

PeDRA POST



Pediatric
Dermatology
Research
Alliance

AN E-NEWSLETTER TO UPDATE AND INFORM PeDRA'S COLLABORATIVE RESEARCH NETWORK | SUMMER 2017



THIS ISSUE

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Welcome

We are delighted to present the fourth issue of the PeDRA Post; this publication provides updates on the research endeavors of our expanding organization. PeDRA is a truly innovative collaboration of individuals who seek to improve the lives of children with a variety of dermatologic diseases. By combining efforts with the SPD, PeDRA has been able to make even more grant money available to researchers and enable new investigators to find their niches. As you read about this year's accomplishments and the ongoing efforts of researchers and advocacy groups in this issue, I'm sure you will feel just as inspired as I do. Welcome to an exciting new year!

I welcome feedback!

Kalyani

– Kalyani Marathe, PeDRA Communications Committee



UPDATES FROM PeDRA STUDY GROUPS

Collaborative groups of investigators have formed under the PeDRA umbrella to pursue pediatric dermatology studies.

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Birthmarks and Procedural

The Birthmarks group has been actively conducting research on both vascular birthmarks as well as pigmented lesions. One of our first multicenter studies regarding propranolol use in premature infants has been completed, and the manuscript is currently being prepared. The preliminary result from the multicenter genotype-phenotype study of children with vascular overgrowth syndromes was presented at the Society for Investigative Dermatology meeting where it was well-received. A large multi-center retrospective study on evaluation for PHACE syndrome is ongoing, as is a survey study looking at current management of infantile hemangiomas. Several studies are being initiated, including a retrospective cohort study on ulcerated hemangiomas. Studies that continue to develop include topical rapamycin and pulsed dye laser for capillary malformations, quality of life measurement for children with vascular malformations, and basic science projects including developing vascular tumor cell lines. The pigmented lesion subgroup continues to work on studies that involve developing consensus guidelines for management of congenital melanocytic nevi, the role of MRI to detect neurocutaneous melanosis, and mapping primary congenital melanocytic nevi and their satellite lesions.

For more information, please contact:

Megha Tollefson (tollefson.megha@mayo.edu) or Anita Haggstrom (aahaggstr@iu.edu)

Genetic Skin Disorders

Basal Cell Carcinoma Nevus Syndrome Subgroup

The BCCNS registry, based at Stanford, now has patients from outside institutions enrolled. We have streamlined the consenting process and are excited to hear from more patients who are interested in participating! Additionally, we are working to include Phoenix Children's Hospital as an additional study site. We are looking for more patients, as well as for centers that are interested, and greatly appreciate all the help in putting us in contact with interested parties!

For more information, please contact:

Joyce Teng (jteng3@stanford.edu)

Disorders of Cornification (DOC) Subgroup

The DOC working group, PeDRA, and other collaborators have enrolled 800 subjects in the National Registry for Ichthyosis and Related Skin Types. This project seeks to identify novel genetic causes of ichthyosis and to understand disease pathobiology. The study continues to enroll subjects with disorders of keratinization/cornification, collecting clinical information, photographs, and a saliva or blood sample for genetic analysis.

For more information, please contact:

Keith Choate MD, PhD (Keith.choate@yale.edu)

Epidermolysis Bullosa Subgroup

The Epidermolysis Bullosa Clinical Research Consortium (EBCRC) has 18 (going on 19) centers in the US and Canada. EBCRC's main project, the EB Clinical Characterization and Outcomes Database (EBCCOD), has fully transitioned from Stanford to the University of Colorado and has been redesigned to support longitudinal data collection. There are more than 660 patients enrolled in this study currently. The EB Research Partnership and EB Medical Research Foundation are funding 10 sites that are participating in the EBCCOD. A manuscript describing the EBCCOD and its subjects is underway. Additional active EB studies include:

- Esophageal Strictures in Epidermolysis Bullosa Patients: Incidence, Management Strategies and Patient Outcomes (Elena Pope, PI)
- Characterization of Skin Care Practices and Antimicrobial Resistance Patterns in Epidermolysis Bullosa (Kim Morel, PI)



Studies about access to genetic testing and the transition to adult care are also in the planning phase.

