Rare Skin Disease Referral Initiative

What's Standard Treatment Protocol?

When a dermatologist diagnoses a ***rare skin disease***, the patient is prescribed an appropriate therapy. Predictably, the initial treatment plan will include systemic and topical therapies as appropriate. However, there's something that most, if not all patients are missing: a referral to the Genetic and Rare Diseases Information Center (GARD).

Without a Rare Skin Disease Referral to GARD...

A newly diagnosed patient leaves the dermatology clinic with a treatment plan, prescriptions to fill at the local pharmacy, the required paperwork and an appointment to return at a later date. For patient and caregivers, their journey has begun with little more than the name of the rare skin disease and a tacit referral to Dr. Google and Dr. Yahoo. As questions arise in the days and weeks that follow, the information unearthed via search engines is too often redundant, insufficient, outdated, and typically written for an audience of healthcare professionals.

What Happens With a GARD Rare Disease Referral?

GARD, a program of the National Center for Advancing Translational Sciences, is funded by the National Institutes of Health. The office supports a variety of programs to serve the needs of patients who have any one of approximately 7,000 rare diseases known today. Their rare disease database includes information on each of 597 rare skin diseases.

Who Can GARD Help?

- Your patients diagnosed with a rare skin diseases
- The people who care for your patients: parents, family members, and friends
- Doctors, nurses, and other healthcare providers
- Scientists who are studying rare skin diseases and need information for their research

How will your patients find what they seek?

Reliable information about rare or genetic diseases is often hard to find. Your patients will have a roadmap to the resources they need from this dependable source.

- ***GARD website*** – Your patients have online access to reliable information about their newly diagnosed rare disease to include symptoms, cause, diagnosis, treatment, research, daily life and support organizations.
    - Web: http://rarediseases.info.nih.gov/GARD
- ***GARD Learn More Opportunities*** – Links to resources where patients can find more information, e.g. the National Organization of Rare Disorders.
- ***GARD Information Specialists*** – Whether by phone, fax or email, the public has access to current, reliable, and easy-to-understand information in English or Spanish.
    - Toll-free Telephone: 888 205-2311
    - Email: GARDinfo@NIH.gov/

https://rarediseases.info.nih.gov