

**STATEMENT OF**  
**MR. GARY SINDERBRAND**  
**CHAIRMAN, NATIONAL BOARD OF TRUSTEES**  
**CROHN'S AND COLITIS FOUNDATION OF AMERICA**  
**PRESENTED TO THE HOUSE APPROPRIATIONS SUBCOMMITTEE ON LABOR,**  
**HEALTH AND HUMAN SERVICES, EDUCATION AND RELATED AGENCIES**  
**REGARDING FY10 APPROPRIATIONS FOR THE DEPARTMENT OF HEALTH AND**  
**HUMAN SERVICES**  
**MARCH 18, 2009**

**SUMMARY OF FY10 RECOMMENDATIONS:**

- 1) **7% INCREASE FOR THE NATIONAL INSTITUTES OF HEALTH.**
- 2) **\$700,000 FOR THE NATIONAL INFLAMMATORY BOWEL DISEASE EPIDEMIOLOGICAL PROGRAM AT THE CENTERS FOR DISEASE CONTROL AND PREVENTION.**
- 3) **COMMITTEE RECOMMENDATIONS SUPPORTING THE ESTABLISHMENT OF A PEDIATRIC INFLAMMATORY BOWEL DISEASE PATIENT REGISTRY.**

Mr. Chairman and members of the Subcommittee, thank you for the opportunity to speak with you today on behalf of the 1.4 million Americans living with Crohn's disease and ulcerative colitis. As Congressman Jackson mentioned, my name is Gary Sinderbrand and I have the privilege of serving as the Chairman of the National Board of Trustees for the Crohn's and Colitis Foundation of America. CCFA is the nation's oldest and largest voluntary organization dedicated to finding a cure for Crohn's disease and ulcerative colitis -- collectively known as inflammatory bowel diseases.

Let me say at the outset how appreciative we are for the leadership this Subcommittee has provided in advancing funding for the National Institutes of Health. Hope for a better future for our patients lies in biomedical research and we are grateful for the recent investments that you

have made in this critical area.

Mr. Chairman, Crohn's disease and ulcerative colitis are devastating inflammatory disorders of the digestive tract that cause severe abdominal pain, fever and intestinal bleeding. Complications include arthritis, osteoporosis, anemia, liver disease and colorectal cancer. We do not know their cause, and there is no medical cure. They represent the major cause of morbidity from digestive diseases and forever alter the lives of the people they afflict – particularly children. I know, because I am the father of a child living with Crohn's disease.

Seven years ago, during my daughter, Alexandra's sophomore year in college, she was taken to the ER for what was initially thought to be acute appendicitis. After a series of tests, my wife and I received a call from the attending GI who stated coldly: Your daughter has Crohn's disease, there is no cure and she will be on medication the rest of her life. The news froze us in our tracks. How could our vibrant, beautiful little girl be stricken with a disease that was incurable and has ruined the lives of countless thousands of people?

Over the next several months, Alexandra fluctuated between good days and bad. Bad days would bring on debilitating flares which would rack her body with pain and fever as her system sought equilibrium. Our hearts were filled with sorrow as we realized how we were so incapable of protecting our child.

Her doctor was trying increasingly aggressive therapies to bring the flares under control. Asacol, Steroids, Mercaptopurine, Methotrexate and finally Remicade. Each treatment came with its own set of side effects and risks. Every time A would call from school, my heart would jump before I picked up the call in fear of hearing that my child was in pain as the flares had returned. Ironically, the worst call came from one of her friends to report that A was back in the ER and being evaluated by a GI surgeon to determine if an emergency procedure was needed to clear an intestinal blockage that was caused by the disease. Several hours later, a brilliant surgeon at the University of Chicago, removed over a foot of diseased tissue from her intestine. The surgery saved her life, but did not cure her. We continue to live every day knowing that the disease could flare at any time with devastating consequences.

From the point of hearing the news, I refused to accept the fact that this disease could not be cured. As I studied all the relevant data I could find, I reached out to the organization that seemed to be repeatedly mentioned, The CCFA. This organization is leading the fight in research, education and support on behalf of the 1.4myn Americans that suffer from these illnesses.

I made a pest of myself at the National office seeking knowledge about how the fight was being staged. The more I learned the more I believed that we could do better. I was invited to join the national board and 6 years later, I have the privilege of leading an extraordinary staff of professionals and a network of volunteers across our entire country.

We are making dramatic progress that is the result of the scientific excellence of our funded researchers and our volunteer scientific leadership as well as the rapid advancement of available technology. It is now not "if" we will cure IBD, but "when"

The time to a cure is now a function of available funding.

Mr. Chairman, I will focus the remainder of my testimony on our appropriations recommendations for fiscal year 2010.

## **RECOMMENDATIONS FOR FISCAL YEAR 2010**

### **1) NATIONAL INSTITUTES OF HEALTH**

Throughout its 40 year history, CCFA has forged remarkably successful research partnerships with the NIH, particularly the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which sponsors the majority of IBD research, and the National Institute of Allergy and Infectious Diseases (NIAID). CCFA provides crucial “seed-funding” to researchers, helping investigators gather preliminary findings, which in turn enables them to pursue advanced IBD research projects through the NIH. This approach led to the identification of the first gene associated with Crohn's -- a landmark breakthrough in understanding this disease.

