

SPECIAL
EDITION
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SPECIAL
EDITOR
LOREN
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Cancer
Organizations
Working
Together

ON
"Joint Advocacy Day
for Blood Cancers"

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Blood Cancer Advocacy

Special Edition

Congressional Hearing and Advocacy Day for Blood Cancers: Huge Success

The Congressional Hearing and Joint Advocacy Day event for Blood Cancers held on June 20th and 21st, 2001 was an overwhelming success culminating in Senator Kay Bailey Hutchison's announcement of her sponsorship of a bill requesting \$250 million for blood cancer research in fiscal year 2002.

The Hearing and Advocacy Day was the result of a year's worth of hard work by George Dahlman (Leukemia and Lymphoma Society, LLS), Kathy Giusti (Multiple Myeloma Research Foundation, MMRF), and Ilene Penn Miller (Cure For Lymphoma Foundation, CFL) who were selected as the advocacy representatives for the Leukemia, Lymphoma and Myeloma Progress Review Group (LLM-PRG) initiated by the National Cancer Institute (NCI). Knowing there is strength in numbers, George, Kathy and Ilene reached out to all blood cancer organizations who took an active role in helping to identify advocates and refine the message. The combined effort resulted in over 300 leukemia, lymphoma and myeloma advocates representing 39 states actively participating in advocacy training, making Congressional visits, attending the hearing and raising the awareness of blood cancers like never before.



Co-Chairs for the Blood Cancer Congressional Hearing and Joint Advocacy Day (L-R) Ilene Penn Miller (CFL), George Dahlman (LLS) and Kathy Giusti (MMRF)



A very special thank you goes to Geraldine Ferraro, a key witness at the special Congressional hearing for blood cancers. Diagnosed with multiple myeloma in 1998, former Vice Presidential candidate, Ferraro, eloquently shared her battle with the disease and urged Congress to take action around blood cancer research.



Advocates Trained and United Storm Capitol Hill

Representing the nearly 700,000 Americans living with a blood cancer today and the more than 110,000 Americans who will be diagnosed with leukemia, lymphoma or myeloma this year, more than 300 advocates gathered together for a day of training. Grouped together by state, advocates were given their marching orders for Congressional visits by Elizabeth Goss of Bennett Turner and Coleman regarding recommending Congressional initiatives to accelerate the development of new therapies for blood-related cancers. Representative Deborah Pryce (OH), gave pointers on meeting with members of the legislature and provided insight around her bill "Access to Cancer Clinical Trials Act of 2001." Dr. Wyndham Wilson, Executive Director of the NCI, also educated advocates about the LLMPRG initiatives and recommendations.



Senator Charles Schumer (NY) (center) meeting with over 40 blood cancer advocates, is flanked by CFL public policy Committee Members (L-R) Joan and Dennis McComb, Eric Betron, Alayna Kassan, and myeloma advocate Carol Goldschein .

Well trained, the advocates took their united message to the Hill making nearly 300 congressional visits on the afternoon of June 20th urging their Members of Congress to:

- Require the NCI to develop, by December 31, 2001, a budget and business plan that will guide implementation of the LLMPRG research recommendations;
- Enact H.R. 1624 / S. 913, the Access to Cancer Therapies Act of 2001 to guarantee Medicare reimbursement for new oral anti-cancer therapies;
- Enact H.R. 967, the Access to Cancer Clinical Trials Act of 2001;
- Support the Congressionally Directed Medical Research Program at the Department of Defense (DoD) and its expansion to include research on hematological cancers.



As Karen Andrews, twin sister of Kathy Giusti and co-founder of the MMRF, addresses Senator Joseph Lieberman's office, (R-L) Paul Giusti and leukemia advocates Jeffrey and Jonathan Treiber listen intently.



Carol Krupwick (L) and Libby Glazer (R) thank Rep. Vic Snyder (AR) at the Capitol Hill reception for his commitment to introduce companion legislation in the House of Representatives to increase funding for blood cancer research.

Senators Kay Bailey Hutchison (TX) and Sam Brownback (KS); and Representatives Marge Roukema (NJ), Philip Crane (IL), and Vic Snyder (AR), mingled with advocates at the Capital Hill reception that concluded the day and announced their enthusiastic support of blood cancer research.



After making opening remarks at the reception, Senator Kay Bailey Hutchison relaxes with her brother Allan Bailey (right) and Dr. Kenneth Anderson (center).

Blood Cancer Congressional Hearing

The Congressional Hearing on Blood Cancers sponsored by the Senate Appropriations Subcommittee for Labor, Health and Human Services (HHS) and Education was a pivotal part of the two-day event. Chairman and Senator Tom Harkin (IA), and Senators Arlen Specter (PA), Kay Bailey Hutchison (TX), Patty Murray (WA), Ted Stevens (AK), and Barbara Mikulski (MD) had insightful questions for the witnesses and enthusiastic praise for the overflowing room of passionate advocates.



