

Research Collaborations: Lessons from PeDRA and the SPD

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No conflicts of interest





Organizing to Promote Research

Society for Pediatric Dermatology: Founded in 1975

- Tremendous educational meetings
- Highly interactive and collaborative members
- Numerous case series/ facilitated diagnoses

Strategic Planning Session:

Research is Top Priority to drive forward advances for optimal pediatric patient care

How can busy practitioners engage in research?

The launch of PeDRA

Pediatric Dermatology Research Alliance

Strategic Planning
of SPD: Research
is top priority

NIAMS holds
Pediatric
Dermatology
Roundtable

Annual R13-funded
freestanding meetings

2009

2010

2011

2012

2013

2014

2015

Concept
of PeDRA



Pediatric Dermatology Research Alliance
A solid foundation for pediatric skin research

NIAMS Roundtable Conference

December, 2011 at NIH

11 invited participants

- **Clinical and bench researchers – SPD members**
- **Physician-scientists - research that impacts PD**
- **Coalition advocate**

44 SPD members surveyed to explore unmet needs:

- **High priority/high impact clinical trials**
- **Infrastructure needs**
- **Knowledge and training gaps**
- **Scientific advances ready for translation**
- **Barriers to translation**

Conclusions

Huge unmet needs - Little investigation

- Few therapeutic advances

Expediting dose, safety and efficacy trials for new therapies – and approving them for children

- Applying pathogenesis-based approaches (e.g., genodermatoses, immune-mediated disorders)**

Ancillary mechanism-of-action studies (e.g., beta-blockers for hemangiomas)

Comparative effectiveness trials

Epidemiologic studies

Registries for side effect prevalence

Official launch: July, 2012



ped
rock



Pediatric Dermatology Research Alliance

A solid foundation for pediatric skin research



- **7/12 planning session: ~20 SPD leaders dedicated to research + NIAMS/ CARRA representatives**
- **Mission:** Promote and facilitate high quality collaborative clinical, translational, educational, and basic science research in pediatric dermatology
- **Recognized that only collaboratively could we have patient numbers to approach rare disorders and severe variants of common disorders in testing hypotheses and new therapeutic possibilities**
 - **PeDRA as vehicle for performing research that cannot be done at a single institution**

Initial Goals

- **Facilitate design and conduct of clinical research**
- **Engage bench scientists/ share research resource**
- **Establish/perpetuate repositories and disease-specific databases**
- **Raise funds to support research through unified organization**
- **Leverage existing networks and establish new ones**
- **Raise awareness of institutional resources: CTSA sites, SDRCs, science at our institutions**
- **Encourage and provide better training for physician-scientists, outcomes and clinical research in pedi derm**

Governance

- **July, 2012: Created initial roadmap and chose co-Chairs/ 7 member Executive Committee**
 - **Co-Chairs, Secy-Treas, Chairs of major committees: Communications, Development, Membership, Science**
- **Other committees took shape: Bylaws, Ethics, Finance and Audit, Grants, Nominating, Young Investigator**
- **Ratified bylaws to codify PeDRA governance structure were ratified 2014**





Pediatric Dermatology Research Alliance

Website: www.pedraresearch.org

Contact Us
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About Us Research Areas For Researchers For Patients Annual Conference Calendar



Welcome

Dermatologic disorders in children are more than skin deep. PeDRA was formed to accelerate collaborative research and provide answers for hard-hitting skin diseases. PeDRA's mission is to produce groundbreaking discoveries, and one day, cures that benefit countless young patients.

Current Studies

Find out what researchers are currently working on, as well as what opportunities might fit your interest or expertise.

Upcoming Conference

We are looking forward to our third annual research conference, planned for November 6-7, 2015, in Dallas, TX. Click to learn more.

Get Involved

Our mission is ambitious and there are many opportunities to help achieve it!

I am a researcher or clinician

I am a patient or organization with interest



Fundraising

- **Able to obtain multi-year seed funding from SPD**
 - **Bring on part-time Executive Director**
 - **Two PeDRA fellows**
- **R13 NIH grant to support PeDRA scientific meetings for 2013 and 2014; competitive renewal submitted**
- **Support from Industry**
- **Funding from Coalition partners**
- **Donations from Individuals (SPD members and beyond)**

Specific Aims: R13 for 3-day stand-alone meetings

Aim 1: To provide new and established PeDRA investigators with an essential knowledge base and infrastructure to conduct high-quality multicenter research in pediatric skin disorders.

Aim 2: To create a bridge between basic scientists and clinicians to enhance opportunities for translational research initiatives.

Aim 3: To identify and prioritize the clinical needs and therapeutic opportunities in disease-specific areas

Oct, 2013: 80 participants; **Nov, 2014:** 110 participants

Resubmitted for 2015, 2016: Fundable score

PeDRA meeting: Tips from experts

- **Collaboratives: Children's Oncology Group (COG), Childhood Arthritis and Rheumatology Research Alliance (CARRA), and PROMIS ("How to bring researchers together and keep them engaged")**
- **Core Centers: Center for Mendelian Genetics**
- **Scientists: Rational therapeutics for ichthyosis**
- **Institutional Resources: Getting the most out of your Institutional Resources; Top 10 Pitfalls for the Multi-Center IRB; Writing Grant Proposals**
- **NIAMS: Funding opportunities**



PeDRA meeting: Tips from our own

- **Databases**
- **Patient recruiting**
- **Forming registries**
- **Best Pharmaceuticals for Children Act**
- **Ongoing research involving groups within PeDRA**
- **Research activities internationally**

