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May 22, 2009

The Honorable Max Baucus
United States Senate
Washington, DC 20510

The Honorable Charles Grassley
United States Senate
Washington, DC 20510

Dear Chairman Baucus and Senator Grassley:

On behalf of the patients we serve, National Patient Advocate Foundation would like to thank you for the opportunity to comment on "Expanding Health Care Coverage: Proposals to Provide Affordable Coverage to All Americans." We commend the insightful text of your proposals that capture well the details of health care reform relative to coverage issues that Patient Advocate Foundation, our direct patient services organization, has dealt with daily since 1996.

National Patient Advocate Foundation (NPAF) is a non-profit organization dedicated to improving access to healthcare services through policy reform. The advocacy activities of NPAF are informed and influenced by the experience of patients who receive case management services from our companion organization, Patient Advocate Foundation (PAF). Last year, PAF provided 48,369 patients with full case management services. These services involved an average of 11.3 contacts with the stakeholders involved in order to reach a positive resolution of the specific access-to-care issue being addressed by PAF staff. In addition, PAF received more than 9.5 million inquiries by phone or on the Internet from individuals throughout the United States seeking assistance for access to care issues resulting from diagnoses of a chronic, debilitating or life-threatening disease.

While there are many issues outlined in the policy options paper that are of importance to NPAF, we would like to mention some that are of particular importance to patients across America. We ask that you consider these when drafting comprehensive health care reform legislation.

Section I: Individual Market Reforms

Non-Group and Micro-Group Market Reforms

NPAF supports prohibiting the exclusion of coverage for preexisting health conditions outlined on page 3 of the options paper. The impact of preexisting conditions is evidenced through the case work of our companion organization PAF. As more and more Americans lose their medical insurance because of unemployment, preexisting condition exclusions and waiting periods deprive them of insurance that would enable them to access life-saving treatments or even basic medical care. Uninsured patients seeking assistance from PAF continued to increase in 2008. This group is uninsured for a variety of reasons. The effect of preexisting medical conditions on a person's insurability was identified by PAF as a significant access issue through the course of patient case work. In 2007, PAF documented 1,580 unique cases where preexisting conditions posed a barrier to health coverage. In 2008 this number jumped dramatically to 3,889, a 146% increase from the previous year.

NPAF commends the Senate Finance Committee health reform policy recommendation to eliminate the preexisting condition limitation periods for all individuals in the private and non-group health insurance market. This policy change supports the principle that health insurance must be available to all Americans regardless of their health status, thus providing a vital safeguard to ensuring that all Americans have access to health care when in need.

NPAF also would like to express our complete support for the concept of shared responsibility incorporated into your paper on coverage options and for including provisions in comprehensive health care reform legislation that reduce financial and other barriers to important evidence-based preventive health services. Such programs can help individuals lead healthy lives and also lower overall health care costs.

However, we strongly oppose proposals that would allow health plans to alter premiums based on behaviors including tobacco use as suggested on page 3 of the options paper. Such an approach has the potential to make insurance less affordable for those who need health care the most; discriminate against individuals with chronic disease; compromise an employee's right to privacy in the workplace; and are unproven strategies for improving health or lowering health care costs. NPAF supports a broad incentive approach within health plans to reward healthy lifestyle choices.

The most significant barriers employees cite for not adopting a healthy lifestyle are the lack of time to exercise before, during, and after work; and the inconvenience and location of programs, screenings and exercise facilities. Making available on site health promotion services, such as smoking cessation programs, would be far more effective in improving employee health – and reducing employer health care costs – than applying financial incentives through employer-sponsored insurance. In this regard, we support legislation that provides “wellness” tax credits for employers who choose to provide these incentives in the workplace. We commend the Senate Finance Committee for including these tax incentives for employer health promotion activities in the policy options paper and urge that they be included in the Committee's legislative proposal.

We are also deeply concerned that allowing health insurance companies to charge older consumers up to 5 times more than younger adults based on their age in the non-group, micro-group, and small group markets (the 5:1 rating rules) will result in many older Americans not having access to affordable, quality coverage. Job-lock results for many 55-64 year olds who are ready to retire and cannot because they have no options for health care coverage in the private market. Further, if these consumers are not offered insurance in the private individual insurance market at an affordable price, they become dependent on Medicaid in the event of a catastrophic illness or injury.

Age rating is a concern in part because age is strongly associated with health status. As Americans age, they are more likely to experience chronic conditions such as heart disease, cancer, stroke, and diabetes. This proposal would simply impose a new mechanism to disincent consumers to purchase health care coverage.

In Massachusetts, the state has capped the rating for age, as well as other specified factors, at no more than 2:1. Yet affordability is still a significant issue for many older people in Massachusetts. At that 2:1 age rating, the lowest cost “bronze” benefit package costs 60-year-olds between \$420 and \$575 per month. If the rate band were set at 5:1, the bronze package would cost \$1,050 to \$1,335 monthly, or up to \$16,020 a year – more than half the median annual income of \$30,000 among older *uninsured* Americans ages 50-64 today.

