



# National Health Council<sup>TM</sup>

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December 9, 2009

Dear Representative:

The National Health Council<sup>1</sup> (NHC) strongly supports the efforts of Congress to enact meaningful health care reform in this session. We urge you to work to complete this process that will benefit millions of people living with chronic conditions.

The Institute of Medicine has stated that the goal of any health care delivery system is to get “the right care at the right time to the right patient for the right price.” We could not agree more. Under the auspices of the NHC, the patient advocacy community has come together in support of five health reform principles:

Achieves Health Coverage for Everyone  
Curbs Costs Responsibly  
Guarantees Coverage Despite Pre-Existing Conditions  
Eliminates Lifetime Caps on Health Insurance  
Ensures Access to Quality Long-Term Care and Respect at the End of Life

The NHC applauds both the House and Senate for addressing all five of these principles in their respective bills. The insurance market and delivery system reforms will, together, provide greater access to improved care for those with chronic diseases and disabilities. Coverage of preventive services and other benefits outlined in the legislation will help people prevent or better manage their conditions, while the CLASS Act will provide access to long-term care that will become increasingly important in our aging society. Changes to Medicare Part D will benefit seniors through drug discounts for those who reach the “donut hole” and the eventual elimination of the coverage gap. Better care coordination will result in savings to the health care system while providing patients with improved care.

Both the House and Senate bills include language to facilitate the development of follow-on biologics (FOBs). The NHC views the development of FOBs as essential to improving patient access to vital treatments as well as being beneficial to the health system overall by reducing costs. We thank Members of Congress for addressing this critical issue and ask that the legislative language on FOBs be retained in any health care reform legislation.

The NHC thanks Members of the House for inclusion of these essential provisions. In addition, the NHC has identified three areas where we ask you to strengthen and improve the reforms in order to further benefit the patient and caregiver communities we represent:

- **Move up the implementation date for all insurance market reforms**  
We greatly appreciate the House bill's elimination of lifetime caps and prohibition on rescissions beginning in 2010. The bill also makes improvements in the rules governing exclusion based on pre-existing conditions by implementing some reforms, such as shortening the look back window to 30 days, in 2010.

<sup>1</sup> The National Health Council (NHC) is the only organization of its kind that brings together all segments of the health community to provide a united voice for the more than 133 million people with chronic diseases and disabilities and their family caregivers. Made up of more than 100 member organizations and businesses, our core membership includes 50 of the nation's leading patient advocacy groups. Other members include professional and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device, and biotechnology companies.

However, a full ban on coverage and treatment denials based on pre-existing conditions does not take effect until 2013, while the Senate bill delays implementation of this provision until 2014. Limitations on insurers' ability to charge more based on age, gender, and health status are also implemented in 2013 and 2014 in the House and Senate bills, respectively. These delays present significant access barriers to those with chronic diseases and disabilities.

We ask that Congress accelerate these market reforms, thereby ensuring greater access to the health care system for those most likely to face exclusion either through outright denial of insurance or through unaffordable premiums.

- **Ensure Comparative Effectiveness Research (CER) is meaningful at the point of care**  
The NHC supports comparative effectiveness research to identify the best, most effective treatments for patients. At present, the House and Senate bills both provide for CER but take different approaches, with the House bill placing responsibility for CER with the Agency for Health Research and Quality while the Senate bill establishes an independent private, nonprofit institute to conduct such research. We appreciate the leadership role that AHRQ has taken in this area and understand the House's support for basing CER with the agency, but we ask that you adopt the Senate approach of creating an independent, nonprofit institute. We believe that such an institution is best suited to provide objective research needed to ensure credibility with the public and more specifically people with chronic conditions. In addition, the independent body would avoid the potential problem of the government appearing to issue standards that would then be interpreted to influence coverage or treatment decisions. As seen with the response to the recent release of the U.S. Preventative Services Task Force's guidelines on mammography, there is a very real possibility of misinterpretation and misunderstanding when such findings are released by a government entity.

In addition to asking that you support adoption of the Senate bill's approach, the NHC also requests that final legislation include language providing for guidance on the usefulness of CER study results concerning various types of health care decisions. To accomplish this, the NHC promotes establishment of guidance on the usefulness of CER in decision-making at the point of care as well as a mechanism to appraise CER against such guidance. This could be accomplished by expanding the functions of the methodology committee of a CER entity to include development of usefulness guidelines; similarly, the functions of an advisory panel could be increased to include the appraisal of CER to determine if it meets such guidance. Both bodies should guarantee inclusion of a broad range of stakeholders, including patients. Such usefulness guidance will be critical to ensuring that doctors and patients have the information needed to guide real-world clinical treatment decisions. The NHC urges the inclusion of such provisions in health care reform legislation to ensure the research provides the utmost benefit to patients.

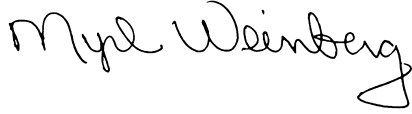
- **Enhance delivery system reform**  
Reorientation of the delivery system to focus on patient-centered care is a high priority for the NHC. Both the House and Senate bills include delivery system reforms to begin this process. The NHC is grateful for their inclusion in the House legislation, but asks that you support the more expansive provisions included in the Senate legislation. The Senate bill, in addition to establishing the Center for Quality Improvement and Patient Safety, would establish the Center for Medicare and Medicaid Innovation to test innovative payment and service delivery models, which, if successful, could be expanded throughout Medicare and Medicaid.

The Senate bill also expands delivery system reforms outside of the Medicare and Medicaid by authorizing grants that establish community health teams to support patient-centered medical home models. This program will be an incredible benefit to those with chronic diseases and disabilities and therefore strongly supported by the NHC. However, we are concerned that the provision in the Senate bill lacks a specified funding source. We urge you to support inclusion of this program, with an authorization of appropriations for the grants, in the final legislation that emerges from the House-Senate conference.

## National Health Council Comments on the Health Care Reform legislation, Page Three

Health care reform is at a critical juncture. We are closer than we have ever been to achieving significant reforms that will ensure access and improved care to people living with chronic diseases and disabilities. The NHC thanks Members of Congress for the substantial progress that has been made so far and urges you – in the strongest possible terms – to complete this process. The health – even the lives – of millions of Americans depends on it. The NHC looks forward to working with you to see enactment of this long-sought goal.

Sincerely,

A handwritten signature in black ink that reads "Myrl Weinberg". The signature is written in a cursive style with a large, looping "W" and a long, sweeping underline.

Myrl Weinberg, CAE  
President, National Health Council