

**STATEMENT OF ELLEN STOVALL
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BEFORE THE
SENATE COMMITTEE ON FINANCE
SUBCOMMITTEE ON HEALTH
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Good morning, my name is Ellen Stovall. I am an almost 30-year two-time survivor of hodgkin's disease, a cancer of the lymphatic system. As President and CEO of the National Coalition for Cancer Survivorship, or NCCS, I have the privilege of translating my personal commitment to cancer care into an enriching professional experience. One of the oldest patient advocacy organizations, NCCS was founded in 1986 by and for people with cancer and those who care for them. Since 1992, when our headquarters moved to Washington, NCCS has increasingly focused on public policy as the most efficient way to ensure quality cancer care for all Americans, which is our core mission.

Given that mission, I am delighted to have the opportunity to address the question of quality cancer care from two perspectives: first, the impact on patients of potential changes to payment for chemotherapy in physician offices; and second, the shortfall in cancer drug coverage for Medicare beneficiaries who seek any of the life-extending drugs that are available only in oral form.

I am particularly pleased that these issues are being reviewed under the Subcommittee Leadership of Senator Rockefeller and Senator Snowe, both of whom have well-established track records on the issue of oral drug coverage for Medicare beneficiaries with cancer, as well as the more general question of access to quality care for people with cancer and other chronic diseases.

The limited coverage of oral cancer drugs currently available under the Medicare statute is almost exclusively due to the hard work and dedication of Senator Rockefeller from 1991, when his bill was first introduced, to 1993, when it became law. As a result of that legislation, Medicare covers oral anti-cancer drugs that also have an injectable dosage form. Unfortunately, there are only 7 such drugs, but they establish a clear precedent for cancer drugs to be treated differently by Medicare, and we are pleased that the Access to Cancer Therapies Act builds on that precedent. (I should also add that the entire cancer community is grateful for the strong, and ultimately successful, effort by Senator Rockefeller throughout the 1990's to persuade the Medicare program to cover routine patient care costs in cancer clinical trials.)

Senator Snowe has also been involved in a later, parallel effort to extend Medicare coverage to tamoxifen and other hormonal agents that successfully prevent recurrence of breast cancer but are not covered by the program because they are available only in oral form. S. 913 will address this shortfall and will also include other important drugs not currently covered, including hormonal agents for prostate cancer and thalidomide for multiple myeloma.

Coverage of these existing anti-cancer drugs will provide welcome relief to beneficiaries struggling to obtain access to life-extending cancer therapies. An equal or perhaps even greater cause for excitement is the prospect of coverage for the many promising new agents in the product pipeline. Our nation's substantial investment in biomedical research is finally beginning to pay dividends as translational and clinical research find ways to utilize our new understanding, through basic science, of the biological activity that leads to cancer.

With this new knowledge, scientists are able to design drugs that specifically target the gene or protein or cellular receptor that cause cancer and disrupt growth of cancer cells without collateral damage to surrounding tissue. These targeted drugs are a vast improvement over traditional chemotherapy, which threaten all cells in order to attack the more rapidly dividing cancer cells. The new drugs feature few and only relatively minor side effects.

The first of these drugs to emerge was STI-571, or Gleevec, approved last year for the treatment of chronic myelogenous leukemia, or CML, a rare but deadly blood cancer. CML patients taking this drug have been in remission for months with virtually no side effects. Previously, patients with CML faced two unpleasant alternatives that were both costly and toxic, bone marrow transplantation or high dose interferon therapy.

This year the Food and Drug Administration approved Gleevec for treatment of another rare cancer, known as gastrointestinal stromal tumor or GIST, for which there was previously no reliable treatment. The drug could also show activity in a variety of other solid tumors that express the same protein as CML and GIST, including cancers of the breast, lung and prostate

and some of the most deadly forms of brain tumor. A second targeted therapy, indicated for non-small cell lung cancer, is expected to be approved later this year.

All of this remarkable research and development activity will be for naught if patients cannot afford to access these new drugs. That is why this legislation introduced by Senators Rockefeller and Snowe (and currently enjoying more than 30 co-sponsors) is so timely and important. The need of beneficiaries with cancer is immediate, and the relief should also be immediate.

