



November 8, 2017

Boni E. Elewski, M.D., Chair  
University of Alabama School of Medicine  
Department of Dermatology  
Eye Foundation Hospital 500  
1720 2nd Avenue South  
Birmingham, AL 35294-0009

Dear Dr. Elewski,

There is a universal problem associated with 597 rare skin diseases – a problem that your leadership and the Department of Dermatology may help solve through the Rare Skin Disease Referral Initiative.

When a dermatologist diagnoses a rare skin disease, the patient is prescribed an appropriate therapy. For example, I was diagnosed with *pityriasis rubra pilaris* in November, 2012. My treatment plan included acitretin (25mg); the twice-daily application of Desonide® (face), Clobetasol® (palms and soles), and triamcinilone (body); and hydroxyzine (itch relief). I was also referred to Dr. Google and Dr. Yahoo for additional information.

My experience using the internet was a disaster. The information I unearthed via search engines was redundant, insufficient, outdated, and typically written for an audience of healthcare professionals.

There is a far better referral option for your dermatologists to consider for patients presenting with a rare skin disease. Direct them to the Genetic and Rare Diseases Information Center's website. GARD, a program of the National Center for Advancing Translational Sciences, is funded by the National Institutes of Health. They serve patients, caregivers, and healthcare professionals.

With the cooperation and support of GARD and the National Organization of Rare Disorders, the PRP Alliance has taken the lead on the Rare Skin Disease Referral Initiative. We hope you will share our message with your dermatologists and students?

Sincerely,

Bill McCue  
Founder/President