For more information, please contact:

Anna Bruckner, MD (anna.bruckner@ucdenver.edu)

Genetic Investigation of Cutaneous Mosaic Disorders

Cutaneous mosaic disorders are severe, rare genetic skin disorders appearing in patterns due to a somatic mutation during embryonic development. The timing of the mutation determines the identity and extent of affected tissue, and given contributions of ectoderm (keratinocytes), mesoderm (fibroblasts, cutaneous vessels), and neural crest (melanocytes) to the skin, one or multiple cell types can be affected. We have successfully identified several novel genetic causes of these conditions and now propose to expand our cohort of well-phenotyped cutaneous mosaic disorders, to screen for mutations in potential causative genes, and to employ exome sequencing in mutation-unknown subjects with reflex to genome sequencing for unsolved cases to discover novel genetic causes. Included are proliferative/hamartomatous conditions including congenital fascial dystrophy, nevus comedonicus, and congenital hemangiomas, as well as rare mosaic presentations of common disorders including acne, psoriasis, lichen planus, and discoid lupus erythematosus, which provide an opportunity to identify pathways relevant to autoimmunity and inflammation.

For more information, please contact:

Keith Choate MD, PhD (Keith.choate@yale.edu)

Inflammatory Skin Disorders

Acne and Hidradenitis Subgroup

Epidemiologic data of hidradenitis suppurativa (HS) in children is lacking. By reviewing the clinical presentation and management of HS in children our goal is to create an efficient protocol for treating this condition and preventing its complications. We are currently recruiting sites interested in participating in a retrospective chart review of pediatric patients with HS.

For more information, please contact:

Irene Lara-Corrales (irene.lara-corrales@sickkids.ca).

Atopic Dermatitis Subgroup

The prospective, observational study of traditional systemic agents remains ongoing with subject enrollment (Wynn Tom, wtom@rchsd.org). A number of PeDRA sites will be involved in upcoming pediatric studies on dupilumab, and we anticipate discussion of incorporation of this and other exciting new therapies into our studies. We are looking for additional investigators interested in contributing to the design and execution of the following studies: occurrence of topical antibiotic and antimicrobial resistance (Christine Lauren, cat35@columbia.edu) and assessment of AD lesional morphology by race/ethnicity (Minnelly Luu, mluu@chla.usc.edu). We also welcome other project ideas and encourage submission for discussion at the 2017 PeDRA Annual Conference.

Connective Tissue Disease Subgroup

The Connective Tissue Disease subgroup continues to thrive with several active studies. Collaborations with CARRA have continued and PeDRA was again represented at the CARRA Annual Meeting in May in Houston, Texas. PeDRA and CARRA are working together on a retrospective study of discoid lupus erythematosus, funded by a CARRA grant, which will pave the way for a prospective investigation on systemic lupus erythematosus progression. We also successfully competed for a CARRA grant to develop a photograph atlas for juvenile dermatomyositis. The morphea registry continues to enroll patients, and genetic studies are ongoing. Data collection is almost complete for the morphea mapping study funded by a PeDRA pilot grant in 2015. The Connective Tissue Disease subgroup welcomes new members and is recruiting additional investigators for its studies; trainees and early investigators are encouraged to participate.

For more information, please contact:

Yvonne Chiu (ychiu@mcw.edu)

Hair, Nail and Autoimmune Subgroup

Parties interested in projects of this subgroup should contact Nanette Silverberg (nsilverb@chpnet.org).

Psoriasis Investigator Group (PsIG):

The PsIG has been busy with several studies in various phases. The CAPP Survey (Clinical Approaches to Pediatric Psoriasis) has been deployed in the US and Canada and is now in the manuscript preparation phase. In addition, data from our Retrospective Review of Systemic Therapies and Phototherapy for moderate to severe plaque psoriasis in children was presented at the Society for Investigative Dermatology, the European Society for Pediatric Dermatology, and the SPD meetings. Ten PeDRA centers participated in the US and ten in Europe through their European Pediatric Psoriasis Working Group (EPPWG), and 445 patient records comprised the study population with adequate data for assessment. A manuscript has been submitted. PsIG was able to get funding from the International Psoriasis Council to support this study.

