

Annual Steering Board Meeting Summary

In January of 2017, the [PEDSnet Steering Board](#) convened for its annual in-person meeting to discuss the future state of the network. The Board expressed a vision for an integrated PEDSnet Learning Health System Consortium that focuses on improving outcomes. Importantly, the Board agreed to pursue the development of a business plan for a PEDSnet New Company, i.e., a multi-services company that reflects alignment/integration with networks. PEDSnet leadership is continuing to develop the business plan with sufficient detail to be able to present to the Steering Board for consideration.

In other noteworthy news related to sustainability, [PCORnet](#) has established a new non-profit organization committed to accelerating people-driven research known as the People-Centered Research Foundation (PCRF). [Read more.](#)

QUICK LINKS

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Research Updates

The [Automating Quality and Safety Benchmarking for Children Study \(PI: Walsh\)](#) has made great progress since notice of award. To date, in addition to the execution of the primary subcontract, the CCHMC protocol has been approved, and all participating PEDSnet sites have executed reliance agreements, therefore demonstrating the incremental gains in IRB efficiency that PEDSnet is beginning to make for multi-site studies.

PEDSnet Collaboration on NIH HCS Pragmatic Clinical Trial Proposals

PEDSnet recently reached out to investigators based at our eight institutions

PEDSnet at AMIA 2017 Joint Summits on Translational Science

The PEDSnet Informatics team will be well represented at the [2017 American Medical Informatics Association Joint Summits on Translational Science](#) in San Francisco at the end of this month. Poster presentations will include:

- **Standardizing Clinical Diagnoses: Impact of Alternate Terminology Selection** (Burrows, et al.)
- **Understanding the Gaps Between Data Quality Checks and Research Capabilities in a Pediatric CDRN** (Khare, et al.)
- **Managing Science Query Traffic in a Large Pediatric Data Research Network** (Razzaghi, et al.)
- **Developing Computable Phenotypes for Pediatric Chronic Conditions in PEDSnet** (Utidjian, et al.)

Welcome New Staff

Several new CHOP Research Institute hires will contribute to PEDSnet efforts.

with an invitation to collaborate on the [NIH Health Care Systems Research Collaboratory-Demonstration Projects for Pragmatic Clinical Trials UG3/UH3 RFA](#). PEDSnet was specifically designed to support large-scale pragmatic clinical trials and is uniquely positioned to help investigators by providing access to a variety of tools and resources that will strengthen applications and streamline study implementation. We are excited that investigative teams from four of our eight institutions responded to this collaboration opportunity and are currently preparing to submit applications for the June 1 deadline.

PEDSnet Demonstration Project Co-PIs Receive U01 Sub-Award

PEDSnet would like to congratulate Nemours Investigators and PEDSnet Demonstration Project Co-PIs, Dr. Jim Franciosi and Dr. John Lima, who in collaboration with colleagues at the University of Florida were recently granted a U01 sub-award entitled, "**Genomic Medicine Implementation: The Personalized Medicine Program**" from the National Human Genome Research Institute to study a pharmacogenetic approach to optimizing proton pump inhibitor treatment in children. This project will coincide with the work being completed for the PEDSnet Demonstration Project, "[Unanticipated Consequences of Proton Pump Inhibitor Use](#)."

SMART IRB The NIH issued a final policy on the use of a Single IRB that will take effect September 25, 2017. The PCORnet Collaborative network of CDRNs and PPRNs is continuing to move sites toward fully executed joinder agreements for SMART IRB. Six of eight PEDSnet sites have executed SMART IRB agreements.

Communications Updates

Website User Authentication PEDSnet will soon enable "user authentication" on our website. This will allow for login access to appointed areas of the site in addition to the public-facing areas. We plan to establish logins for key groups in PEDSnet such as Leadership, Project Managers, Study Teams, and Stakeholders to start, but are unlimited as far as the creation of member-specific areas of the site and our ability to tailor access. With this flexibility in mind, we welcome suggestions on how best to utilize this new feature. Please stay tuned for the rollout announcement.

