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WesternConnecticutHealthNetwork.org
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April 18, 2012

Doris Lefkowitz Reports Clearance Officer Agency for Healthcare Research and Quality

Dear Ms. Lefkowitz,

The Western Connecticut Health Network currently supports the state of Connecticut's only Lyme disease Registry. The mission of the Lyme disease Registry is to create a comprehensive database of patients with Lyme disease that will serve as the basis for multidisciplinary research leading to a better understanding of:

- The course of the disease and how people are affected;
- Causes of persistent symptoms;
- Improved diagnosis and treatment.

As such, we welcome the creation of a *Registry of Registries (RoPR)* by the Agency for Healthcare Research and Quality as outlined in the Federal Register on February 23, 2012. Like ClinicalTrials.gov, RoPR would provide a valuable resource that will facilitate collaboration and reduce redundancy in the development and implementation of patient registries. In addition, we would look to RoPR as an opportunity to promote our registry to eligible and interested patients.

Dr. Petrini attended the initial RoPR stakeholders meeting in January 2011 and offered input into the components of RoPR. We congratulate AHRQ for compiling the group's recommendations into a system that will have practical utility for those of us who administer patient registries.

Thank you for the time and energy that has been devoted to this important initiative.

Sincerely,

Ramin Ahmadi, MD, MPH

Joann R. Petrini, PhD, MPH

Department of Medical Education and Research