

## Fasano speech

(Continued from Page 1)

parts-per-million (ppm) may be reduced to 20 ppm. The idea of zero ppm is impractical as that would require 'clean room' technology for all food processing, from the fields to the consumer.

He said the idea that in Europe it is mostly the Irish and Italian populations presenting with CD is outdated. It may be that they are diagnosed more frequently since they present symptoms in a "typical" pattern. While most celiacs have the genetic markers HLA-DQ2 or HLA-DQ8, about 0.5% seem to have neither gene. He also described his own work with "zonulin", a protein found in higher levels in celiacs.

Dr. Fasano is proud of the fact that two weeks prior to his talk the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) published "Guidelines for the Diagnosis and Treatment of CD in Children". The foundation associated with this group, the Children's Digestive Health and Nutrition Foundation (CDHNF) provides information on pediatric gastrointestinal, liver and nutritional issues. CDHNF has a website, [www.celiachealth.org](http://www.celiachealth.org), and Dr. Fasano is the Chair of the CDHNF CD Educational Campaign. He gave Georgina Rubal, President of SACS, a copy of a CD-ROM from this group. [Note: copies of this CD are available. See notice page 2 and order form page 6.]

Some of the important points Dr. Fasano covered in his nearly 2 1/2 hour non-stop talk included:

✦ The importance of the private donations received from the International Walks to help fund the activities of the CFCR. The CFCR works hard to improve the quality of life for celiacs and their families.

✦ The exciting developments in understanding the mechanisms of how gluten is damaging to the celiac patient, and how CD presents the best model for researching other autoimmune disorders such as thyroid disease, multiple sclerosis, rheumatoid arthritis and Type 1 diabetes.

✦ The lack of a definition of the word "Gluten-Free" in the U.S. He described working with the FDA on this subject currently. For those of us who follow a gluten-free diet the lack of standardization is a subject that we must pay attention to closely.

✦ The prevalence of CD does not appear to be increasing (unlike childhood asthma, for example), and increased awareness is leading to more cases of CD being diagnosed. That said, however, autoimmune disorders appear to be rising sharply.

The occasional accidental ingestion of gluten appears to be less harmful than a regular intake of gluten (for example, in a daily pill).

Many thanks to Cleo Anderson and the rest of the SACS Board for inviting Dr. Fasano and Ms. King to Tucson to address our group. His talk was inspiring and will hopefully encourage us all to become involved in the 4<sup>th</sup> Annual International Walk taking place on April 23, 2005 at the University of Arizona. SACS sends 85% of proceeds from this event to the CFCR and keeps 15% for group educational purposes.

**The occasional accidental ingestion of gluten appears to be less harmful than a regular intake of gluten (for example, in a daily pill).**

**Roundtable March 16 this month**

## Thank You!

**A big thanks to Jim and Diane Perrine** for escorting Dr. Fasano and Ms. King to the Jan. 14<sup>th</sup> dinner at the Arizona Inn and to Georgina Rubal for organizing the event.

Many SACS members also attended. The food was excellent and the conversation wide-ranging and instructive. These topics included:

► There are gluten-free pizzerias in Naples, Italy!

► Dr. Fasano estimates that up to 100,000 people across the US have now been diagnosed with CD, with perhaps over two million still undiagnosed. He also said that for every male being diagnosed, five to eight females are being diagnosed.

► Teens who are having difficulty with the gluten-free diet frequently ask him if he has tried it personally. He has -- for one week -- and clearly appreciates the challenges young adults, and all of us have, being gluten-free.

► The National Institute of Health is planning a publicity campaign to increase awareness of CD.

## Email to supplement SACS phone tree

**The good news is that SACS is growing;** the *bad* news is our phone tree members can't keep up with notifying everyone about meetings,

events and/or changes in publicized plans.

So, phone tree 'news' will be sent out to everyone with a valid email address and members without email will continue receiving reminder phone calls.

If you did *not* get an email notice about the February 16 Dining Club meeting, then you are not on the email list. If you want to add or remove your email address from the list, please contact [info@SouthernArizonaCeliacSupport.org](mailto:info@SouthernArizonaCeliacSupport.org)