Dr. Richard Klausner, testifies before the Senate Appropriations Subcommittee for Health and Human Services.

Dr. Richard Klausner, Director of the NCI, spoke first focusing on the human toll of leukemia, lymphoma and myeloma and the scientific and therapeutic advances that must be prioritized in cancer research. The magnitude of blood cancer's impact in this country becomes readily apparent "if we lump leukemia, lymphoma and multiple myeloma together. Last year's figures show that the mortality rate for blood cancers was second only to lung cancer, 20% higher than colon cancer, one third higher than breast cancer and almost twice as high as prostate cancer."

Witnesses in the first panel were Dr. Sandra Horning, Professor at Stanford University School of Medicine; Larry Lucchino, President and CEO of the San Diego Padres and a survivor of non-Hodgkin's lymphoma; Dr. Hagop Kantarjian, Professor at M.D. Anderson



Hearing witnesses Dr. Sandra Horning and Larry Lucchino thank Sen. Arlen Specter (PA) (center) for being a key supporter of the landmark Congressional Hearing for blood cancers.

Cancer Center; and Miles Pendleton, a chronic lymphocytic leukemia survivor. Dr. Horning stressed the importance of partnerships between the NCI and pharmaceutical companies and prioritizing comprehensive insurance coverage. Lucchino emphasized activism aimed at public cancer education; federal funding of biomedical research; and private sector research efforts. "CFL and other private organizations make a valuable contribution to the field, and their financial resources are an important complement to federal research funding," he said. Paraphrasing an expression from the world of sports advertising, Lucchino added: "Life is short; research hard."

The hearings final panel of witnesses included Geraldine Ferraro, former Vice Presidential candidate and multiple myeloma patient; Kathy Giusti, President of the MMRF and multiple myeloma patient; Dr. Kenneth Anderson, Professor of Medicine at Harvard Medical School and Dana-Farber Cancer Institute; and John Holaday, Chairman, President & CEO of Entremed Inc. Ferraro, diagnosed with multiple myeloma in 1998, reminded the Senators that researchers and clinicians "need more awareness and attention to be paid to blood cancers so that people will test early and be diagnosed earlier;

they need research dollars to continue to search for new treatments and a cure, and they need faster approval by the FDA of new drugs."

Operating like a venture capital firm, the MMRF, "together with the LLS, the McCarty Cancer Foundation and the International Myeloma Foundation, will fund \$10 million in myeloma research this year. The NCI will distribute

\$18 million in funds. This is one of the highest ratios of private to public support seen in the cancer field," said Giusti. Dr. Anderson summarized his testimony with the statement "science advances now offer an unprecedented opportunity to effectively treat blood cancers. The roadmap to achieve this goal has been laid out by the LLMPRG process of the NCI."

In her compelling testimony, Giusti echoed the sentiment of her co-chairs Ilene Penn Miller and George Dahlman, and of all the advocates and witnesses present at the hearing... "You can make the Progress Review Group priorities a reality," she exclaimed.

"Right now we have a list of priorities that will reduce the time it takes to bring new compounds to market from the current 7.2 years to 2 years. That list must now be developed and quantified in terms of manpower, time and funding. We need a clear action plan by year-end," said Giusti.



You can help by writing to your congressman today! Go to <http://www.multiplemyeloma.org/events/writelegislator.html> for a sample letter you can use.

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Senator Hutchison to Support \$250 million for Blood Cancer Research in FY 2002



Senator
Kay Bailey Hutchison (TX)

Senator Kay Bailey Hutchison drew cheers at the Capitol Hill reception and the Congressional Hearing with the announcement of her bill, "The Hematological Cancer Research Investment and Education Act of 2001." S.1094 authorizes \$250 million in fiscal year 2002 for blood cancer research and another \$25 million to inform and educate the general public around blood cancers. "Although blood cancers account for 11% of all cancer deaths they only receive 5% of the NCI's

budget," Hutchison said. Co-sponsors of the bill include Senators Barbara Mikulski (MD), Patty Murray (WA) and Daniel Inouye (HI). Senator Hutchison's support of blood cancer research is a personal as well as a political priority as she shared with the public that her brother, Allan Bailey, is a multiple myeloma patient.

"Although blood cancers account for 11% of all cancer deaths they only receive 5% of the NCI's budget."



Kathy Giusti and Geraldine Ferraro share a personal moment of triumph after testifying before the HHS subcommittee to gain much needed support for blood cancer research.

Special thanks to the following companies for sponsoring Joint Advocacy Day for Blood Cancers: Ortho Biotech, Novartis, Eli Lilly, Corixa, IDEC and GlaxoSmithKline. This special edition newsletter was sponsored by Celgene.