

Hi Boulder/Longmont CSA Support Group Members,

Lorraine and I would like to share with you our experiences at a digestive disease forum we recently attended in Washington, DC.

THE DIGESTIVE DISEASE NATIONAL COALITION PUBLIC POLICY FORUM IN WASHINGTON, DC, MARCH 11-12

Lorraine and I just returned from Washington, D.C. where we attended the DDNC (Digestive Disease National Coalition) Public Policy Forum on behalf of CSA (Celiac Sprue Association). The DDNC is an organization comprised of 23 voluntary health organizations and professional societies concerned with diseases of the digestive tract. The coalition promotes a strong federal investment in digestive disease research, patient care, prevention, and public awareness.

CSA representatives included Mary Schluckebier, Executive Director (NE); Tom Sullivan, Past President (MI); Bill Eyl, President-elect (CO); James Blank, Secretary (NY); Diane Eve Paley, former CSA president and current DDNC treasurer (NJ); Lorraine Eyl, supporter, (CO); and Justin Bangert, CSA intern (NE).

Some of the diseases included in the DDNC are Inflammatory Bowel Disease, Irritable Bowel Syndrome, Ulcers, Metabolic Disorders, **Celiac Disease**, Hemochromatosis, Hepatitis and other Liver Diseases, Diseases of the Pancreas, Pediatric & Adult Gastroesophageal Reflux, Colorectal Cancer, Motility Disorders and other serious ailments of the digestive tract.

Among the **DDNC's goals: Supporting increased funding for the National Institutes of Health, supporting the efforts of the National Commission on Digestive Disease Research**, the Inflammatory Bowel Disease Enhancement Act (currently House Bill 1113), **labeling of prescription and generic drugs, increased funding for awareness of celiac disease** and diseases of the pancreas, **additional resources in the area of celiac disease research, supporting goals and ideals of National Celiac Awareness Month**, increased funding for the VA Medical Research Program, encouraging the NIH to devote more resources to research in the area of diseases of the pancreas, supporting the NIDDK (National Institute of Diabetes and Digestive and Kidney Disease) in developing a strategic plan for Irritable Bowel Syndrome and to raise awareness on Fecal Incontinence and other Motility Disorders.

During the first day we heard speakers from the NIH, the NIDDK and CDC discuss their work and goals. Dr. Griffen Rodgers, acting director¹ of the NIH, spoke of the goals of the NIDDK and the need for additional funding for the NIH as it correlates to digestive disease research. He reported that there has been a significant decline in the number of colorectal cancers cases due to the improved screening program funded by the NIH. Dr. Rodgers also mentioned the possible new digestive disease topics that are of broad interest to the NIH, among these are: Microbiomes, inflammation as a common disease

mechanism, clinical trials and the need for both new investigators and mentors. He also mentioned **the NIH and NIDDK now have web sites for both Celiac Disease and Crohn's Disease, in addition to their Celiac Disease Awareness Campaign for both physicians and the general public. The website is www.celiac.nih.gov Check it out.**

Dr. Rodgers was followed by Dr. Frank Hamilton, Director of the Intestinal Disease branch of the NIDDK. **Dr. Hamilton initiated the NIH National Consensus Meeting on Celiac Disease in 2004, which confirmed the research on the prevalence of celiac disease as 1 in 133 in the U.S.**

Dr. Hamilton mentioned that 90% of those finally diagnosed with Celiac Disease initially presented with atypical symptoms such as anemia. He feels we must raise public awareness, as recently a focus panel of more than 1,000 doctors indicated that many consider Celiac Disease a "rare" disease. Dr. Hamilton helped launch the NIH Celiac Awareness Campaign making available printer-friendly materials through their website. He is a strong supporter of CSA and attended the CSA national conference in 2006, in Green Bay, WI. Dr. Hamilton also discussed Gastroparesis noting that it affects approx. 5 million in the U.S. with women outnumbering men by two to one. It is Dr. Hamilton's feeling that IBD could be due to a combination of genetic and environmental interactions. He noted that ten different chromosomal regions may be linked to IBD and Crohn's Disease.

Dr. Ian Williams, Acting Chief of the Epidemiology and Surveillance Branch of Viral Hepatitis for the CDC, discussed the prevention and control of Viral Hepatitis in the U.S. In 2005 there were approximately 42,000 cases of HAV, more than 50,000 cases of HBV and 20,000 cases of HCV. There are currently approximately one million cases of HBV with approximately 3,000-5,000 deaths annually. He also mentioned that HAV is the cause of most community-wide outbreaks and is transmitted primarily person to person.

Diane Paley, past CSA president and treasurer of the DDNC, spoke on Celiac Disease—A Patient Perspective. Her talk focused on patient concerns when dealing with celiac disease and emphasized the importance of CSA and its support groups.

VISITS AT THE CONGRESSIONAL OFFICES

The attendees were split into seven groups based on geographic location. **Lorraine, Mary and I were assigned to visit ten Representatives and Senators from Colorado, Nebraska and Missouri.**

We met for approximately 30 minutes with a legislative assistant for each Representative and Senator. **Among the topics discussed: the DDNC goals, the concerns of CSA's members including the labeling of prescription, generic and over the counter medications for gluten containing additives, the proposed FDA gluten-free definition, celiac disease information and the goals of CSA.**

Members of our group visited the following congressional offices: Sen. Jake Swanton (D-NE), Sen. Clair McCaskill (D-MO), Sen. Kit Bond (R-MO), Congressman Jeff Fortenberry (R-NE), Sen. Ken Salazar (D-CO), Congresswoman Marilyn Musgrave (R-CO), Congressman Lee Terry (R-NE), Sen. Chuck Hagel (R-NE), Sen. Wayne Allard (R-CO), Congressman Todd Akin (R-MO). It was a full day!!

All of the CSA representatives were graciously received in each office and we found that the legislative assistants were interested and promised to provide our information to the Representative or Senator. All but one said that the Rep. or Sen. would support the increase in funding NIH is requesting, assuming the money is there.

At the end of the day we were all exhausted but elated by what we had accomplished. Since this was our first DDNC Public Policy Forum, we are definitely looking forward to attending next year to increase awareness of celiac disease, to express the concerns of celiacs, and to encourage federal funding for digestive disease research.

CSA had the largest contingent present at the DDNC forum and is the only celiac organization² that is a member of the DDNC. **Attending this national meeting to advocate for celiacs is just a small portion of what CSA does on behalf of its members and celiacs everywhere. We urge you to join CSA to support its mission of Celiacs Helping Celiacs.**

Please contact me if you have questions or would like further information.

Bill Eyl, President-elect, CSA and member Boulder/Longmont CSA support group

1. Dr. Rodgers has since been confirmed as Director of the NIH by the senate.
2. I unintentionally left out the American Celiac Society since they were not in attendance at the general meeting. Annette Bentley, attended the DDNC board meeting by conference phone.