A new natural history study for guttate psoriasis (GP) in 8-17 year olds (150 subjects) has been drafted with the goals of: i) determining the conversion rate to chronic plaque psoriasis (CPP) within 2 years; ii) identifying biomarkers in blood, cultures, and skin that may be associated with increases in conversion from GP to CPP; and iii) defining the gene expression and immune cell expression profile of GP. Severity, pruritus, and quality of life will be evaluated at 7 visits. PsIG is working with Janssen to fund this project with PeDRA, and we are looking for more investigator sites.

PsIG members and other multidisciplinary experts developed the first set of pediatric psoriasis comorbidity screening guidelines, supported by PeDRA and the National Psoriasis Foundation. They are now published in JAMA Dermatology. This has been followed by development of an online "app" to facilitate the screening process. We are in the testing phase of the app, and are open to new sites to join to assess pre- and post-app ease of screening. Please contact Wynn Tom, MD (wtom@rchsd.org) for more information.

Finally, a series on patients with TNF-induced psoriasiform dermatitis is in the early data collection phase.

If you are interested in joining this group, have study ideas or would like to participate in other PsIG studies, please contact:

Co-Chair, Kelly Cordoro, MD (kelly.cordoro@ucsf.edu) or
Co-Chair Amy Paller, MS, MD (apaller@northwestern.edu)



Neonatal

The neonatal skin working group is interested in improving our understanding of skin health in premature and term neonates. A study characterizing neonatal hospital skin care practices across the U.S. and Canada is underway. Additionally, a pilot project examining clinical outcomes of afebrile neonates with pustulosis has been completed, and there are plans to generalize this project to include multiple other institutions. Projects in development include evaluation of scarring in premature infants and identification of neonatal dermatology knowledge gaps among NICU fellows. New ideas and participants are needed and welcomed!

If interested in contributing to our efforts, please contact:

Raegan Hunt MD
(rdhunt@texaschildrens.org) or
Christine Lauren
(cat35@cumc.columbia.edu)

Skin Tumors and Reactions to Cancer Therapies (STARC)

The Skin Tumors And Reactions to Cancer therapies (STARC) group is working on 10 projects, six of which are recruiting additional investigators:

STARC studies recruiting investigators:

- Impact of dermatologic care on chronic graft versus host disease
Contact: Jeff Yu, MD (YUJ1@EMAIL.CHOP.EDU)
- Fatal pediatric melanoma
Contact: Elena Hawryluk, MD (Elena.Hawryluk@childrens.harvard.edu)
- Cutaneous reactions to targeted anticancer therapies
Contact: Christina Boull, MD (oehr0005@umn.edu)
- Basal Cell Carcinoma Nevus Syndrome (BCCNS) Clinical Registry
Contact: Joyce M. Teng, MD (jteng3@stanford.edu)
- Registry for PLC in children
Contact: Elena Pope, MD (elena.pope@sickkids.ca)
- Developing consensus guidelines for the diagnosis and management of pediatric cutaneous chronic GVHD
Contact: Dominique Pichard, MD (dominique.pichard@nih.gov)

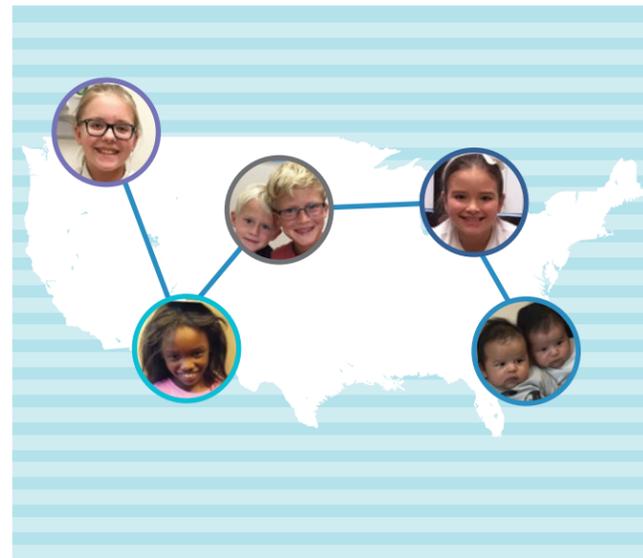
STARC studies closed to new investigators:

