

From Proclamation to Legislation: An Advocacy Skill Building Workshop

Resource Page

I. PH Advocacy Opportunities and Resource

- For advocacy information, advocacy materials, or to sign up for the *435 Campaign* contact Katie Kroner, Director of Advocacy and Awareness at Katherine@PHAssociation.org; 301-565-3004 X109.
- For updates and action alerts on issues that impact the PH community: www.PHAssociation.org/advocacy/Current_Issues.asp
- For information on calling, writing or *visiting* your elected officials: www.PHAssociation.org/Tips_Resources.asp
- For an overview of the legislative process: www.phassociation.org/advocacy/ltl.asp
- To update PHA on action you've taken, or a response you received from your elected officials...you guessed it! Contact Katie at Katherine@PHAssociation.org or 301-565-3004 x740



II. PH Research Act Status

- PHA and the PH community are in a unique position...the PH Research and Education Act of 2007 was introduced in July, 2007 by Congressman Tom Lantos.
- Six months later, Congressman Lantos, a long-time champion of the PH community passed away after being diagnosed with cancer of the esophagus.
- His passing is a great loss to the community, and PHA has the opportunity to re-introduce our bill in his honor as the Tom Lantos Pulmonary Hypertension Research and Education Act of 2008.
- Re-introducing the bill means that representatives who co-sponsored in 2007 will have to step up to the plate and co-sponsor again.
- However, we feel this is an important, and fitting tribute of a hero of our community.
- PHA will post information and action-opportunities as soon as the new bill is introduced. You can begin talking about it during a local visit to your representative in August.



III. Additional Updates and Successes

The PH Research and Education Act is only the beginning of PHA's legislative advocacy. Through the PH Research and Education Act, the PH community builds relationships with their elected officials and raises awareness of PH in Congress. This process leads to success in many areas. Here are just a few...

- **Genetic Information Non-Discrimination Act Victory**
After passing Congress on May 1, the Genetic Information Non-Discrimination Act (GINA) was signed into law by the President on May 21. GINA sets strict standards for the use and disclosure of genetic information and imposes penalties against companies that violate these provisions.
- **Federal Budget Testimony**
On March 13, 2008 PHA board member Joanne Sperando-Schmidt spoke before the House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, and Education. PHA was one of only 30 organizations selected from approximately 700 applicants to testify before the Subcommittee.
- **Centers for Disease Control PH Awareness Program**
In December, 2007 President Bush signed a bill that provides \$195,000 to the "Pulmonary Hypertension Association, Silver Spring, MD for public education and outreach." This allocation is part of the Centers for Disease Control and Prevention Budget and will be used to build an online medical education program as well as increased public awareness of PH through contact with the media.
- **PH Research Opportunity through Department of Defense**
PH first appeared as a disease eligible for study under the Department of Defense Peer Review Medical Research Program (PRMP) during fiscal year 2006 and was one of only twenty-two research topics included. In that year, **7.5% of the proposals received by this program were funded, and a PH proposal was one of them!** The Fiscal Year 2008 Defense Appropriations Act provides \$50 million to the Department of Defense PRMRP and pulmonary hypertension is again one of twenty-one congressionally directed topic areas eligible for study under the program.

