



RECRUITING SITES!

The PeDRA “Big” Study on Burden of Pediatric Skin Disease

PLEASE PARTICIPATE

We are excited to be recruiting up to 3500 parent/child combinations in US and Canada to be able to address the role of stigma in so many of our pediatric skin disorders – and how it relates to anxiety, depression, and social functioning of children with these diseases. This will provide important pediatric burden information. All PeDRA work group leads have been canvassed for their interest and are committed to the study. An organizing task force was organized in 2017 and has been active in shaping the project. Patient advocacy organization partners will form an advisory group to leverage and help disseminate findings.

Send us a note NOW that you are interested – a single center can have multiple PIs.

Funding is available to defray or cover costs of IRB submission based on how many subjects are recruited.

REQUIREMENTS & EXPECTATIONS:

SIGN UP WITH US BY THE END OF MARCH 2018: We plan to open all sites for enrollment at once with a 6-month period of recruitment. The study will be managed through a Data Coordinating Center at Northwestern University.

Submit to your IRB: Sites will be provided with protocol and ICF templates.

Minimal expectation of enrolling at least 50 children/parent combinations per site during 6 months.

Subjects must be 8-17 years old with a chronic skin condition severe enough and/or in a visible location that could be stigmatizing as determined by the study doctor.

Subject and parent must both be English-speaking with at least one parent/guardian who will complete the questionnaires.

Can complete study on paper or electronically: All sites will be given 2 iPads for study use: All data will be stored on a REDCap database hosted at Northwestern

DATA TO BE COLLECTED:

- Demographic data (age, sex, ethnicity, zip code and Fitzpatrick skin phototype, insurance log per CARRA categories), clinical information, and PRO measures

- Parent will provide some information and fill out proxy forms regarding the perceived stigma, anxiety, depression and social functioning experienced by the child (each with 6-8 questions)
- Concurrently, the child will fill out questionnaires about stigma, anxiety, depression and social function, as well as Skindex-Teen
- Physician/assistant will capture the Fitzpatrick skin type, diagnosis and its duration/severity/visibility-location, other medical issues, and family medical issues of relevance.

SIGN UP BEFORE THE END OF MARCH 2018

CONTACT: Dr. Stephanie Rangel (stephanie.rangel@northwestern.edu) or Dr. Amy Paller (apaller@northwestern.edu) [Note: some sites have signed up – check with us to confirm]