Patient Advocacy Groups

- **Needs of our patients**
- **Reminder of our goals**



PeDRA meeting: Networking

- **Learning more about each other**
 - **Speed networking**
 - **Posters**
 - **Short abstract presentations at dinner**
 - **Brainstorming sessions**
 - **Informal interactions**
 - **Dinner, lunch, bar...**
- **Meeting others: Guest speakers, Advocacy group leaders, NIAMS support**



PeDRA meeting: Focused Working Groups

- **Birthmarks (Vascular, Pigmented)**
- **Inflammatory Skin Disease (Psoriasis, Connective Tissue and Auto-inflammatory, Atopic Dermatitis, Acne & Hidradenitis, Hair/Nails)**
- **Genetic Skin Disorders (Epidermolysis bullosa, Disorders of Cornification)**
- **Skin Tumors and Reactions to Cancer Therapies (STARC)**
- **Neonatal Skin Care**



PeDRA meeting: Focused Working Groups

- 1. To expand collaborative relationships across PeDRA and beyond**
 - 2. To plans projects to execute now (with existing funding) and during next few years (through grants) to advance pediatric dermatology research and PeDRA**
- ~15 research projects now initiated (some “low hanging fruit” = surveys, consensus guidelines)**
- With other groups: TREAT-US; Psoriasis; CARRA**
- Competitive grants for 4 projects and more to come**



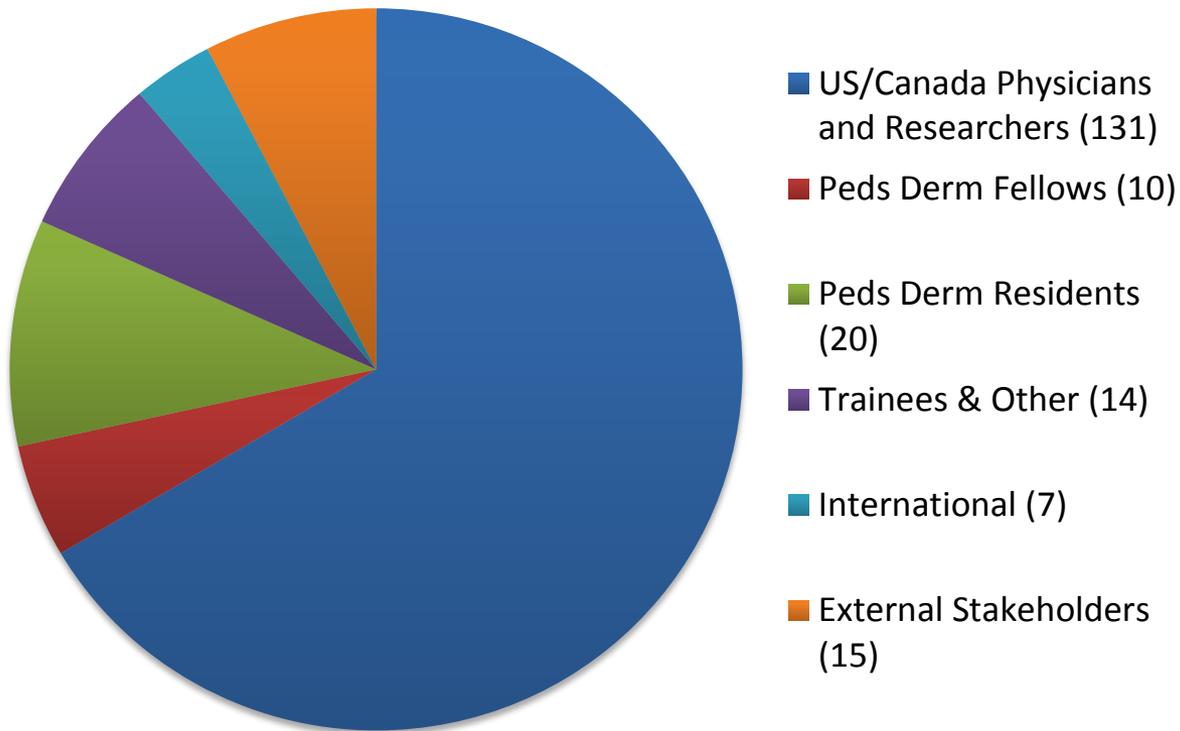
Advocacy

- **Started a series of meetings with FDA to discuss drug development for pediatric skin disease**
- **Commented on NIH draft policy for central IRB**
- **Participated in DODAC* meeting to bring new systemic medications to children**
- **Advocating for researchers who are engaged in projects that advance PeDRA goals**

DODAC = Derm and Ophtho Drug Advisory Committee

PeDRA is growing

Engaged in PeDRA (197 Total)



- **68 institutions**
- **13 private practices**

Challenges

- **How can PeDRA best support busy clinicians who have limited infrastructure: engaging in research (surveys, retrospective reviews with trainees, prospective registry enrollment)?**
- **Should PeDRA establish its own database?**
- **Should PeDRA have a central IRB or project-specific central IRBs?**
- **How to initiate centralized biobanking?**
- **How to best fundraise – and provide grant support?**
- **How to best link with other groups, including scientists, to think about pediatric research (scientific investigation, biobanking)**



Collaboration with MDS

- **Considerable overlap in research goals**
- **Comparative research in adults vs. pediatric populations: prevalence, manifestations, comorbidities, interventions and prognosis**
- **Membership not restricted to pediatric practitioners:**
 - **Any board-certified dermatologist is eligible to become an active member**

Thanks for your attention



Pediatric
Dermatology
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Alliance

<http://pedraresearch.org>