Pulmonary Hypertension Association of Japan

A-209 5-8 Tsukimino, Yamato-shi,
Kanagawa-ken 242-0002
Phone & FAX: 050-1031-3706
http://www.pha-japan.ne.jp/

August 29, 2014

News Release
To Members of the Press:

Specified Nonprofit Corporation
Pulmonary Hypertension Association of Japan

3.5 Years on Average Until the Start of Consultations with a Specialist

Revealed in Patient Surveys on Chronic Thromboembolic Pulmonary Hypertension and Pulmonary Arterial Hypertension

A survey conducted for the first time by the Pulmonary Hypertension Association of Japan (President: Noriko Murakami, 160 members) revealed that for patients with chronic thromboembolic pulmonary hypertension and pulmonary arterial hypertension, intractable diseases where the progression of symptoms can lead to death, a considerable length of time passes from the time of onset until a diagnosis is made by a specialist. The average length of time until diagnosis by a specialist was 3.5 years, with a maximum length of 18.5 years. With the enactment of the new Intractable Disease Health Care Act approaching, the Ministry of Health, Labour and Welfare has begun the task of certifying designated medical care providers, and in order to reduce the burden on patients, we believe that measures such as the allocation of specialists according to case performance and experience is crucial.

This survey was conducted anonymously (by post) among 160 members of the Association nationwide, from Hokkaido to Okinawa, from July 18th to August 17th, in order to raise the Association's demands to the government with regards to the new Intractable Disease Health Care Act that was established in May of this year. 93 responses were tabulated. As the responses are all from members who are receiving medical expense benefits for specified diseases, all are patients who fall under the Intractable Disease Health Care Act. While 87% of the patients are currently being seen by a specialist, there were a prominent number of cases where a considerable amount of time passed from the time of onset until the patient reached a specialist.

Pulmonary hypertension progresses in a short period of time after onset. If symptoms progress, they may lead to death (*). For this reason, early determination of the disease and start of treatment by a specialist are essential. We receive many inquiries from members regarding medical institutions with resident specialists, and at our meetings held throughout Japan including Tokyo, Osaka, Kyushu, and Hokkaido, there is an active exchange of information among members regarding medical institutions.

According to the survey, the number of medical institutions seen until the patient reached a specialist was one to two for 60% of patients, and three to five for 23% of patients. The reason for the considerable length of time required to be seen by a specialist in spite of the relatively small number of medical institutions seen is thought to be due to feelings of deference towards the physician they are currently seeing. In response to the question, "How would you feel if the government or municipality referred you to a specialist?", 51% of patients responded, "I would first need to consult my current physician," far outnumbering those who responded, "I would want to be seen by a specialist" (23%) and "I am worried about whether it is a commutable distance" (31%).

In addition, of those members currently being seen by a general physician, 31% responded that they were “not satisfied”. Of these, 88% noted that “I know there are specialists, but they are not at a commutable distance.” Currently, there are few specialists in pulmonary hypertension, and they are not evenly distributed across the respective prefectures. For this reason, there are some members living in rural areas for whom there is the risk of it taking an even longer amount of time to actually be seen by a specialist even if the government decides on designated medical care providers.

Please refer to the appendix for detailed survey results.

(*) There are survey results indicating that approximately 50% of patients diagnosed with pulmonary arterial hypertension die within five years, and the average survival time of PAH patients not receiving treatment is approximately three years, making the need for prompt and accurate definitive diagnoses an important issue. “PAH: Recommendations for Improving Patient Outcomes” Pulmonary Hypertension Association (USA) Ed.

About the Pulmonary Hypertension Association of Japan

The Pulmonary Hypertension Association of Japan is a patient advocacy group that works to support patients diagnosed with pulmonary hypertension including chronic thromboembolic pulmonary hypertension and pulmonary arterial hypertension, rare and intractable diseases, and their families, conducting activities to enable patients to live with their illness, sharing information with others who have the same illness, and enabling them to make an informed selection of treatment methods without regrets. The Association has also established relationships with patient advocacy groups overseas that have the same purpose, and strives to exchange the latest medical information. The Association is also in collaboration with healthcare professionals, etc. who have expressed support for the activities of the Association.
The goals of the Association are as follows:

1. For patients with pulmonary hypertension and their families to “know the disease”
2. For patients with pulmonary hypertension and their families to “fight the disease”
3. To “create and improve the medical and social environment” to ensure that patients with pulmonary hypertension and their families can feel secure in their fight against the disease
4. To “raise social awareness and understanding” of pulmonary hypertension

Inquiries regarding this release:
Specified Nonprofit Corporation
Pulmonary Hypertension Association of Japan
A-209 5-8 Tsukimino, Yamato-shi, Kanagawa-ken 242-0002
Phone & FAX: 050-1031-3706

[Appendix]

[Q1] What kind of physician oversees your treatment?

1. Specialist	2. Specialist Pediatrician	3. General Physician
61%	26%	17%

[Q2] For patients being seen by a specialist,
A) Are you satisfied with your current treatment?

1. Yes	2. No
77%	10%

B) How did you hear of this specialist?

1. By word of mouth from other patients or through a referral from a family member or acquaintance	2. By referral from my physician	3. Other
25%	38%	26%

C) After onset, how many physicians in how many locations did you see before reaching a specialist? How much time passed from onset until you were seen by your current specialist?

1-2 locations	3-5 locations	6 locations or more
60%	23%	0%

Length of time until you were seen by your current specialist
(Free response) Average 41.68 months

[Q3] For patients who selected “3” as their response to Q1:
A) Are you satisfied with your current treatment?

1. Yes	2. No
69%	31%

B) Are you aware that there are specialists who can treat you?

1. I do not know where they are	2. I want to know which medical facilities they are at	3. I know that there are specialists, but they are not within a commutable distance
13%	13%	88%

[Q4] How would you feel if the government or municipality referred you to a specialist?

I would want to be seen by a specialist	The issue is whether it is a commutable distance	I would first need to consult my current physician	Other
23%	31%	51%	8%

[Q5] What do you feel is a reasonable distance to commute for treatment?
*If using public transportation such as trains or buses

Within one hour	Within two hours	Other
61%	23%	6%

*If driving

Within one hour	Within two hours	Other
55%	27%	5%

[Q6] Please indicate any concerns or insecurities you have about your treatment.
Omitted