Please welcome:

- **Heather Johnson**,
Administrative Director
- **Rahul Darwar**,
Informatics Coordinator
- **David Soler**,
RIA Programmer
- **Susan Hague**,
RIA Programmer
- **Harris Weinstein**,
Bioinformatics Engineer
- **Shweta Chavan**,
Bioinformatics Engineer

PEDSnet Engagement Committee

We are pleased to announce that the PEDSnet Engagement Committee has now formed. Drs. Peter Margolis and Michael Seid will lead the committee, while RaeAnne Davis and Lisa Boerger of the PEDSnet Management Office will manage committee operations. The Committee is currently working out meeting schedule and other logistics, in addition to finalizing their Charter. The list of Engagement Committee members and their institutions follows:

- **Katie Litterer**,
Boston Children's Hospital
- **Alissa Scharpen**,
Children's Hospital Colorado
- **Amy Kratchman**,
Children's Hospital of Philadelphia
- **Jeannette Holiday**,
Cincinnati Children's Hospital
Medical Center
- **Sarah O'Brien, MD**,
Nationwide Children's Hospital
- **Ana Maria Schwandt, DDS**,
Nemours Children's Health System
- **Elizabeth Kruvand**,
St. Louis Children's Hospital
- **Jen Faultner**,
Seattle Children's Hospital



Data Network Updates

PEDSnet Communications Resources

Please click on the links below to view and share PEDSnet communications resources:

- [PEDSnet One-Pager](#)
- [PEDSnet 15-minute Talk](#)
- [PEDSnet Data Domains Infosheet](#)

Antibiotics & Obesity Study Investigators Respond to Provocative Article

Drs. Forrest, Block, and Bailey, representing the [PCORnet Antibiotics and Obesity Study](#), submitted a commentary in response to a recent article in The Lancet Diabetes and Endocrinology from a research team based at Kaiser Permanente. The results of the KP team's observational study lead them to conclude that "infection, but not antibiotic use, during infancy is associated with risk of childhood obesity." The PCORnet team's response raises a number of questions about their conclusions and calls for future studies to replicate the findings before general acceptance of this claim. Information on accessing full text of both the original article (Li, et al.) and the commentary can be found [here](#).

Send Us Your News!

We want to hear from you. Please email pmo@pedsnet.org with items you would like to see in our next newsletter.

Data Refresh PEDSnet data through December 2016 is slated to 'go live' by next week. Another data cycle is scheduled to begin in late April.

Pediatric CRG Updates

Phase II Funding The Pediatric Collaborative Research Group, lead by Dr. Chris Forrest of PEDSnet and Dr. Betsy Shenkman of the OneFlorida CDRN, was one of 11 CRGs selected to receive Pilot Program Expansion funding. Research Interest Groups that have formed within the Pediatric CRG include **Autism, Epilepsy, Sickle Cell Disease, Cerebral Palsy, and Hypertension**. Network partners should expect to see collaboration opportunities related to the RIGs in the near future. In the meantime, please send an email to pedsorg@email.chop.edu if you would like to find out more about the CRG, RIGs, or how to get involved.

Pediatric CDE Meeting a Success

As detailed in our fall newsletter, the PCORnet Pediatric Clinical Research Group has launched the Pediatric Common Data Element (CDE) project with the goal of producing a minimum set of common data elements that should be collected and standardized for every child in PCORnet. The CDE Working Group, consisting of researcher-scientists, clinicians, and informaticians representing several PPRNs and CDRNs, recently convened at a Face-to-Face meeting in Philadelphia, and have produced a draft of a **Table 1** of the agreed-upon CDE. More to come on this exciting effort.

Upcoming Events

Big Data for Patients (BD4P) Training Opportunity

Big Data for Patients (BD4P) is a data science training program that seeks to give patient advocates a basic understanding of the science of big data to enable them to participate more fully and effectively in big data initiatives. The program will serve to empower patients and advocates by enhancing data science literacy and critical appraisal skills. **BD4P is currently accepting [applications](#) for the second [BD4P Training Workshop](#) on April 25-26, 2017.**

March 24, 2017 Grand Rounds

John Spertus, MD, MPH, FACC, FAHA, Daniel Lauer/Missouri Endowed Chair and Professor at University of Missouri Kansas City will present "**The Role of Patient-Reported Outcomes in Clinical Trials, Quality Assessment and Clinical Practice**" at the 3/24 NIH Health Care Services Research Collaboratory and PCORnet Grand Rounds. [Click for full information.](#)

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