

# To Make a Difference:

## The Founding of the Crohn's and Colitis Foundation of America

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### Abstract

In 1965, with the help of Dr. Henry D. Janowitz, Irwin M. Rosenthal established the Foundation for Research in Ileitis, Inc., now known as the Crohn's and Colitis Foundation of America, Inc. He was joined shortly thereafter by William D. Modell. At that time, the entire annual NIH budget for research on inflammatory bowel disease was only \$25,000. Successful fund raising made it possible to recruit a research fellow at The Mount Sinai Hospital in the Division of Gastroenterology to study ileitis. Thereafter, the efforts of the foundation expanded nationwide. It supported a nationally coordinated research program and sponsored education for physicians, patients and the public. In addition, it established support groups to help patients and their families cope with Crohn's disease and ulcerative colitis. With the energy and philanthropy of the foundation's many lay leaders, tens of millions of dollars have been raised for research and education in inflammatory bowel disease.

**Key Words:** Ileitis, ulcerative colitis, colitis, regional enteritis, Crohn's disease, Crohn's and Colitis Foundation of America.

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IN 1965 HENRY D. JANOWITZ, M.D. and Irwin M. Rosenthal took the first steps in creating what was to become the world's largest public, non-profit inflammatory bowel disease (IBD) research, education and support organization: the Crohn's and Colitis Foundation of America, Inc. (CCFA). Each brought to their partnership a unique set of abilities and a deep commitment to the major goal of the foundation: to find the cause and cure for Crohn's disease and ulcerative colitis. Dr. Janowitz provided the expertise of a skilled clinician and scientist who, as chief of the Division of Gastroenterology of The Mount Sinai Hospital, had the authority to determine the direction of research and clinical care. Irwin Rosenthal, an attorney, provided the organization legal and leadership skills. The establishment of the foundation was completed shortly thereafter when Bill Modell, Chairman of the Board of the Modell's Sporting Goods chain, joined as a co-founder, providing the fund-raising, organizational and networking capabilities of one of the city's leading merchants.

Irwin was to remain president of the foundation for 10 years, and Henry, the founding chairman of the National Scientific Advisory Committee (NSAC) for 8 years. The third founding partner, Bill Modell, served as Chairman of the Board for 10 years. All three were critical to the financial success of the foundation as it grew over the years, changing its name from the Foundation for Research in Ileitis, to the National Foundation for

Ileitis and Colitis (NFIC), and finally to the Crohn's and Colitis Foundation of America.

Henry D. Janowitz, MD, the physician member of this unique partnership, started his medical career at The Mount Sinai Hospital, concentrating on basic research in pancreatic inflammatory disease. In 1952, Dr. Janowitz moved into clinical medicine and, with the influence of Drs. Crohn and Ginzburg, together with the sheer number of IBD patients that he saw at Mount Sinai, was drawn into research on inflammatory bowel disease, publishing a number of important papers that advanced the knowledge of IBD clinical manifestations.

In 1958, Dr. Janowitz was asked by Dr. Alexander Gutman, the chief of Medicine at Mount Sinai, to form a division of gastroenterology. From the start, he knew that the division would have to engage physicians to combine classical practice with the intellectual rigor and academic curiosity of a laboratory scientist or clinical investigator. This philosophy prevailed, as he went on to train more than 125 fellows including Drs. Burton I. Korelitz, Daniel H. Present, Peter Banks, David Sachar, Lloyd Mayer, Jerome Waye, Lawrence Brandt, Eugene Strauss and dozens of others who, in time, would make their own contributions to the field. Dr. Janowitz's enthusiasm and expertise would soon play a major role in the founding of the Crohn's and Colitis Foundation of America.

In August 1956, Suzanne and Irwin Rosenthal were finally married — after several postponements because of Suzanne's painful and mysterious intestinal illness. Some three years later, the problem was diagnosed by Dr. Janowitz as ileitis. At that time, there were few

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medical and surgical treatments for this disease of unknown etiology.