- Retrospective evaluation of pediatric cutaneous mastocytosis
Contact: Leslie Lawley, MD (lpotter@emory.edu)
- Melanoma and nonmelanoma skin cancer in children and young adults
Contact: Jennifer Huang, MD (jennifer.huang@childrens.harvard.edu)
- Current practices in diagnosis and management of chronic cutaneous graft versus host disease among dermatologists and transplant providers
Contact: Dominique Pichard, MD (dominique.pichard@nih.gov)
- Patient education for children at risk for skin cancer
Contact: Carrie C. Coughlin, MD (coughlinc@wustl.edu)

STARC welcomes new members and project proposals. For more information or to submit a project proposal, please contact:

Jennifer Huang, MD (jennifer.huang@childrens.harvard.edu) or
Carrie C. Coughlin, MD (coughlinc@wustl.edu)

PeDRA BRANCHES OUT WITH FIRST PAN-PE DRA STUDY



PeDRA is launching a “Pan-PeDRA” study, which will assess anxiety, depression, and social functional issues in addition to stigma in children with skin diseases. This project, our first to cross all PeDRA study areas, has the potential to underscore the burden of disease and highlight the need for ancillary or integrated support services for kids with skin diseases, increased insurance coverage for diseases routinely denied as “cosmetic,” and dermatology curricula on what patients and their families experience and need. We anticipate starting this study by fall 2017. Northwestern University is the lead center with Amy Paller, MS, MD and Sarah Chamlin, MD, as national Co-Principal Investigators and with an organizing committee representing a broad group of leading investigators and advisors. Other members of the organizing committee are: Gabriella Andrade, Lisa Arkin, Leslie Castelo-Soccio, Kristi Holland, Jeanette Jakus, Steve Humphrey, Irene Lara-Corrales, Margaret Lee, Dawn Siegel, Karin Vivar, and Dennis West. We anticipate that 25-50 investigators will participate in this study through PeDRA, and have set a minimum enrollment of 50 patients/dyads with parents per site. This study will only be conducted in the US, although we are considering the inclusion of Canada, and the study will be open for 6 months after initiation.

For more information about this innovative project, please contact Amy Paller, MS, MD (apaller@northwestern.edu) or Sarah Chamlin, MD (schamlin@luriechildrens.org).

EARLY CAREER INVESTIGATORS IN PeDRA

EIC Forum at PeDRA Annual Conference

The Early Investigator Committee (EIC) has planned a special training workshop being held on **Thursday afternoon, October 26** in conjunction with the PeDRA Annual Conference, October 26-28, 2017. This **Early Investigator Forum**, beginning at 3:00 PM and called *Selling Your Science*, will include:

Drew Bixby: “Writing an Effective Specific Aims Page”

Drew Bixby teaches Magazine Writing, Advanced Magazine Writing, and Composition and is the Assistant Director of the Writing Center at University of Colorado Denver. In the format of an interactive workshop, Drew will build presentation analysis and explanations from a sample specific aims page.

Melissa Marshall: “Transforming Slide Design”

For almost a decade, Melissa Marshall has traveled around the world to work with Fortune 100 corporations, institutions and universities, teaching the proven strategies that she has mastered through her consulting work and as a faculty member with the Department of Communication Arts & Sciences at Penn State University. In this workshop, Melissa will teach early investigators to create better presentation slides using a design strategy proven to make technical presentations more understandable, memorable, and persuasive.

Networking Reception for early investigators and senior PeDRA leaders

Melissa Marshall: Keynote Dinner Presentation “Talk Nerdy To Me” for all PeDRA conference attendees

PeDRA Mentorship Program

A big thank-you to Lisa Arkin for leading this program! We have some excellent feedback and data on the experience thus far with the mentorship program. Our current plan is to re-launch and re-match interested PeDRA members (mentors + mentees) soon. We will revise the survey that matches mentors/mentees, announce the re-opening of this program at WCPD, and send out the link to sign up immediately after our announcement. We are currently considering improvements and changes to the program. Please let us know if you have any feedback or ideas! Please contact Lisa Arkin (lisa.arkin@gmail.com) or Jennifer Huang (jennifer.huang@childrens.harvard.edu)

EARLY CAREER INVESTIGATORS IN PeDRA

Webinar

The Early Investigator Committee has organized three webinars to date: “How to Write a Grant” and two webinars on “Job Negotiations.” (Transcripts available at <http://pedraresearch.org/resources-for-researchers>.) We extend a hearty thank-you to Heather Brandling-Bennett, Lisa Arkin and Yvonne Chiu for these excellent interactive sessions this winter. They were very well received and beneficial to people at all stages of their career. **Are there topics important to you that you would like to see covered in a webinar?** Please send ideas to Jennifer Huang (jennifer.huang@childrens.harvard.edu).



