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A National Network for Healthcare Reform

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RE: SB 275: Coverage for routine care costs associated with clinical trials

The National Patient Advocate Foundation (NPAF) is keenly interested in legislation such as SB 275, which provides routine care costs for participants in clinical trials and establishes the Pennsylvania Cancer Clinical Trial Review Board.

Participation in clinical trials is essential for the continued development of new medications to effectively treat and/or cure patients with chronic and life-threatening illnesses; unfortunately, only 5% of cancer patients participate in clinical trials. A significant barrier to clinical trial participation is lack of insurance coverage for routine care costs such as office visits, hospital stays, laboratory tests, or other services that would normally be covered if the patient were not enrolled in a clinical trial. This added financial burden can discourage patient participation and slow the development of innovative and potentially life-saving treatments.

We urge legislation to include provision for routine care costs for:

- Any phase of clinical trial for cancer
- Adults and children
- Out-of-state clinical trial participation

Several states have passed legislation requiring insurance companies to cover routine care costs during clinical trials. As of the submission of this letter, the following states have taken action on this issue: Arizona, California, Connecticut, Delaware, Georgia, Louisiana, Maine, Massachusetts, Michigan, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, North Carolina, Ohio, Tennessee, Vermont, Virginia, West Virginia, and Wyoming. For specific information about the legislative action taken in those states, visit the National Cancer Institute website at <http://www.cancer.gov/clinicaltrials/developments/laws-about-clinical-trial-costs>.

National Patient Advocate Foundation (NPAF) is dedicated to improving access to care through legislative and policy reform at both the state and federal levels. NPAF advocacy activities are influenced by the experience of the patients we serve through our companion organization, Patient Advocate Foundation (PAF). PAF provides case management services directly to patients at no charge to help resolve insurance, job retention, and/or debt crisis matters relative to a serious diagnosis. In 2006, over 6 million Americans contacted Patient Advocate Foundation with a request for assistance. We invite you to review the NPAF and PAF websites to learn more about both organizations: www.npaf.org and www.patientadvocate.org

On behalf of NPAF's Pennsylvania Volunteer State Policy Liaisons, Eilene Frierson and Sheri Putnam, the NPAF Advocates Network volunteers in Pennsylvania, and NPAF's State Government Affairs, thank you for your work to expand coverage for routine care costs associated with clinical trials. If we can be of assistance in this work, please don't hesitate to contact your Pennsylvania NPAF State Policy Liaisons or NPAF State Government Affairs at 202-347-8009.