Irwin, a young Yale Law School graduate and attorney with one of New York's leading corporate securities law firms, had been an activist in a number of civic and political organizations. So it was not unusual for him to challenge Dr. Janowitz, demanding of him a response to a question formed in the heat of his and Suzanne's deep frustration and anger, "Why doesn't someone do something about it?" Dr. Janowitz responded by challenging Irwin to fund a gastroenterology fellow to concentrate on ileitis research. It would cost at least \$25,000 annually, which Dr. Janowitz informed Irwin was the amount of ileitis research then funded by the National Institutes of Health. Irwin accepted the challenge.

By early 1963, they were planning the establishment of an organizational effort to start "doing something about it." On December 17, 1965, the Foundation for Research in Ileitis, Inc. was officially incorporated in New York State, with Dr. Janowitz as its director of research and Irwin as its president. They now had the legal authorization to start raising money in New York State to support research. Together, they formulated the lay and medical partnership philosophy of the foundation; many of its principal medical research and research training concepts and programs are still in force today. They also determined that the NIH grant review system would be utilized to protect the quality of the research and the credibility of the foundation. All research monies, no matter where they came from, would flow into a single research fund, to be appropriated as determined by the grant reviewers and the Board of Trustees.

In January 1966, the very first meeting of the Board of Trustees of this new foundation was held at The Mount Sinai Hospital. The principles espoused by Dr. Janowitz and Irwin were unanimously approved. Irwin and Henry particularly had recruited Drs. Burrill Crohn, Leon Ginzburg and Gordon Oppenheimer, the three scientist-clinicians who discovered ileitis, as honorary co-chairmen of its scientific advisory board. Also recruited were Dr. Arthur H. Aufses, Jr., Suzanne's surgeon; Dr. Arthur Ludwig, her internist; Dr. Samuel K. Elster; Dr. Richard Marshak, the leading abdominal radiologist; and others who cared deeply about helping this young couple and Henry to find the cause and cure of ileitis. Friends and clients of Irwin's completed the lay portion of the foundation Board.

In 1966, with the foundation's legal basis in place, the research program officially began.

Daniel H. Present, one of Henry's gastroenterology fellows, was recruited to organize a comprehensive research program, by compiling a list of existing and planned research projects. Mount Sinai gastroenterologists, surgeons, radiologists, nutritionists and immunologists were recruited to work either individually or jointly on a multidisciplinary approach to "A Comprehensive Study of Regional Enteritis," including the effects of diet on motility, the mechanisms that cause kidney stones in ileitis patients, and the immunologic status of ileitis. The studies were conducted from 1966 to 1974, by Burton I. Korrelitz, Robert Taub, Shelly Brown, Gerald Friedman and Charles Gerson, doctors then at Mount Sinai. One summer, a Mr. Barry Collier, then a medical student at New York University, was recruited to assist Dr. Present. Dr. Collier would later become the Murray M. Rosenberg Professor and chairman of the Department of Medicine at the Mount Sinai School of Medicine.

To conduct these studies, a small space in an unused apartment at 19 East 98th Street, provided by Mount Sinai, became the "research center." The bathtub was used to store pharmaceutical supplies, including those provided by Pharmacia, an early supporter of the foundation, to study the effects of Azulfidine suppositories on the treatment of proctitis. Beds for research patients were promised, and a group of patients was admitted to the Clinical Research Center, supported by a grant from the NIH. These patients were evaluated for various motility disturbances and symptomatology. Some patients remained under observation for as long as three weeks.

In 1966, with the Rosenthals' dining room table used as the foundation's "administrative office," Irwin began the fund-raising efforts which resulted in \$25,000 for the first year's research. He accomplished this by letters of appeal concerning Suzanne's battle with ileitis. He sent them to family and friends, and to more than 1,000 members of his synagogue, with the blessing and permission of Rabbi Israel Mowshowitz. He urged them to help him raise funds to support ileitis research at Mount Sinai, and raised several thousand dollars. Each time Suzanne was hospitalized that year, and in future years, Irwin would prowling the halls of Mount Sinai to recruit the fathers, husbands and wives of other ileitis patients on the medical and surgical floors, to help raise money. Suzanne and Jane Present were recruited to prepare letters to send to Dr. Crohn's ileitis patients, asking for their assistance.

