

NATIONAL BREAST CANCER COALITION

• a grassroots advocacy effort •

April 30, 1998

The Honorable Tom Daschle
U.S. Senate
Washington, DC 20510

Dear Senator Daschle:

On behalf of the National Breast Cancer Coalition (NBCC), I applaud Sens. Daschle and Kennedy and Reps. Gephardt and Dingell and the additional Congressional supporters of the "Patients' Bill of Rights Act of 1998." The NBCC is committed to working to ensure access to effective, quality health care for all Americans. We support this legislation which is an important step toward that goal.

The health care system in the U.S. is changing rapidly. NBCC believes it is vital that those changes do not come at the expense of quality care for consumers. While there have been excesses in the fee-for-service system, the growth of managed care and the drive to decrease costs also have led to abuses. Too often, choices of health care providers, treatment, hospital stays and clinical trial participation (to name a few) are determined by health insurance plans without regard to what constitutes quality care and thus is in the best interest of the consumer.

The NBCC believes that patients have fundamental rights, including: the right to receive accurate information about their health plans; access to the right providers; involvement in treatment decisions that are based on good science; confidentiality of their health information; protection from genetic discrimination; and coverage for routine health care costs associated with participation in clinical trials.

One of the NBCC's most pressing concerns is that managed care plans are increasingly refusing reimbursement for routine patient costs when breast cancer patients participate in approved clinical trials. The NBCC believes clinical research is our best hope for finding desperately needed science-based answers to deadly and debilitating diseases and improving the health of all Americans. Individual states, such as Maryland and Rhode Island (whose law has a specific cancer focus) have taken important legislative steps to protect clinical research, by ensuring health plans cover the routine patient costs of clinical trial participation. We are particularly pleased that the "Patients' Bill of Rights Act of 1998." will provide coverage for the routine patient costs incurred during approved clinical trial participation.

We applaud your leadership to ensure that consumer rights are firmly established into law. We look forward to continuing to work together.

Sincerely,

Frances M. Visco
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President