THE PATIENT ADVOCACY NEWS BOARD

A page dedicated to news, announcements & invitations in disease areas that PeDRA is researching!



BIRTHMARKS AND PROCEDURAL

GENETIC SKIN DISORDERS

INFLAMMATORY SKIN DISORDERS

NEONATAL

STARC



The Dystrophic Epidermolysis Bullosa Research Association of America (debra)

FUNDING ALERT: For Fiscal Year 2017, epidermolysis bullosa has been added to the list of 48 eligible diseases for federal research funding through the Department of Defense’s Peer-Reviewed Medical Research Program (PRMRP). \$300 million has been allocated for this program. When EB had last been included in the PRMRP in Fiscal Year 2011, more than \$1 million was allocated to EB research. If you are interested in applying, debra of America can help expedite the vetting process by sending us your CV, as requested by the PRMRP Program Administrator. For more information, please contact Joe Murray, Director of Government & Legal Affairs at debra of America, joe@debra.org, 202-779-3681.

The Foundation for Ichthyosis & Related Skin Types (FIRST)

is hosting face-to-face patient meetings throughout the United States and Canada. These meetings are comprised of medical discussions led by a member of FIRST’s Medical & Scientific Advisory Board. Additionally, research updates, product sharing, skin care routines and networking with other families and individuals affected by ichthyosis are on the agenda for the attendees. FIRST invites PeDRA members, their patients, and anyone who would benefit from meeting others, to attend. The meeting schedule can be found on the FIRST website at firstskinfoundation.org/patient-support-forums. FIRST appreciates dissemination of this announcement and encouragement of patients to attend!

The National Eczema Association (NEA)

NEA will award three \$30,000 grants for research on the impact that atopic dermatitis (AD) has on patients, related to burden of disease. General areas include quality of life, psychosocial, economic burden, marital status, time, and academic/occupational pursuits. The evidence generated by these research projects is essential to NEA’s advocacy efforts. Please visit <https://nationaleczema.org/nea-funded-research/> for more information.

The National Psoriasis Foundation (NPF) encourages PeDRA members to get involved.

- Become a **professional member** for preferential listing in NPF’s provider directory, complimentary CME offerings, discounts on study recruitment, and much more.
- Join us at the 2017 NPF **Research Symposium**, August 3-5 in Chicago.
- Submit your research to the **Journal of Psoriasis and Psoriatic Arthritis**.
- Become a site and enroll for the **Corrona Psoriasis Registry**.
- And much more!

Visit us online at www.psoriasis.org to learn more.

GRANTS—SPD AND PeDRA TEAMED UP AND IT'S WORKING

For 2017, the program has a combined **\$91,000** to allocate.

PeDRA and the Society for Pediatric Dermatology (SPD) decided to maximize resources and harmonize their respective grant programs by merging into one single program. The PeDRA/SPD joint program launched about a year ago and awarded ~\$82,000 across two grant cycles in 2016. The number of applications has markedly increased and the program was able to fund seven different multisite and single site projects. For 2017, the program has a combined \$91,000 to allocate. At the time of this writing, awards are being decided for the May submission cycle. Next one up: December 1! For that cycle, we will have an online portal for grant submissions. This will streamline the process greatly. Watch for announcements and keep checking <http://pedresearch.org/grants-to-support-research>.

RESEARCH TOOLS & RESOURCES



***Study tracking tool**—PeDRA has invested in an online tool for entering and tracking all studies in the network. This effort will facilitate future updates and produce statistics, enabling us to convey the value of all of our hard work. Principal Investigators have been entering their studies but we are still not complete. To enter or update a study, login to your Account page on pedresearch.org and then scroll down to “PeDRA Study Updates.”



