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EDITORIAL

The fifth world symposium on pulmonary hypertension will REVEAL the impact of registries

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One of the meanings of ''reveal'' is ''to disclose through prophets''. In the world of pulmonary arterial hypertension (PAH), REVEAL refers more modestly to the Registry to EValuate Early and Long-term PAH Disease Management [1–3]. In the current issue of the *European Respiratory Review*, two of the key contributors to this modern era registry have elegantly summarised their recent findings and future research plans [4].

The ability to identify and evaluate factors that affect survival in patients with PAH is of critical interest to clinicians. The first of several registries (Patient Registry for the Characterization of Primary Pulmonary Hypertension), supported by the National Institutes of Health (NIH) and the National Heart, Lung, and Blood Institute, was initiated in 1981 [5, 6]. This registry enrolled patients with ''primary pulmonary hypertension'', a category that at the time included those with idiopathic, familial/heritable and drug/toxin-induced PAH [5]. Although shown to be a powerful tool for improving our understanding of PAH, interpretations of data from the NIH registry are limited because of the era during which these data were collected (more than 20 yrs ago and, most importantly, prior to the availability of PAH therapies) [7–10]. Thus, a number of contemporary registries have been initiated worldwide to complement and update information from the pioneering NIH registry [1–4, 8–22], and data generated by these registries have been extremely helpful for investigators. As examples of the practical interest of such research, developing countries have produced high-quality data demonstrating the rapid progress of disease management in China [19, 20], and the specific causes and outcomes of PAH subsets in Brazil (where schistosomiasis remains a major burden) [21, 22]. More recently, specific registries have studied other forms of pulmonary hypertension, such as chronic thromboembolic pulmonary hypertension, a major cause of pulmonary vascular disease that can be cured by pulmonary endarterectomy [23].

We have come a long way since the early 1970s, when the World Health Organization sponsored the first international meeting in Geneva, Switzerland (October 15–17, 1973), on a mysterious condition named ''primary pulmonary hypertension'', spurred by the interest created by the sudden increase in the disease in patients who had used the anorexigen, aminorex fumarate [24]. Amazing achievements have been made in the field since then, as reflected by the World Pulmonary Hypertension conferences, which have taken place three more times since 1973 (Evian, France, September 6–10, 1998; Venice,

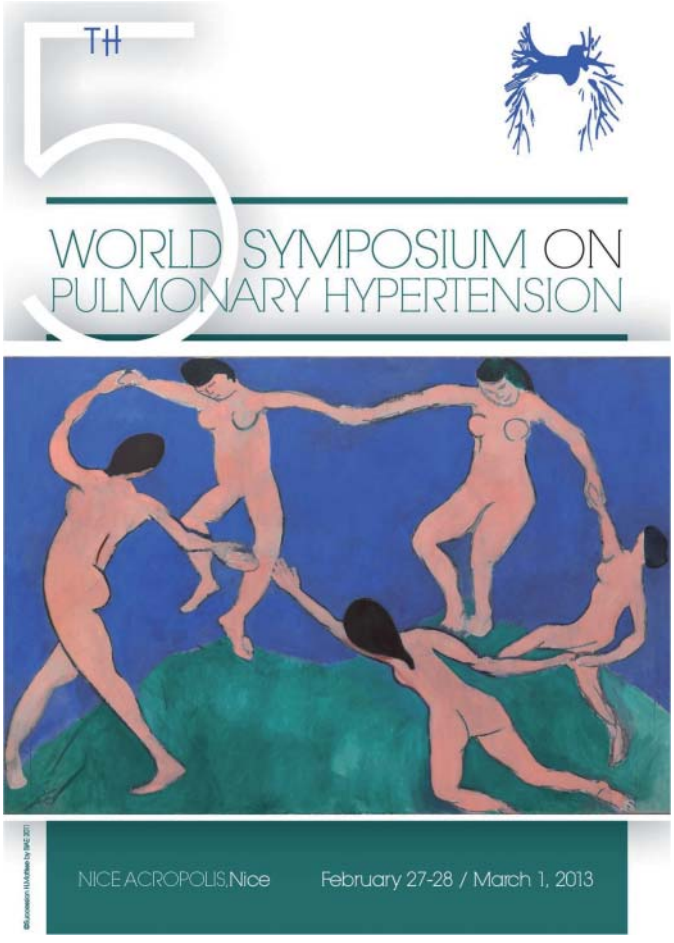

FIGURE 1. First announcement of the fifth world symposium on pulmonary hypertension (Nice, France, February 26 to March 1, 2013).

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Italy, June 23–25, 2003; and Dana Point, CA, USA, February 11–14, 2008) [25]. The fifth world symposium on pulmonary hypertension will take place next year in Nice, France (February 26 to March 1, 2013) (fig. 1). The international symposium steering committee of 10 European and American specialists has identified 12 task forces which will review the whole spectrum of pulmonary hypertension basic and clinical science (www.wsph2013.com). In recognition of the critical importance of registries, a task force will be dedicated to examine the epidemiology of pulmonary hypertension with an emphasis on registries. Participants from nine developed and developing countries will represent European, US, Latin American and Chinese sites, where multicentre registries have already been implemented. The task force members will provide guidance on interpretation of current data and promotion of future research. Among key questions, the task force members will address the changing phenotypes in developing and developed countries as well as guidelines for registries implementation.

STATEMENT OF INTEREST

M. Humbert has relationships with drug companies including Actelion, AstraZeneca, Bayer, BMS, GSK, Merck, Novartis, Nycomed, Pfizer, Stallergènes, TEVA and United Therapeutics. In addition to being an investigator in trials involving these companies, relationships include consultancy service and membership of scientific advisory boards.

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