

beneficiaries, regardless of where they live. A uniform advance directive would enable people to document the kind of care they wish to get at the end of their lives in a way that is easily recognizable and understood by everyone.

The compassionate care bill also focuses on the need to improve end-of-life care for Medicare beneficiaries. This bill will encourage seniors and families to have more open communication with health care providers concerning their preferences for end-of-life care. The bill also addresses the need to develop models of compassionate care and quality measures for medical care during this period.

Currently, there are few standards available to assess the quality of care provided to Medicare beneficiaries at the end of their lives. The tremendous geographic variation in medical care that currently exists reinforces the notion that many people do not receive care driven by quality concerns, but rather by the availability of medical resources in the community and other factors not related to quality care.

The bill requires the Secretary of Health and Human Services, in conjunction with the Health Care Financing Administration, National Institutes of Health, and the Agency for Health Care Policy and Research, to develop outcome standards and other measures to evaluate the quality of care provided to patients at the end of their lives.

The only Medicare benefit aimed at improving end-of-life care for Medicare beneficiaries is hospice care, which only serves a small number of beneficiaries. In 1994, the Medicare hospice benefit was provided to 340,000 patients for the last few weeks of their lives. The hospice benefit is limited to beneficiaries who have a terminal illness with a life expectancy of 6 months or less. A review of studies done by an Institute of Medicine panel found that 40 to 80 percent of patients with a terminal illness were inadequately treated for pain "despite the availability of effective pharmacological and other options for relieving pain."

The compassionate care bill provides funding for demonstration projects to develop new and innovative approaches to improving end-of-life care provided to Medicare beneficiaries, in particular those individuals who do not qualify for, or select, hospice care. Also, it includes funding to evaluate existing pilot programs that are providing innovative approaches to end-of-life care.

With a few exceptions, Medicare does not generally pay the cost of self-administered drugs prescribed for outpatient use. The only outpatient pain medications currently covered by Medicare are those that are administered by a portable pump. The pump is covered by Medicare as durable medical equipment, and the drugs associated with that pump are also covered. It is widely recognized among physicians treating patients with cancer and other life-threatening diseases that self-administered pain medications, including oral drugs and transdermal patches, offer alternatives that are equally effective at controlling pain, more comfortable for the patient, and much less costly than the pump. The bill requires Medicare coverage for self-administered pain medications prescribed for outpatient use for patients with life-threatening disease and chronic pain.

Instead of allowing these important end-of-life issues to be eclipsed by the debate over physician-assisted suicide, this legislation seeks to ensure that the medical care of pa-

tients at the end of their lives reflects their desires, increases comfort to the extent possible and is of the highest quality.

INTERNAL REVENUE SERVICE RESTRUCTURING AND REFORM ACT OF 1997

SPEECH OF

HON. MAX SANDLIN

OF TEXAS

IN THE HOUSE OF REPRESENTATIVES

Wednesday, November 5, 1997

Mr. SANDLIN. Mr. Speaker, I rise today in strong support of H.R. 2676, the IRS Restructuring and Reform Act. I thank the gentleman from Maryland [Mr. CARDIN] and the gentleman from Ohio [Mr. PORTMAN] for their hard work on this issue. I am a cosponsor of their legislation, H.R. 2292, which is the foundation of the legislation we are passing today, and I have been a strong supporter of initiatives to improve customer service, increase management accountability, and give the taxpayer expanded rights.

The oversight board should bring private sector expertise to the IRS, streamlining procedures, easing citizen interaction, and improving efficiency. The provisions regarding the oversight board have been carefully drafted to avoid privacy violation and conflict of interest concerns while still injecting the experience and skills of business managers and tax experts to the IRS agency. Taxpayers should see immediate and long lasting improvements in the service and efficiency of the agency.

The provisions in this bill that shift some of the burden of proof in tax disputes from the taxpayer to the IRS encourage my belief that the Government can become more responsive and more accountable to the people. When law-abiding citizens live in fear of threats from Government bureaucrats, it is time to change the way the Government conducts its business. Most taxpayers accept IRS challenges to valid exemptions because they are intimidated or can't afford to fight the Federal Government in court. By shifting the burden of proof to align the IRS code with the values of our criminal justice system, the IRS is forced to back up its challenges so that law abiding taxpayers are not forced to forfeit money that is legally theirs.

These reforms are only the first step in our struggle to reduce the impact of Federal taxes on taxpayer's lives. The real problem is the several thousand page Tax Code, created by Congress, that the IRS attempts to administer. This year alone, Congress added 600 pages to the Code by passing \$85 billion in tax cuts. When a tax cut makes the Tax Code more complex, you know it is time to scrap this Code and start over with one that is simple, fair, and understandable.

PERSONAL EXPLANATION

HON. ALLEN BOYD

OF FLORIDA

IN THE HOUSE OF REPRESENTATIVES

Sunday, November 9, 1997

Mr. BOYD. Mr. Speaker, today, November 9, I was unavoidably detained and missed the vote on H.R. 1129. Had I been present, I

would like the RECORD to reflect that I would have voted "yes."

INTRODUCTION OF THE CLINICAL RESEARCH ENHANCEMENT ACT

HON. NANCY L. JOHNSON

OF CONNECTICUT

IN THE HOUSE OF REPRESENTATIVES

Sunday, November 9, 1997

Mrs. JOHNSON of Connecticut. Mr. Speaker, I rise today to announce with my good friend from New York, Congresswoman NITA LOWEY, the introduction of the Clinical Research Enhancement Act that will improve the quality of health care by enhancing our investment in clinical research. We introduced a similar bill in the 104th Congress, and I am once again glad to be working with Congresswoman LOWEY and the health research community, led by the American Federation for Medical Research, on this proposal.

Clinical research is the critical component we need to bring the discoveries of basic research to the patient in the form of medical treatments. Our Government makes significant investments each year in basic research through the National Institutes of Health. In fact, the Federal Government is the major source of investment in basic biomedical research. However, it is crucial that the Government focus not only on basic research but also on the translational research that utilizes the discoveries of basic research to improve our ability to prevent, treat, and cure disease and disability.

While there is industry support for clinical research and clinical trials, private funding is very difficult to secure for the initial steps of translational research, which may have little or no commercial potential. Examples of this initial research include nutritional therapies, new approaches to disease prevention, transplantation techniques, behavioral interventions, and studies of off-label uses of approved drugs. These initial steps of clinical research used to be subsidized in part from patient care revenues to academic medical centers. As we heard in our debate on Medicare reform and graduate medical education, however, these teaching hospitals are more and more stretched for teaching and patient care dollars. They are finding it much more difficult to maintain their teaching role, let alone their investment in clinical research. Therefore, it is more important than ever that NIH devote greater attention and resources to providing support for clinical research.

Without the important link of clinical research, the investment that our country makes in basic research does not have the impact on the quality of health care that it could have. We have heard concerns from the research community that clinical research based on our basic research discoveries is going on overseas because it does not have financial support in the United States. It would be ironic if our expanding commitment to medical research, as evidenced in by NIH's growing budget, should create jobs overseas because we fail to address the need to fund clinical research, the link between basic research and a vital biomedical industry on our soil.

This legislation also will encourage more of our young researchers and physicians to pursue careers in clinical research. The data