This leads to the question that begs to be answered by all of us who favor immediate passage of S. 913: why not wait for enactment of a comprehensive Medicare drug benefit that will cover these drugs as well as those to treat every other disease. In answering that question, I believe that each of us who support the Rockefeller-Snowe legislation also seeks comprehensive coverage. The fiscal and political hurdles to achieving that goal in the short run seem daunting, however, and, like the 20 national senior citizen advocacy groups that support this legislation, we would rather have a significant first step toward coverage than no movement at all.

It is important to recognize that, even if comprehensive coverage became law this year, the absence of an implementation strategy in place and the necessary infrastructure to support such comprehensive change would mean that seniors in all likelihood would not see the fruits of the legislation for several years. In contrast, your legislation would envision immediate coverage under the existing payment mechanisms of Medicare Part B. Some oral cancer drugs are already

being reimbursed under that system; adding more should pose no problem. (As an aside, let me say that this direct straightforward solution to a potential conundrum is completely characteristic of the effective pragmatic approach of both Senators Rockefeller and Snowe.)

My message, then, to you, Senators Rockefeller and Snowe, and to the Finance Committee, the Senate and the entire Congress, is: pass this legislation now so that beneficiaries with cancer can rest assured that they will have access to the best quality cancer care. The cost is relatively modest and will represent a down-payment on the cost of an eventual comprehensive Medicare drug benefit.

This leads me to the other topic for this hearing—reimbursement for chemotherapy services in physician offices—another matter of extreme concern to cancer patients. As we all know, the problem is that Medicare is paying too much for drugs and too little for the services required to administer the drugs in physician offices. The excessive payment for drugs is not something that anyone defends or wants to continue. At the same time, no one has suggested an orderly and effective way to reform payment for the associated services to correct what everyone perceives as a shortfall.

The position of patient advocates—not just my organization but the overwhelming majority of the groups comprising the Cancer Leadership Council—is that further study is needed before the system should be changed. The important background to the issue of further study is that Congresswoman Nancy Johnson drafted very specific legislation that was included in the 1999 Benefits Improvement and Protection Act detailing what questions should be

answered by the General Accounting Office (GAO) before Medicare sought to address the drug overpayments and physician services underpayments. Unfortunately, GAO did not answer those questions, and Medicare is thus left ill-equipped to take action.

As a member of the National Cancer Policy Board—an arm of the Institute of Medicine (IOM), I have worked with Mrs. Johnson's office and with the IOM staff to enlist the expert analysis of the IOM in addressing those unanswered questions. We should not underestimate the difficulty of assessing what services are necessary and at what cost in order to administer chemotherapy in a non-hospital setting. Even the GAO, with all its resources, essentially said it could not answer the questions that Mrs. Johnson inserted in the 1999 legislation, but I have not heard anyone assert that these are not important questions.

At the same time that we are told that overall payment to physicians for administering chemotherapy should be significantly reduced and further told that life-extending new oral cancer drugs will not be covered by Medicare, it is also being reported that hospital outpatient departments are not being paid adequately for new breakthrough drugs for cancer because pass-through payments under the new outpatient prospective payment system are either capped or not timely available or both. Thus, it seems that cancer treatment is under siege regardless of the setting in which that treatment is delivered. We have great concern about taking from one sector of the overall treatment system to pay for shortfalls in another sector.

Instead, I wonder if we couldn't recognize that we have an aging population increasingly subject to cancer, which is a disease of the elderly, and admit that more resources are correspondingly required to keep the treatment system functional. To some degree, we are the victims of our own success. Death can be a cheap alternative to treatment, and advances in cancer therapy have kept death at bay in many cancers. But that leaves more people dealing with cancer as a chronic disease.

Senator Rockefeller and Senator Snowe, regrettably I don't know where to find additional resources to meet what I think is a clear need. But I think it is important that patient advocates keep reminding our political leadership of the tremendous burden that cancer imposes on our people and the responsibility of government to assume its appropriate share of that burden.

Thank you for your time and the energy that you devote to these important issues.