



Asociación Nacional de
HIPERTENSIÓN PULMONAR



First Celebration of the
World Pulmonary Hypertension Day
Madrid, Spain
May 5, 2012

Good afternoon and thank you for being here with us to share this celebration.

Today is a very special day. For the first time we are gathering with the intention to influence the lives of those in the global PH community. Patients and health professionals have joined together to give hope and work towards a better quality life for the millions who suffer from PH.

When I speak about PH patients, I want it to be understood that I am speaking about the whole person; patients are not only defined by their physical afflictions but also by their social, familial, political, economic and emotional circumstances. Emotions, fears, projects, achievements, disappointments and struggles affect how we reach our goals. Although these qualities have different degrees of impact, they are important for each individual.

When I speak about health professionals, I am not only speaking about doctors, nurses, physiotherapists, psychologists, etc. I am also including researchers and politicians whose decisions allow access to treatments that save our lives, but simultaneously could condemn us to disabilities and early death. I am also speaking about technicians, regardless of their profession or specialty, those who work at regulatory agencies such as health technology assessment agencies and entities like FDA and EMA, who contribute in making our lives not only possible but also offer us dignity for our quality of life.

Although pulmonary hypertension has been known for many years and we have had impressive progress in the last 10 to 15 years, we are still in the early stages. We have only started the fight in a long battle in which, unfortunately, there are more victims than survivors in the world.

But we have hope and we trust that we will grow stronger each day. Some of us had the privilege to be born in countries with affordable health care and a better quality of life, where treatment costs are covered. However, most PH patients literally suffocate, strive for each breath, and die without knowing the cause of their suffering.

We are now on a path to change this. Patients have come together through local and national organizations that in turn group into international organizations. We have grown enough to support health professionals, promote research, and facilitate communication and dialogue. We have the ability to negotiate with health authorities about improvements that will offer to us the possibility to maintain our independence as organizations, while contributing to historical, social and economic development.

Today I have the great honor to welcome you to the first celebration of the World Pulmonary Hypertension Day.

I want to convey an important message: open your minds and your hearts because what you will hear during this celebration will give us the drive to change lives for millions of people all over the world.

I thank from the bottom of my heart the members of the Scientific and Honor Committees for accepting our invitation and for placing their trust in what seemed to be a dream. Thank you to the speakers and moderators who answered our call and shared their wisdom with us. Thanks to the pharmaceutical industry because this would have not been possible without your support. Thanks to presidents of patients' organizations who are here today and are sharing this great celebration with us. Thanks to the members of the Spanish National PH Association who supported from the very beginning of what ANHP is today and thanks to the new members who have placed their trust in us. I want to give special thanks to my comrade in this process, Juan Fuertes, the ANHP coordinator, for his tireless work and focus, for his dedication, his capacity to communicate in different languages, and because this project would have never become reality without his help and enthusiasm.

And last but not least, thanks to all who are here today with us; those both physically present and those who are celebrating from their homes. Thanks to your tenacity, your vision, and your efforts. We have faith that there is a future in which everyone will have the right to breathe.

I welcome you again and officially declare the start of the first World Pulmonary Hypertension Day.

Thank you very much.

Irene Delgado
President
Asociación Nacional de Hipertensión Pulmonar