In the spring of 1966, Irwin asked Irving Rubin, from Detroit, Michigan, whose daughter

was hospitalized at Mount Sinai, to help. Irving recruited his family and business associates, and he himself contributed funds for a very significant research effort. He was asked to underwrite an important conference with eminent gastroenterologists, on designing clinical trials, including a review of Drs. Present and Korelitz's proposed research protocol. Invited to attend were Dr. Joseph B. Kirsner of the University of Chicago, Dr. Fred Kern of the University of Denver, and Dr. Thomas Chalmers, a world renowned expert in the design of clinical trials. Dr. Chalmers, who was then serving at the NIH, would become the President/Dean of Mount Sinai in 1973.

While planning the research program of this new organization, Dr. Janowitz and his associates saw that clinical trials on the use of pharmaceuticals for ileitis were to be a major element. Dr. Daniel H. Present was awarded the first grant from the Foundation for Research in Ileitis, to prospectively study the pharmacological and therapeutic properties and side effects of 6-mercaptopurine (6-MP) in a controlled, double-blind study. Collaborators in the study included Drs. Burton I. Korelitz, David Sachar, and Nathaniel Wisch. The primary therapeutic effect to be studied was improvement of bowel function, fistulae and steroid sparing. There was careful monitoring of blood count to avoid marrow depression. The controlled trial ultimately took eight years to complete and was published in the *New England Journal of Medicine* in 1980 (N Engl J Med 1980; 302:981–987). An update on the history of drug treatment of inflammatory bowel disease can be found in Mt Sinai J Med 2000; 67:214–226.

This first Foundation for Research in Ileitis grant award and other Mount Sinai studies were to have an immense impact on today's scientific knowledge concerning inflammatory bowel disease. It was Burton I. Korelitz, one of Suzanne's original physicians at Mount Sinai, who had published a number of articles concerning ulcerative colitis (particularly with regard to the use of 6-MP in children and adults), who suggested to Irwin that the foundation include the study of ulcerative colitis in its research program. Dr. Janowitz concurred, and ulcerative colitis studies were added to the foundation's research portfolio. In 1967, the name of the foundation was changed to the National Foundation for Ileitis and Colitis (NFIC).

Bill Modell and his dynamic and talented wife, Shelby, joined the foundation efforts when their son Michael, then 14 years old, was diagnosed with ileitis by Dr. Burrill Crohn. They

were referred to Irwin and Suzanne to learn how they could help find the cause and cure of the disease afflicting their son. With Michael as their inspiration, they provided the strong financial support for the foundation that was critical to its success, as well as to the progress of the ileitis and colitis research programs of the Division of Gastroenterology at Mount Sinai.

The Modells, experienced fund-raisers with strong business connections from their sporting goods stores in New York State, and with legions of caring family and friends, offered to chair the foundation's first major fund-raising event. In December 1967, a dinner dance at the glamorous nightclub of the Americana Hotel was arranged. With the Modells' huge and devoted following, Irwin and Suzanne's friends and clients, and members of the Board, the commitment to the hotel was met. The gala featured entertainment by Ella Fitzgerald, as well as a brief ceremony to honor Drs. Crohn, Ginzburg, and Oppenheimer.

Subsequently, with each passing year, with Shelby and Bill Modell as dinner chairpersons, the size of the banquet room increased to accommodate the burgeoning crowds of generous contributors. In addition to funds raised from the dinner, there were funds raised from journal ads for a journal book dedicated to the honorees. In the early years, Jane Present edited these successful journals. The list of honorees through the years has included people from the world of merchandising, politics, banking, government, medicine, pharmaceuticals and entertainment. The honorees also added to the excitement and glamour of the dinner dances, helping make them successful events. The net proceeds from the journal and the dinner, which came to be known as the Greater New York Chapter Annual Dinner, for many years contributed one-third of the national organization's gross revenue.

Today, the dinner, the largest single fund-raising event, still provides more than \$1 million annually to the budget of the national foundation, now called the Crohn's and Colitis Foundation of America (CCFA). Bill Modell and Shelby co-chaired this dinner for 25 consecutive years until 1993, when they turned the dinner chairmanship over to their son Michael and his wife Abby, who continue in this role. Through the years, Shelby and Bill, and the Modell family have been responsible for raising more than \$40 million for research and education. Bill Modell is still chairman of the board, emeritus, and Shelby is national vice-president of the Board. They have been instrumental in the founding and development of the foundation's

Long Island chapter and the Gold Coast chapter of Boca Raton, Florida, contributing to the great financial success of each of these chapters.

