

LETTERS

Innovative Approaches to Studying Health Outcomes in Rare Diseases

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To the Editor: As emphasized by the valuable *Journal of General Internal Medicine* supplement, rare diseases are important (Volume 29, Issue 3 Supplement, August 2014).^{1,2} They constitute heavy burdens of suffering for patients, growing problems for our health care system and important areas for scientific research. The care of patients with rare diseases is also an important aspect of primary care practice.³ Primary care physicians are specialists in the care of common problems, but common patients sometimes have rare diseases. Primary care includes the responsibility for recognizing such problems and managing such patients. Practice-based research documents that primary care physicians care for patients with a wide variety of rare disorders across the spectrum of patient age and sex, organ system involved, and medical specialty area.⁴ In the majority of cases, primary care physicians identify the rare problem, diagnose the disorder, and provide acute and continuing care, even for life-threatening conditions.⁴ Patients with rare diseases have common needs, too, and primary care physicians manage most of that continuing care.⁵ For the practicing primary care clinician, this responsibility is

much more than a collection of rare diseases or memorable cases. It is the care of exceptional patients with special needs and it offers professional challenges and opportunities for personal growth.

Conflict of Interest: The author declares that he does not have a conflict of interest.

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