***Search for Professionals**—How can you find collaborators for research projects? How can you better understand the strengths, interests and assets brought into the network by PeDRA investigators? One easy answer: our “Search for Professionals” tool for PeDRA members on pedresearch.org. However, in order for the Search to reflect the capacity of all active researchers, it needs to be populated! If you haven't already, please take a few moments to complete our research capacity survey: <http://pedresearch.org/research-capacity-survey>. Your profile will then be integrated into the Search for Professionals.



***Basecamp for PeDRA**—Basecamp allows PeDRA members collaborating on research projects to share documents, improve editing flow, align project schedules and more. Use of Basecamp is optional but study groups are finding it to be a useful tool. The Communications Committee has teamed up with PeDRA study group leaders to help streamline the process. We welcome feedback on Basecamp as a research tool! Please contact Kim Morel (km208@columbia.edu).

HAVE YOU RECENTLY...
BECOME A MEMBER? PAID
YOUR DUES? UPDATED YOUR
PROFILE? **THANK YOU.**



PEDRA MEMBERSHIP

You are our greatest asset and keeping up your membership allows us to grow our ranks, bring in revenue to support both our core mission and build infrastructure that holds us together as an organization.

ACTIVE MEMBERS: Please log in and pay membership dues here: <https://pedsderm.net/pedra/>. There is also the option of paying or renewing PeDRA dues when you pay your SPD dues. **TRAINEE MEMBERS:** If you have moved, are no longer in a trainee program, or have changed any of your professional “stats,” we need you to update your profile! This takes just a few easy keystrokes. This ensures collaborators and PeDRA-Central can reach you and that you will stay a connected and active participant. Please visit: <http://pedresearch.org/account>, log-in, and then follow the prompts to User Profile and then Edit profile. **NON-MEMBERS:** Join today! Membership is a two-step process. Apply here: <http://pedresearch.org/membership-application>.

Any questions about membership or your dues payment? Please contact Jenn Dawson, Membership Liaison, jennifer.dawson@pedresearch.org.

IMPORTANT DATES AND REMINDERS

Save the Date:

The 5th PeDRA Annual Conference, October 26-28, 2017

Hyatt Regency
Aurora-Denver Conference Center
Aurora, CO

Registration opens soon!

Watch for conference information here: <http://pedresearch.org/annual-conference>



PeDRA grants: Deadline for submissions for the next grant cycle is December 1, 2017. See article in this issue for details.

PeDRA reviews and approves surveys before dissemination to our members. The next application deadline is August 15, 2017. Please visit <http://pedresearch.org/pedra-survey-policy> for application details.



PeDRA Published Papers

[JAMA Dermatology | Consensus Statement \(Online: May 2017\)](#)

Pediatric Psoriasis Comorbidity Screening Guidelines

Emily Osier, MD*; Audrey S. Wang, MD*; Megha M. Tollefson, MD; Kelly M. Cordoro, MD; Stephen R. Daniels, MD, PhD; Andrew Eichenfield, MD; Joel M. Gelfand, MD, MSCE; Alice B. Gottlieb, MD, PhD; Alexa B. Kimball, MD, MPH; Mark Lebwohl, MD; Nehal N. Mehta, MD, MSCE; Amy S. Paller, MD; Jeffrey B. Schwimmer, MD; Dennis M. Styne, MD; Abby S. Van Voorhees, MD; Wynniss L. Tom, MD*; Lawrence F. Eichenfield, MD*