Suzanne Rosenthal was the original inspiration for the founding of the CCFA and for Mount Sinai's intensified research efforts in the field of ileitis. She brought to the organization the management skills she learned at her college's business school and the wide knowledge she acquired about ileitis and colitis, and their treatment. These were of great value when she established the ladies auxiliary of the Board, with officers including Shelby Modell, Jane Present, Toby Fuchs, Dee Hollander and other women dedicated to building the foundation. Suzanne served as president and created committees for fund-raising, membership and patient education. Anticipating the growth of chapters, she wrote the operating manuals for chapter governance, membership, and education, as well as for chapter scientific advisory committees. Suzanne was well enough between hospitalizations to travel to many cities to help develop NFIC chapters along the East Coast, starting with the New York City boroughs and Long Island, then New Jersey, Westchester, Rhode Island, Boston, Philadelphia, Washington, D.C. and Greater Miami. In addition, Suzanne formed the government advocacy committee to help increase the NIH – National Institute for Diabetes, Digestive and Kidney Diseases' (NIDDK) inflammatory bowel disease research portfolio. Suzanne later became national president and remains chairman of the Board, emeritus.

In New York City, open education meetings for the public, with panels of ileitis and colitis medical experts (often Mount Sinai gastroenterologists), were held monthly. Upwards of one hundred patients and their families turned out for each meeting. In addition to the foundation's top priority of finding the cause and cure of inflammatory bowel diseases, patient and professional education became important goals. Eventually, mutual-help support groups would appear, first in New York City. This important program also became a major priority of the foundation.

During its first decade, the foundation was viewed as a Mount Sinai Hospital project, even though grants had been awarded to many researchers at other hospitals. In order to alter that perception, chairmanship of the National Scientific Advisory Board was to be rotated nationally among the leading IBD clinicians and scientists. NFIC President Irwin Rosenthal recruited Dr. Joseph B. Kirsner from the University of Chicago Medical Center as National Scientific Advisory

Board chairman, and Dr. Kurt Isselbacher from Massachusetts General Hospital as Grant Review Committee chairman. He was to succeed Dr. Kirsner as NSAC chairman. Dr. Burton I. Korelitz, then chairman of Gastroenterology at Lenox Hill Hospital in New York, succeeded Dr. Isselbacher and formed subcommittees of the NSAC to address research training, professional education and patient education. He encouraged IBD clinical research investigators to participate more actively on committees, and organized conferences with research scientists and clinicians to exchange ideas. Word was widely circulated that funds were available to investigators from all over the United States and abroad.

Today, the CCFA has a large suite of offices at 386 Park Avenue South at 27th Street in New York City, to appropriately service an organization with a \$21 million budget. The CCFA has 60,000 lay and physician members. Its 55 chapters across the country offer more than 350 support groups. It has published four books for patients and distributes annually more than one million educational IBD brochures, newsletters, etc. CCFA publishes *Inflammatory Bowel Disease*, its own medical journal, which is now listed in the Index Medicus. The CCFA is a partner with the NIH in research conferences and workshops that significantly advance IBD research. Through its strong Congressional advocacy efforts, it has helped two NIH institutes to progressively expand their funding for IBD research portfolios. Today, the NIDDK funds more than \$21 million in IBD research grants. The National Institute for Allergy and Infectious Diseases (NIAID) funds close to \$3 million for IBD immunology research.

More than 75% of the research investigators funded by the NIH in the last five years were first funded with CCFA seed money to help them develop and refine their projects. This was the vision of its founders. Irwin and William remain active with the foundation to this day. The CCFA continues to provide seed money for the development of IBD research to enable investigators to compete more successfully for the highly competitive NIH grant awards that provide considerably more funds for research projects.

As CCFA enters a new millennium in which many questions about IBD remain to be answered, clinicians and scientists at Mount Sinai and around the world are increasingly more hopeful that the cause and cure of these diseases will be found within the next decade. When this happens, CCFA members will know that they have played an important part in this success — that they have made a difference.