bridging the knowledge gap on rare disease

A survey on behalf of Global Genes reflects a growing appreciation among primary care physicians (PCPs) and specialists of the societal impact of rare diseases, while also underscoring the burden shouldered by patients and family members.

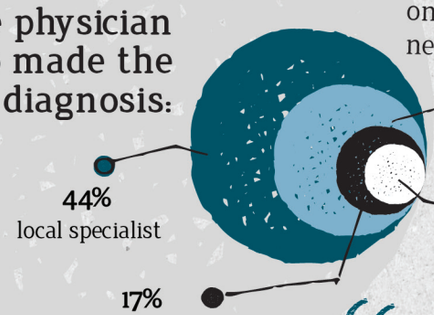
7.3

Average number of physicians seen before receiving a diagnosis.

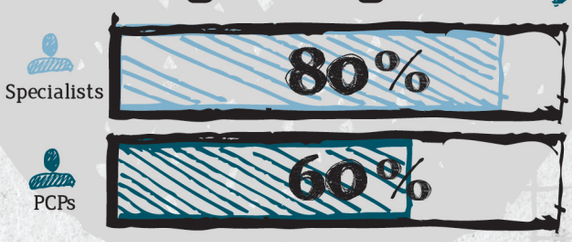
44 percent

of patients said that because of a slow diagnosis, treatment was delayed and the impact on their condition has been negative.

The physician who made the diagnosis:



> "I welcome the challenge that rare diseases bring and want to be part of finding a diagnosis."



> "I lack sufficient time to do a workup for a rare disease even when I suspect the patient may have one."

19% of PCPs felt their knowledge of rare disease was excellent or good at time of diagnosis; **59%** rated their current level of rare disease knowledge as excellent or good

59% of specialists felt their knowledge of rare disease was excellent or good at time of diagnosis; **77%** rated their current level of rare disease knowledge as excellent or good

70% of physicians

"It would be helpful to receive additional training in rare diseases."

Global Genes™
Allies in Rare Disease

About the Survey

This survey was conducted by Engage Health, Inc. and provided data for 920 patients in 26 countries, and 367 HCPs in 13 countries. 805 patients, parents and spouses provided evaluable data, including those with more than one child with a rare disease.

The survey was administered using a standardized questionnaire and required special security measures to ensure patient confidentiality. The survey was conducted over a period of 12 months and closed in August of 2013.

Find the article here.

Reference

Engel P.A., Gabal S., Broback M., Boice N. Physician and patient perceptions regarding physician training in rare diseases: the need for stronger educational initiatives for physicians. Journal of Rare Disease 2013; 1(2).