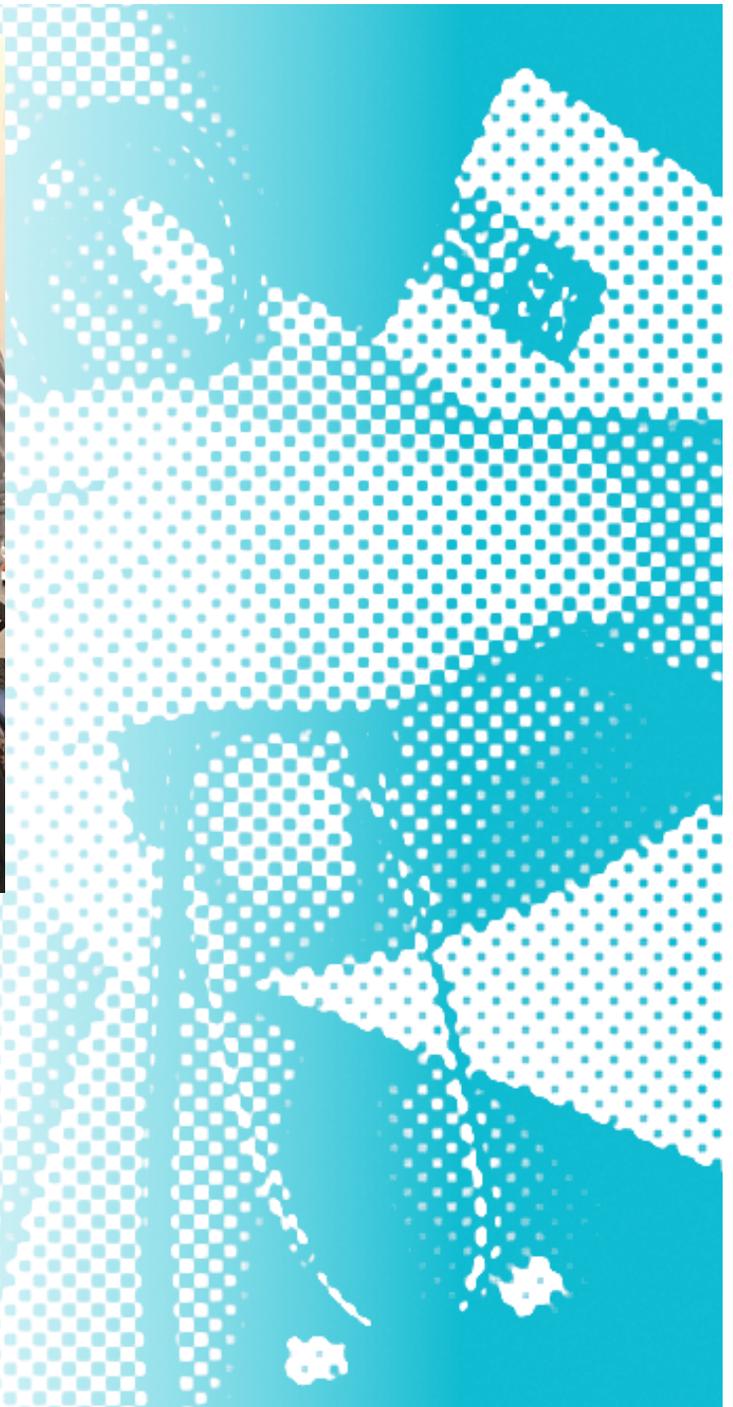
*contributed equally to this work

[Journal of the American Academy of Dermatology \(February 2017 issue\)](#)

Prescribing practices for systemic agents in the treatment of severe pediatric atopic dermatitis in the US and Canada: The PeDRA TREAT survey

Christine R. Totri, MD, MAS*, Lawrence F. Eichenfield, MD*, Kirsty Logan, PhD, Laura Proudfoot, MD, PhD, Jochen Schmitt, MD, MPH, Irene Lara-Corrales, MD, MS, Jeffrey Sugarman, MD, PhD, Wynniss Tom, MD, Elaine Siegfried, MD, Kelly Cordoro, MD, Amy S. Paller, MD, MS, and Carsten Flohr, MD, PhD

*contributed equally to this work



Thank you to the PeDRA Communications Committee for contributions to this newsletter!

Yvonne Chiu
Colleen Cotton
Cyndee DeKlotz
Elena Hawryluk
Kristen Hook
Raegan Hunt
Christine Lauren
Marilyn Liang

Julianne Mann
Kalyani Marathe
Kimberly Morel (Chair)
Elena Pope
Kate Puttgen
Megha Tollefson
Wynnis Tom
Albert Yan



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<http://pedraresearch.org>

Questions? Please contact:

Sheila Rittenberg, PeDRA Executive Director,
sheila.rittenberg@pedraresearch.org
Jennifer Dawson, PeDRA Liaison,
jennifer.dawson@pedraresearch.org



Look for **PeDRA** on Facebook! Special thank you to Cyndee DeKlotz, Facebook page master.

PeDRA Post design: Carrie Geygan Design