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FOR IMMEDIATE RELEASE

**For Pulmonary Hypertension Community,
*Research and Education Act a Labor of Love***

SILVER SPRING, MD—3/13/2009—Pulmonary hypertension (PH) patients don't have a lot of breath to spare, but the PH community is doing what it takes to spread the word about the *Tom Lantos Pulmonary Hypertension Research and Education Act of 2009* (H.R. 1030). The bill was introduced February 13 by Representative Kevin Brady (R-TX) and Representative Lois Capps (D-CA) who, despite their parties' differences, are united in their fight against this rare, incurable disease.

Diane Ramirez, a pulmonary hypertension patient, has been waiting for H.R. 1030 since the conclusion of the 110th Congress last year. Diane is one of a handful of long-term PH survivors and one of hundreds of PH community members determined to see the *Tom Lantos Pulmonary Hypertension Research and Education Act of 2009* become law this year.

Pulmonary hypertension is a rare, deadly disease caused by continuous high blood pressure in the pulmonary artery in the lungs, resulting in an enlarged heart which can lose its ability to pump. Early symptoms are similar to asthma and include chest pain, low energy, breathlessness, dizziness and bluish lips and skin.

H.R. 1030 is named after former Representative Tom Lantos, whose granddaughter was diagnosed with the disease in 2004 at the age of twenty. Lantos kept pulmonary hypertension at the top of his legislative agenda until his death in 2008. H.R. 1030 honors his memory by seeking to support PH research and increase medical education and public awareness, with the goal of diagnosing and treating PH more effectively and finding a cure for the disease.

Diane's Ramirez' journey with PH began in the 1980's, when she spent two and a half years seeking an explanation for her fainting and shortness of breath. In 2008, twenty years after her diagnosis, Diane became the Advocacy Chair of her pulmonary hypertension support group in North Carolina. Since then, she's been the organizing force behind visits to seven Members of Congress. This year, her goal is to get the entire North Carolina delegation to co-sponsor H.R. 1030.

“Being the Advocacy Chair of my support group is exciting,” says Diane. “It's educational and very fulfilling. I love it...I've learned about just dealing with congressional members...but the most important thing that I've learned as far as dealing with Members of Congress is that they're human just like we are. PH advocacy seems to be my niche. I will stay involved in advocacy in whichever way that it takes me.”

Diane's passion is echoed by members of the Pulmonary Hypertension Association's (PHA) grassroots advocacy network across the country. With the help of Representatives Brady and Capps, these PH advocates are outworking hard to make sure that every Member of Congress understands the importance of co-sponsoring the *Tom Lantos Pulmonary Hypertension Research and Education Act of 2009*.

PHA was founded in 1990 by four women around a kitchen table at a time when the only federal study of the disease identified 187 patients. Funding the organization out of their pockets, they developed a patient hotline, a quarterly newsletter, and materials explaining PH to physicians and nurses, most of whom had no previous knowledge of the disease.

Today, PHA has a budget of over \$6 million and there are approximately 30,000 PH patients receiving treatment in the U.S. Membership in the organization has grown from 53 people in 1991 to over 9,000 in 2009, with an additional 30,000 supporters and friends.

For more information on PHA's advocacy efforts and the *Tom Lantos Pulmonary Hypertension Research and Education Act of 2009*, contact Katie Kroner at 240-485-0749. More information is also available at www.PHAssociation.org/media.