 pm	Presentation by celiac patients
3:15 to 4:15 pm	Panel discussion
4:15 pm to 4:30 pm	Prize distribution
4:30 pm onwards	Tea and Gluten free Snacks

Theme
“Wholesome nutrition for celiacs”

Saturday, 3 May 2014

For Details: Dr. Sushma Narayan, Secretary General

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“It took me many years, but I’ve learned that it’s not a hindrance to my performance”



Defending Australian men’s national series cross country mountain bike champion Andrew Blair training at Mount Stromlo Forest Park.

Consuming bars, gels and drinks while on the bike is standard practice for most riders, but it can be a different story if you have special dietary requirements such as Coeliac disease or gluten intolerance.

Coeliac disease affects one in every 100 people, with nearly 75 percent of cases going undiagnosed. Recently endurance mountain bike athlete Andrew Blair about how he manages his Coeliac disease. The 2012 Australian mountain bike marathon champion said: "It took me many years, but I’ve learned that it’s not a hindrance to my performance. It doesn’t stop me from being my best."

Blair also said that it’s definitely easier than it used to be, as most gels and sports drinks are now gluten-free. "I don’t eat solid foods during races, but when training I prefer to eat real food," he said. "I often make

my own cake, which is tasty and full of appropriate energy."

Blair mentioned the importance of not self-diagnosing Coeliac disease or gluten intolerance and consulting your family doctor before taking any action - cutting out gluten could mean that a proper diagnoses cannot be made.

CSO AND DMA CONTINUED...

The panellists were Dr AK Patwari, Dr Ravi Malik, Dr Vidyut Bhatia, Dr Nishant Wadhwa, Ms Charu Dua and Ms Yagya Agnihotri.

The experts were inundated with so many questions and it was strongly felt by many people that we should have many such sessions.

Gluten free snacks were then served



to all the patients and parents and other participants.

Celiac News

A new report from Packaged Facts estimates gluten-free packaged foods to be a \$4.2 billion industry, and expects that number to exceed \$6.2 billion by 2017. The estimates reflect a compound annual growth rate of 28%.

The report noted that gluten-free snacks and granola bars contribute to 15% of this number, which is the largest portion of the industry.

So what has contributed to this growth? The Los Angeles Times says the growth is due to a combination of a few factors, including an increase in celiac disease and food allergy diagnoses, celebrity endorsements of a gluten-free diet for weight loss*, and consumers beginning to steer away from grain-based diets.

Celiac awareness day in the United States

The United States Senate has once again designated September 13th as "National Celiac Awareness Day." According to the resolution, the Senate "recognizes that all people of the United States should become more informed and aware of celiac disease"

Why September 13th, you may ask?

The 13th is the birthday of Samuel Gee, a pediatrician who published the first complete clinical description of celiac disease in 1888. Gee was the first to recognize that the symptoms of celiac disease are related to diet.

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CELIAC FOCUS

Volume 5
Mar 2014

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