

Mid-South Area Pulmonary Hypertension  
Support Group Newsletter



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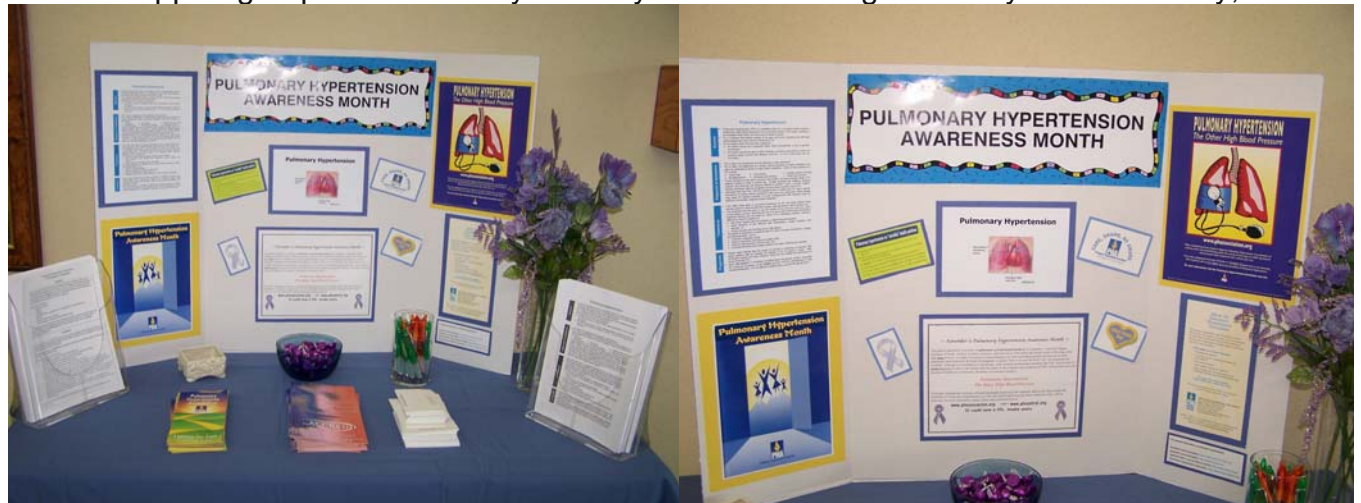
September, 2008 Newsletter  
Mid-South Area Pulmonary Hypertension Support Group  
Reported by Sue Porter



On Thursday, September 18, 2008, the Mid-South Area Pulmonary Hypertension Support Group led by Barbara Thompson met at Logan's Roadhouse on Germantown Parkway. United Therapeutics Medical Science sponsored the dinner and meeting. They were represented by Susan Steinbis and Joanne Sanders. Also in attendance were Lela Scott, Joe Whitman and Judy Corzine of drug distributors, Accredo, who supplied the door prize, a \$25.00 gift card from Logan's Roadhouse.



Barbara began the meeting by welcoming all and recognized that there were many new people in attendance. She discussed the importance of P H Awareness month (November) in disseminating information to the many people who may be experiencing the ill effects of Pulmonary Hypertension without appropriate diagnosis and treatment. A copy of the Proclamation issued by the City of Memphis acknowledging November as PH Awareness Month was shown to the group. Shelby County has not yet responded. The TN Governor's office informed Barbara that they determine November proclamations in October. Members were alerted that a survey would be given at the November meeting to solicit recommendations for speakers/topics for next year's agenda. Barbara also shared information about Gilead being the sponsor for our next meeting. They are the makers of Letairis (Ambrisentan), the latest FDA approved oral drug for treating PH. Gilead plans to bring "thumb-drives" for attendees so patients can store their personal medical information and information about pulmonary hypertension for assuring better services since medical personnel are often uninformed about Pulmonary Hypertension. She also discussed making a display board as our fellow PHer & support group member Betty Mooneyhan made along with Judy Corzine. Betty, we miss you.





Susan Steinbis of United Therapeutics was the first speaker. She began by explaining their role in patient services and clarifying that they do not try to persuade Doctors to prescribe their drug, Remodulin, and do not prescribe to patients. Their purpose is to assist and educate the patients who have been prescribed Remodulin. Susan described how Pulmonary Hypertension is defined and diagnosed. She pointed out that FDA has placed it as being in the “orphan designation” since it is such a rare disorder. Her presentation included information about the types of PH, the functional classifications of PH developed by the World Health Organization, the impact of PAH on quality of life, and the benefits drugs can give. She reviewed the history in treatment of PH and the numerous drugs developed since 1995 giving hope and opportunities to PH patients. [Note: Patients and their families can have information about all the procedures used in diagnosing PH, definition of medical terms used, how this disease is classified, all the possible treatments available and their side effects, and much more by getting a copy of Pulmonary Hypertension: A Patient’s Survival Guide from the Pulmonary Hypertension Association at 301-565-3004 or [www.PHAssociation.org](http://www.PHAssociation.org). The cost for members is \$15 and for non-members is \$25. Membership costs \$15 so you can join and get the Survival Guide for \$30 and receive publications/information throughout the year for just \$5 more than purchasing the Survival Guide as a non-member. This book was written by PH patients who had medical professionals with expertise in all areas concerning PH to supply different chapters.] Joanne Sanders, also with United Therapeutics, described the Remodulin Therapy Assistance Program, an initiative to provide Remodulin patients with non-medical assistance in support of their therapy. This program includes general information about Remodulin, insurance assistance, emotional support through connecting new patients with patients who have been on Remodulin (the PEER network), and other non-medical resources. She explained that when a patient participates in this program, the same assistant works with them all the time and that the patient determines the frequency of contacts.



The next Mid-South Area PH Support Group meeting is scheduled for Thursday, November 6 at 6:00 P.M. at the same location, Logan’s Roadhouse. The guest speaker will be announced prior to the meeting date. For more information on PH, the Support Group, or reservations to attend the next meeting, contact Barbara Thompson at 901-251-1023 or [BarbarainMemphis@aol.com](mailto:BarbarainMemphis@aol.com)



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