

A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS ADDRESSING PUBLIC POLICY ISSUES IN CANCER

September 19, 2001

The Honorable Edward M. KennedyChair, Senate Health, Education, Laborand Pensions Committee315 Russell Senate Office Bldg.Washington, D.C. 20510

Dear Senator Kennedy:

The undersigned organizations, representing cancer patients, providers, and researchers, are writing to urge a balanced approach to the regulation of pain medications. Pain remains a major public health problem in the United States. Despite the availability of a number of drugs and techniques for treating pain, many individuals still suffer needlessly because their pain is inappropriately or inadequately treated.

At least half of those who die from cancer experience pain and other physical distress while dying, and many additional cancer patients will suffer debilitating pain at some point during their diagnosis, treatment, and long-term care. The ability of oncology professionals to prescribe and administer pain-reducing therapies is critical to providing quality cancer care.

Two reports from the Institute of Medicine (IOM), "Approaching Death: Improving Care at the End of Life" (1997) and "Improving Palliative Care for Cancer" (2001), provide convincing evidence that cancer-related pain is woefully undertreated. The 1997 report suggested that the problem of inappropriate pain management is attributable to two principal factors: 1) outdated and scientifically flawed laws and regulations related to the use of opioids; and 2) clinician, regulator, and public misunderstanding of the appropriate use of opioids. The findings were reiterated in the 2001 report.

The cancer community is dedicated to improving the knowledge of health care professionals and patients regarding pain management through clinical research, educational initiatives, training programs, and responsible advocacy. Research is critical for developing a better understanding of the causes of pain and addiction and for optimizing strategies for using pain medications. Education is also important, as some patients shy away from use of pain medications because of the fear of addiction and negative stigma. Some providers also have misconceptions about

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addiction and a fear that prescribing adequate amounts of pain medication may bring regulatory scrutiny. This reluctance to prescribe and use proper pain medications occurs despite the fact that there is extensive evidence indicating that cancer patients who use pain medications do not become drug abusers.

We are very sensitive to the problems that can result from diversion and abuse of pain medications, and we have been dismayed by the devastation experienced in some communities as a result of such abuse. The cancer community acknowledges the importance of efforts to prevent and reduce illegal use of pain therapies but believes that such policies should in no way threaten legitimate use of pain medication by people with cancer. As Congress considers options for addressing the troubling problem of opioid abuse, we remind you of the suffering of cancer patients and others who experience serious pain and recommend that you take no action that would unreasonably limit their access to proper pain medication. Any actions taken to deal with the abuses of pain-relieving drugs that inhibit oncology professionals from providing adequate pain relief will be a serious setback to our community's efforts to ensure compassionate and high-quality care.

We look forward to a continued dialogue with you and your colleagues on this important issue.

Sincerely,

cc:

Cancer Leadership Council

Alliance for Lung Cancer Advocacy, Support, and Education American Cancer Society
American Society of Clinical Oncology
American Society for Therapeutic Radiology & Oncology, Inc.
Association of American Cancer Institutes
Cancer Care, Inc.
The Children's Cause, Inc.
Coalition of National Cancer Cooperative Groups
Colorectal Cancer Network
Cure For Lymphoma Foundation
International Myeloma Foundation

National Alliance of Breast Cancer Organizations
National Coalition for Cancer Survivorship
National Patient Advocate Foundation
North American Brain Tumor Coalition
Oncology Nursing Society
Pancreatic Cancer Action Network
The Susan G. Komen Breast Cancer Foundation
The Wellness Community
US TOO! International, Inc.
Y-ME National Breast Cancer Organization

Kidney Cancer Association

The Honorable Christopher J. Dodd
The Honorable Tom Harkin
The Honorable Barbara A. Mikulski
The Honorable Jeff Bingaman
The Honorable Paul David Wellstone
The Honorable Patty Murray
The Honorable Jack Reed
The Honorable John R. Edwards
The Honorable Hillary Rodham Clinton
The Honorable Judd Gregg, Ranking Member

The Honorable Bill Frist
The Honorable Michael B. Enzi
The Honorable Tim Hutchinson
The Honorable John W. Warner
The Honorable Christopher S. Bond
The Honorable Pat Roberts
The Honorable Susan M. Collins
The Honorable Jeff Sessions
The Honorable Mike DeWine
The Honorable James M. Jeffords

Asa Hutchinson, Administrator Drug Enforcement Administration

Bernard A. Schwetz, D.V.M., Ph.D. Acting Principal Deputy Commissioner Food and Drug Administration