To further accelerate genetic research and advance understanding of IBD, NIDDK issued a research solicitation to establish an IBD Genetics Consortium approximately 8 years ago. This effort was informed by recommendations from external experts. Funding for the Consortium's six centers began in 2002, and intensive data and sample collection, genetic analysis, and recruitment of new patients and their families have been under way. In 2006, the Consortium published the major discovery of a new IBD gene. Some sequence variations in this gene, called *IL23R*, were found to increase susceptibility to IBD, while another variant actually confers protection. This gene was known previously to be involved in inflammation, and its newly-discovered association with IBD may lead to the development of better therapies for IBD. In recognition of the success of the Consortium's large-scale collaborative effort, NIDDK decided to continue support for the program beyond its initial 5-year period which was slated to end in FY07.

Renewed funding in FY08 has enabled the Consortium to continue its genetic studies and recruit additional patients and relatives (as well as subjects without IBD for comparison). This expansion will facilitate the identification of additional predisposing genes and enable genetic analyses of certain patient subgroups, such as those from minority populations or those who experience an early-onset form of IBD. These findings may then be used to pursue genetically-based diagnostic tests that allow for earlier diagnosis and treatment intervention. In addition, the data can be used to identify new molecular targets for therapeutic development that are specifically targeted to a unique subset of patients.

Mr. Chairman, we are grateful for the leadership of Dr. Stephen James, Director of NIDDK's Division of Digestive Diseases and Nutrition, for pursuing this and other opportunities in IBD research aggressively. Fortunately, the field of IBD is widely viewed within the scientific community as one of tremendous potential. CCFA's scientific leaders, with significant

involvement from NIDDK, have developed an ambitious research agenda entitled “Challenges in Inflammatory Bowel Diseases” that seeks to address many opportunities that currently exist. We look forward to working with NIDDK and the Subcommittee to pursue these research goals in the coming years.

For FY10, CCFA joins with other patient and medical organizations in recommending a 7% increase in funding for the NIH. We specifically encourage the subcommittee to support the invaluable work of the NIDDK and NIAID.

## **2) CENTERS FOR DISEASE CONTROL AND PREVENTION**

### **INFLAMMATORY BOWEL DISEASE EPIDEMIOLOGY PROGRAM**

Mr. Chairman, as I mentioned earlier CCFA estimates that 1.4 million people in the United States suffer from IBD, but there could be many more. We do not have an exact number due to these diseases' complexity and the difficulty in identifying them.

We are extremely grateful for your leadership in providing funding over the past five years for an epidemiology program on IBD at the Centers for Disease Control and Prevention. This program is yielding valuable information about the prevalence of IBD and increasing our knowledge of the demographic characteristics of the IBD patient population. If we are able to generate an accurate analysis of the geographic makeup of the IBD patient population, it will provide us with invaluable clues about the potential causes of IBD.

Appreciating Congressman Kennedy's strong interest in autoimmune diseases like IBD, I should note that the latest phase of this project focuses on Rhode Island. The “Ocean State Crohn's & Colitis Area Registry” is identifying each new case of inflammatory bowel disease diagnosed in the state. The result will be a unique, population-based cohort of newly diagnosed patients to be followed prospectively over time---the first of its kind in the U.S., and one of very few such cohorts in the world. The goals of the study include: 1) describing the incidence rates of Crohn's disease and ulcerative colitis; 2) describing disease outcomes; and 3) identifying factors that predict disease outcomes. To date over 85 newly diagnosed patients of all ages have been enrolled into the study.

Mr. Chairman, to continue this important epidemiological work in FY10, CCFA recommends a funding level of \$700,000, an increase of \$16,000 over FY09.

### **PEDIATRIC INFLAMMATORY BOWEL DISEASE PATIENT REGISTRY**

Mr. Chairman, the unique challenges faced by children and adolescents battling IBD are of particular concern to CCFA. In recent years we have seen an increased prevalence of IBD among children, particularly those diagnosed at a very early age. To combat this alarming trend CCFA, in partnership with the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition, has instituted an aggressive pediatric research campaign focused on the following areas:

- Growth/Bone Development - How does inflammation cause growth failure and bone disease in children with IBD?
- Genetics – How can we identify early onset Crohn's disease and ulcerative colitis?
- Quality Improvement - Given the wide variation in care provided to children with IBD, how can we standardize treatment and improve patients' growth and well-being?
- Immune Response - What alterations in the childhood immune system put young people at risk for IBD, how does the immune system change with treatment for IBD?
- Psychosocial Functioning – How does diagnosis and treatment for IBD impact depression and anxiety among young people? What approaches work best to improve mood, coping, family function, and quality of life.

The establishment of a national registry of pediatric IBD patients is central to our ability to answer these important research questions. Empowering investigators with HIPPA compliant information on young patients from across the nation will jump-start our effort to expand epidemiologic, basic and clinical research on our pediatric population. We encourage the Subcommittee to support our efforts to establish a Pediatric IBD Patient Registry with the CDC in FY10.

Once again Mr. Chairman, thank you very much for the opportunity to be with you today. I look forward to any questions you may have.

