

**AAHPM ADVOCACY PLAN
FOR INCREASED FUNDING
FOR RESEARCH AND CLINICAL PALLIATIVE CARE OUTCOMES**

Issue Overview

The development of the specialty of palliative medicine has been a critical step in addressing the unmet needs of patients with serious illness and their families and the growth of this field has been remarkable. Nevertheless, the field faces sizeable challenges if care for seriously ill patients and their families is to improve. Unlike other areas of medicine, the knowledge base to support the basic elements of palliative care clinical practice (i.e., pain and symptom management, communication skills, care coordination) is small and systems of care that have been developed to support the needs of patients and families have yet to be fully evaluated. Over the past eight years, a series of reports from the Institute of Medicine, the National Institutes of Health, and the American Academy of Hospice and Palliative Medicine have called for substantial investment in palliative care research to address these knowledge gaps, but despite billions of dollars spent on research in various diseases, there has been almost no investment in research that might significantly alleviate the physical symptoms; psychological distress; and address personal care, family, and social needs of older persons living with advanced illness.

One of the major contributing factors to low levels of research support for care of people with serious and complex illnesses and palliative medicine is that there is no federal agency specifically charged with that mission. With few exceptions, the National Institutes of Health (NIH) are disease-specific and thus palliative care with its applicability to all serious illnesses does not fit well within one particular institute. The National Cancer Institute (NCI), the National Institute on Aging (NIA), the Agency for Healthcare Research and Quality (AHRQ), and the National Institute of Nursing Research (NINR) have supported some research in palliative care but it is not a priority in any of these agencies' annual budgets.

AAHPM Advocacy

AAHPM should consider the following activities to proactively engage with policymakers to increase research funding and develop clinical outcomes for palliative medicine:

- Develop AAHPM materials documenting research needs based on our experience with patients to establish need for increased funding.
- AAHPM should develop and provide information regarding palliative care data for Pennsylvania, Ohio, Iowa and Wisconsin for use during advocacy visits. This information would be included with general information about AAHPM.
- Form AAHPM Group to develop palliative medicine clinical outcome measures that should be further studied to maximize the effectiveness of palliative medicine.

- AAHPM should collect information from wide array of health provider and patient organizations about interest and activities in palliative medicine and then identify and prioritize partnerships to work with other parties on messaging to policymakers regarding this problem.
- Identify notable public speakers, both practitioners and patients, to message on lack of palliative care research funding and need for same.
- AAHPM should provide coaching and advocacy training to interested members with a focus on key states to assist in communication with key lawmakers who can provide increased research funds.
- AAHPM Washington representative will work closely with AAHPM leaders and “key contacts” to arrange and coordinate advocacy meetings and provide talking points for communication regarding palliative medicine research funding.
- Washington representative will work closely with AAHPM leaders to develop “messaging” regarding palliative medicine research funding.
- Implementing a public relations campaign to message regarding need for more funding for palliative medicine research.
- Identify Congressional members and media figures whose lives have been personally affected by chronic illness or end-of-life issues and enlist their help as advocates for more funding for palliative medicine.
- AAHPM should develop and maintain a list of Congressional members and staff with a declared interest in palliative medicine research and funding and consider coordinating with their lawmakers in communications with appropriation.
- Arrange meetings with hospice, palliative care and related organizations to discuss recent Congressional advocacy activities devoted to increasing funding for palliative medicine and other related research.
- Arrange meetings with Congressional members to discuss need for increased funding for palliative medicine research. Priority would be with Congressional members assigned to House and Senate Labor, HHS and Education, Appropriations Subcommittee and Members of Illinois Congressional delegation.
- Conduct joint visits with hospice and palliative medicine advocacy groups to Congressional offices to discuss FY2008 appropriations to increase research funding for palliative medicine.
- Arrange meeting with NIH Director to discuss concerns regarding lack of NIH attention and funding for palliative medicine.

- Arrange meeting with Director of NIH Institutes of Neurological Disorders and Stroke; Dental Research; Cancer; Aging; Allergy and Infectious Disease; Arthritis and Musculoskeletal and Skin Diseases; Deafness and other communication disorders; Drug Abuse; General Medical Sciences; Nursing; and Office of Research on Women's Health to discuss concerns regarding lack of funding for palliative medicine.
- Arrange a meeting and consider forming a coalition of patient organizations who would be interested in advocating for more funds for palliative medicine research.
- Arrange meetings with AMA, AAMC and select medical specialty organizations to establish level of interest in increased palliative medicine research funding. Consider working partnerships with organizations who share this interest.
- Arrange meetings with AHRQ and CMS to determine interest in sharing clinical standards in the area of palliative medicine.
- Arrange meeting with Institute of Medicine to discuss interest in palliative care research and clinical outcomes for palliative medicine.
- Arrange meeting with MedPAC to discuss palliative medicine clinical standards and outcomes.
- Arrange meetings with American Hospital Association; Federation of American Hospitals; National Associates of Public Hospitals and Health Systems; American Association for Homecare; National Association for Home Care & Hospice; American Health Care Association and similar organizations to determine level of interest in palliative care and endorsement and acceptance of clinical standards and outcomes for palliative medicine.
- Arrange briefings/meetings with health staff at General Accounting Office (GAO) and Library of Congress to discuss interest in palliative care clinical outcomes.
- Conduct Congressional briefings on need for funding for palliative medicine research.
- AAHPM should work with partners to obtain Congressional hearing focused on lack of government funded clinical research on palliative medicine. Preferred Congressional Committees to hold hearing would be House/Senate Appropriations Committee; Senate HELP Committee; House Energy and Commerce Committee or Senate Government Reform and Oversight Committee.
- Identify a Congressional member serving on the House or Senate Labor, HHH and Education Appropriations Subcommittee who will insert language in the NIH portion of the FY2008 Report for the HHS Appropriations Bill that directs NIH to fund more palliative care research studies.

- AAHPM effort to gain increased research funds for research on palliative care will focus on appropriations advocacy effort. AAHPM should select and train members from Pennsylvania, Iowa, Ohio and Wisconsin who would be willing and able to visit with representatives Regula (R-OH), Obey (D-Wis.) and Senators Specter and Harkin or their key staff to request increased funding. Additionally, opportunities to meet with lawmakers will be arranged in the state for AAHPM visits to communicate need for increased palliative medicine research funding.
- AAHPM should plan on utilizing their members from Ohio, Wisconsin, Pennsylvania and Iowa to communicate on behalf of AAHPM regarding FY2008 HHS appropriations funding for palliative medicine research.
- AAHPM should visit with all staff and/or members of House and Senate Labor, HHS and Education appropriation subcommittee to determine which lawmaker will serve as strongest advocate for palliative medicine research and funding.
- AAHPM should work with ACS to highlight need for palliative medicine research with Congress and Administration.