Similarly, we are concerned that the Committee envisions allowing premiums, taking all permissible factors together, to vary by as much as a 7.5 to 1 ratio. As noted above, the median family income of the uninsured is \$28,000 to \$31,000. We fear that a variance this large could lead to pricing insurance at unaffordable levels for many in this country. NPAF urges the Committee to cap out-of-pocket health care spending, inclusive of all premiums, copays, deductibles and prescription drug spending, at \$5,000 for an individual and up to \$10,000 for a family in order for health care to be affordable to individuals and families. We believe this needs to be based on a sliding income scale.

Transition

NPAF recommends the transition time periods for federal ratings rules as outlined on page 7 for non-group and micro-group markets (other than for grandfathered plans) should be phased in over a period not to exceed one year from the date the exchange is operational; rather than the January 1, 2013 (or sooner if possible) effective date stipulated in the proposal. We further recommend the federal rating rules for the remainder of the small group market to be phased in over a period not to exceed three years. Our recommendations to accelerate the federal rating rules for the non-group, micro group and small group markets will create a level and consistent platform for the small employer groups and the insurance providers, rather than extending the transition to federal rating potentially over an entire decade. Based on PAF's service to the very healthcare consumers that health care reform is intended to serve, we recognize that healthcare reform is needed today. Delayed implementation is delayed delivery of services.

Role of State Insurance Commissioners

NPAF supports the option outlined on page 8 which establishes a federal fallback and preserves the role and authority of states. Providing state insurance commissioners' oversight of plans with regard to consumer protections (e.g., grievance procedures, external review, oversight of agent practices and training, market conduct), rate reviews, solvency, reserve requirements, and premium taxes will ensure that patients are protected and states have clearly defined responsibilities.

Section II: Making Coverage Affordable

Benefit Options

NPAF supports the option outlined on page 9 which requires all health insurance plans in the non-group and small group market to provide a comprehensive, broad range of medical benefits. In addition, NPAF supports prohibiting plans from including lifetime limits on coverage or annual limits on benefits as outlined in the proposed option.

NPAF supports the maintenance of the current six categories of drug coverage with two drugs per class for all plans offered in the Exchange. In addition, each plan design should be required automatically to meet the class and category of drug coverage requirements in Medicare Part D as expanded by the Secretary in the future.

Low-Income Tax Credits

NPAF supports the option outlined on page 11 which provides refundable and paid in advance tax credits for low income taxpayers defined as those individuals (single or joint filers) with modified adjusted gross income ("MAGI") between 100 and 400 percent of the federal poverty level (FPL). NPAF would like to emphasize that it is extremely important that these subsidies be sufficient to ensure policies are affordable to consumers and patients. NPAF recommends that guidelines be adopted to assure that subsidies go directly to the purchase of approved health plans.

Section III: Public Health Insurance Option

The Committee's options paper on coverage states that the public option, if adopted, would start and accept enrollees on the same date as the Exchange begins. We encourage the Committee to set a specific deadline by which the Secretary will have established the Exchange. As noted above in connection with the Federal Rating Rules, we also encourage the Committee to accelerate implementation timetables to the maximum extent possible.

Section IV: Role of Public Programs

Medicaid Coverage

NPAF supports maintaining current requirements for states to disregard certain amounts and/or types of income (and sometimes expenses, such as child care or health care costs) in determining Medicaid eligibility. NPAF is concerned that using modified adjusted gross income ("MAGI") to determine eligibility will result in fewer people qualifying for Medicaid.

NPAF supports approach 1 outlined on page 16, which requires state Medicaid programs to provide premium assistance to Medicaid-eligible individuals with employer sponsored insurance. Currently, some states provide such assistance, but efforts to establish whether beneficiaries have ESI are occasionally lax. We encourage the Committee to include a strong mandate that states establish whether Medicaid beneficiaries have access to employer sponsored insurance so that all eligible beneficiaries may be assisted.

Enrollment and Retention Simplification

NPAF commends the Committee for extending administrative automatic renewal and express lane renewals to all Medicaid beneficiaries. In addition, NPAF encourages the Committee to streamline the Medicaid enrollment and reenrollment processes by, among other things, establishing universal applications and data bases.

Family Planning Services and Supplies

NPAF encourages the Committee to clarify on page 24 that HPV, STD, gynecological cancers and their treatments are included in “medical diagnosis and treatment services” related to family planning services.

Mandatory Coverage for Prescription Drugs

NPAF commends the Committee for making prescription drugs a mandatory benefit for the categorically and medically needy as outlined on page 26. We encourage the Committee to require state Medicaid programs to provide prescription drug coverage at the same level as plans in the Exchange.

