

TESTIMONY OF DAVID A. PEURA, MD

DIGESTIVE DISEASE NATIONAL COALITION

**BEFORE THE HOUSE ENERGY AND COMMERCE COMMITTEE
SUBCOMMITTEE ON HEALTH**

***ASSESSING DIGESTIVE DISEASES RESEARCH AND TREATMENT
OPPORTUNITIES***

THURSDAY, JULY 8TH, 2004—11:00AM

SUMMARY OF TESTIMONY:

- 1. THE DIGESTIVE DISEASE NATIONAL COALITION'S SUPPORT FOR FEDERAL RESEARCH ON DIGESTIVE DISEASES.**
- 2. THE DIGESTIVE DISEASE NATIONAL COALITION'S SUPPORT FOR H.R. 290, "THE INFLAMMATORY BOWEL DISEASE ACT."**
- 3. THE DIGESTIVE DISEASE NATIONAL COALITION'S SUPPORT FOR H.R. 3756, "THE NATIONAL COMMISSION ON DIGESTIVE DISEASE ACT."**

Mr. Chairman and members of the subcommittee, thank you for initiating this hearing on *Assessing Digestive Disease Research and Treatment Opportunities* and allowing the Digestive Disease National Coalition and to present testimony. I am Dr. David Peura, Associate Chief, Division of Gastroenterology and Hepatology and Professor of Internal Medicine at the University of Virginia Health Sciences Center.

BACKGROUND ON THE DDNC

Established in 1978, the Digestive Disease National Coalition (DDNC) is a national non-profit advocacy organization comprised of the major gastrointestinal volunteer patient organizations and professional societies. Currently there are 25 member organizations that belong to the DDNC. One of the original members of the coalition is the American Gastroenterological Association (AGA) of which I am a member and currently President-elect.

The mission of the Digestive Disease National Coalition is to work cooperatively to improve access to and the quality of digestive disease health care in order to promote the best possible medical outcome and quality of life for current and future patients diagnosed with digestive diseases. The founder of the DDNC was a Crohn's disease patient who saw the need for increased digestive disease research and education.

THE IMPACT OF DIGESTIVE DISEASES

Inflammatory bowel disease is just one of the scores of debilitating gastrointestinal conditions that afflict more than 62 million Americans; others include hepatitis and other liver diseases, irritable bowel syndrome, diseases of the pancreas, ulcers, pediatric and adult gastroesophageal reflux, metabolic disorders, colorectal cancer, celiac disease, motility disorders, hemochromatosis, and other serious ailments.

A recent study, *The Burden of Gastrointestinal Diseases*, conducted by the Lewin Group, concluded that a group of just 17 digestive diseases accounts for more than \$41 billion each year in direct and indirect health care costs. In some of these areas, medical research has brought us closer to developing lifesaving treatments and cures. Examples of this include:

- The application of immunologic advances which have made liver transplantation into a common life saving approach.
- The development of effective screening techniques for colon cancer.
- The genetic contributions to IBD, acute and chronic pancreatitis, pancreatic and colon cancer and chronic diarrheal diseases which are just on the cusp of recognition.

Yet for every breakthrough, we still lack even a basic understanding of the causes, prevention, transmission and treatments for other diseases.

IBD, the name given to Crohn's disease and ulcerative colitis, is a painful and disrupting disorder, which currently has no cure. We see in Crohn's disease the large and small intestines have become inflamed. This inflammation can result in excessive diarrhea, severe rectal

bleeding, anemia, fever, as well as abdominal pain and cramping. Those battling this disorder have the trauma of multiple surgeries and the effects of toxic and potentially dangerous drugs. Ulcerative colitis attacks the large intestine, causing painful diarrhea, bleeding, and can ultimately lead to colon cancer, the third highest cancer population in the United States.

IBD is an unpredictable disorder; symptoms vary in nature, frequency, and intensity. I wish I could say IBD was an easy disease to diagnose, but it is not. Misdiagnosis is common. Because there is no cure for IBD, the goal of medical treatment is to suppress the inflammation of the large and small intestine and the colon. By suppressing this inflammation, intestinal and colon tissue is permitted to heal and relieve many symptoms. Surgery can be an option to remove the diseased segments of the bowel or the colon. While surgery might allow patients to be symptom-free for many years, it is not a cure.

LEGISLATIVE INITIATIVES IN DIGESTIVE DISEASES

Mr. Chairman, the Digestive Disease National Coalition supports the passage of ***H.R. 290, The Inflammatory Bowel Disease Act***. In addition to being endorsed by the coalition, the bill has been endorsed by many of the DDNC member organizations.

The DDNC commends Congresswoman Sue Kelly (R-NY) for her leadership in introducing this legislation. This bipartisan bill has 176 co-sponsors, 17 of which sit on this committee. The broad support of the bill reflects the tremendous potential in biomedical research related to IBD. The scientific community, led by CCFA, has developed a long-range strategic plan for the future of IBD research and is in agreement that an additional investment in IBD research has the potential to yield greater scientific progress in clinical and general research.

The DDNC also supports the passage of ***H.R. 3756, The National Commission on Digestive Diseases Act***, introduced by Congressman Roy Blunt (R-MO) and Congressman Bobby Rush (D-IL). In 1976, Congress passed legislation that authorized the first National Commission on Digestive Diseases. The Commission was charged with assessing the state of digestive diseases in the United States identifying areas in which improvement in the management of digestive diseases could be achieved, and creating a long-range plan to recommend resources to effectively deal with promoting the GI research endeavor. The Commission, because it provided a credible roadmap for research and generated enthusiasm within the biomedical community, precipitated a number of research breakthroughs.

In a time of limited fiscal resources to pursue an almost boundless reservoir of scientific opportunity, it is all the more imperative that the most promising avenues of research are traveled and that only the highest quality grants, trials, centers, and other programs are awarded funds. If the work of the first Commission serves as precedent, this initiative will once again galvanize the government, the research community, and the expanding population of people suffering from digestive diseases in a comprehensive and cost-effective national campaign to end the scourge of digestive disorders. Like its predecessor, the Commission should be directed to develop and recommend a long-range plan for the use and organization of national resources to effectively deal with digestive diseases.

I would again thank you Mr. Chairman and the members of this subcommittee for holding this important hearing and ask that the committee pass ***H.R. 290, The Inflammatory Bowel Disease Act and H.R. 3756, The National Commission on Digestive Diseases Act*** as soon as possible.