Change the Status of Some Excludable Drugs

NPAF supports the proposal on page 27 which would alter Medicaid law to eliminate smoking cessation drugs, barbiturates, and benzodiazepines from Medicaid’s excluded drug list.

Medicare Coverage

NPAF is dedicated to the elimination of the Medicare 24 month waiting period as quickly as possible because it puts effective treatment and care for people with severe disabilities at risk as many in this waiting period lose their health insurance. Of the approaches offered in the policy options paper, NPAF favors approach 3 outlined on page 38 which would reduce the waiting period in six month increments, with complete elimination of the waiting period after one-and-a-half years. NPAF has particular concerns about Approach 4, which would maintain the waiting period for people with access to private insurance that meets or exceeds an actuarial standard. An actuarial standard does not guarantee that coverage is affordable. An actuarial standard does not ensure that out-of-pocket costs for health care are limited, particularly for the majority of people with disabilities with low incomes. We are concerned that private coverage that meets an actuarial standard could still have benefit caps or restrictions on services vital to people with disabilities, such as prosthetics or durable medical equipment. Additionally, while the actuarial standard is being defined in regulation and a mechanism is established to screen out people with access to private coverage, there will be an inevitable delay in beginning the phase-out of the waiting period. We have concerns of the impact of such a delay on remainder of the people with disabilities without any access to insurance.

NPAF is also concerned that approach 4 would not protect individuals with private insurance receiving SSDI who otherwise would be in the 24 month waiting period. We encourage Senate Finance Committee to use the individual’s original date of SSDI eligibility as the start time for their 24 month waiting period. In the event that this individual loses private insurance coverage and has been receiving SSDI for more than 24 months, this individual should be automatically enrolled into Medicare.

Temporary Medicare Buy-In

NPAF commends the inclusion of a temporary Medicare buy-in to smooth the transition to comprehensive healthcare reform outlined on page 39. Nearly 7 million Americans under the age of 65 qualify for Medicare because they have severe and permanent disability. Unfortunately, our

current system requires these individuals to wait years after they have been eligible for Social Security Disability Insurance to receive Medicare coverage. Last year 44.46% of the Medicare patients assisted by the PAF qualified for Medicare due to disability. Elsewhere in the options paper a phased elimination of the waiting period has been suggested, but for those millions already disabled and for millions more Americans aged 55 to 64 in need of care, we urge the Committee to allow a Medicare buy-in to begin January 1, 2010 rather than 2011, or at the earliest possible date.

As you know, a growing number of older adults are without insurance coverage, and once older Americans lose their coverage, they are more likely to remain uninsured for an extended period of time (until becoming eligible for Medicare). In addition, older adults are much more likely to spend a significant portion of their income on health care.

The consequences of not having insurance are also particularly severe for older Americans. One impact of lack of insurance or of being uninsured for older adults is that they may be deferring care until they are eligible for Medicare, which can lead to more serious health problems and higher costs for Medicare. This scenario is borne out by studies that show that uninsured adults in their 50s and early 60s experience worse health outcomes and use more services when they enter the Medicare program, compared to those who were insured.

Section V: Shared Responsibility

Personal Responsibility Coverage Requirement


NPAF commends the Committee for emphasizing the importance of shared responsibility in the options paper. For thirteen years PAF senior navigators have worked with all levels of healthcare stakeholders to solve access issues for patients with chronic, life-threatening and debilitating diseases. At the core of their work is the need for patients, doctors, payers, employers, and government to share in the responsibility of providing access to necessary health services and coverage. Our health care system will be more responsive and accountable if responsibility is clearly defined for all stakeholders.

NPAF understands the desire to incentivize individuals to assume their responsibility and to enroll for insurance coverage, but we believe the imposition of a 9-month preexisting conditions waiting period, outlined on page 39, for those who fail to enroll is an unwise penalty. It potentially deprives those most needing care from accessing it. We recommend that the Committee rely solely on higher premiums for a restricted period of time as a disincentive for failing to enroll. We also encourage the Committee to make the initial enrollment period at least 3 months with guaranteed issue and no preexisting condition limitations. NPAF would like to highlight that the Medicare Modernization Act (MMA) of 2003 mandated an initial enrollment period of 6 months.

We share with Committee members the sense of urgent need for health care reform to be completed this year. Any further delay will only make the hurdles greater and the costs larger and less sustainable. We stand ready to work with you in any way we can to address the concerns we have raised and to seize this historic opportunity to achieve accessible and affordable health coverage for all Americans. We thank you and your staff for your many hours of efforts, your dedication and your commitment.

We would like, as well, to express sincere appreciation to you for allowing NPAF to offer recommendations based on the daily work provided by PAF to patients with chronic, life-threatening and debilitating diseases. On behalf of these patients, we urge your thoughtful consideration of our recommendations for health care reform.

Respectfully submitted,



Nancy Davenport-Ennis
President & CEO