

Participants: Denise Metry, Maria Buethe, Yakir Levin, Buddy Cohen, Jinia Feghaly, Kim Morel, Melenee Finger, Cheryl Bayart, Danielle Despanie, Dawn Eichenfield, Deepti Gupta, Emily Sirotych, Ilona Fieden, Anna Ujvary, Anita Haggstrom, Bella Plumptre, Christy Collins, Lara Wine Lee, Anna Kerr, Laís Lopes Almeida Gomes, Maria Laura Cossio, Turkan Banu Karatas, Lionel Bercovitch, Remie Chrabieh, Moureen Wneik
Staff: Katherine Devenport

SUMMARY

7:18p Call to Order

Discussion	Action
<ul style="list-style-type: none"> • Denise and Maria • Denise shared some basic background on the Birthmarks FSG <ul style="list-style-type: none"> • Subgroups: Hemangiomas, Vascular Malformations, Lasers • View meeting minutes and more on the PeDRA Birthmarks FSG Webpage • Patient advocacy representatives joining the call tonight from the Sturge Weber Foundation, PHACE Syndrome Community, M-CM Network, Klippel-Trenaunay Support Group • Medical Student Task Force is being created – stay tuned for more information on how to get involved with PeDRA as a student • REGISTER for the 2024 PeDRA Conference – October 24-26 in Phoenix, AZ 	

7:25p Hemangioma Subgroup Update

Discussion	Action
<ul style="list-style-type: none"> • Subgroup leads Cheryl Bayart and Jinia El Feghaly shared ongoing projects • Infantile Hemangiomas that “don’t read the textbook” <ul style="list-style-type: none"> • Led by Cheryl Bayart and Ilona Frieden • Retrospective investigator recall project, recruiting patients 10+ with IH with persistent growth, symptoms, bright red, mucosal involvement, late ulceration or other unexpected or atypical outcomes. It will include patients from the PHACE registry, but also will include patients without an associated syndrome • Email Cheryl.bayart@cchmc.org for the intake sheet • Multi-omic sequencing in PHACE and LUMBAR syndrome <ul style="list-style-type: none"> • Led by Dawn Siegel <ul style="list-style-type: none"> • Registry-based; Recruitment help: aiming to recruit 10 families with PHACE for the Stanford GREGoR sequencing project in the next few weeks (April 2024). They would need to give blood samples. We are seeking patients with any of the following: Coarctation or cardiac defects, Individuals with 4-5 of the PHACES features (ie: P+H+A+C+E), History of multiple miscarriages in the mother • SUBPROJECT: LUMBAR registry and genomics – led by Dawn Siegel and Denise Metry <ul style="list-style-type: none"> • Recruiting LUMBAR families, especially those with additional anomalies or discordant twins) for the registry and GREGoR sequencing. 	

<ul style="list-style-type: none"> • For LUMBAR registry, looking at patients who have a ‘segmental’ infantile hemangioma of LUMBAR distribution (no size cut off), and at least one other associated abnormality. • More information here • <u>New project ideas</u> • EMR Template for Hemangiomas – Jinia introduced this idea <ul style="list-style-type: none"> • Kristi Holland had been working on this previously • Dermoscopic features of infantile hemangiomas – Contact Jinia if interested in participating: Jinia_ElFeghaly@URMC.Rochester.edu or jiniaelfeghaly@gmail.com <ul style="list-style-type: none"> • Dermoscopy over time of IH patients on and off propranolol • Identify dermascopic features that could give prognostic information on hemangiomas • Dermoscopic features of IH vs differential diagnosis of IH • Propranolol vs Atenolol – Contact Jinia if interested in participating: Jinia_ElFeghaly@URMC.Rochester.edu or jiniaelfeghaly@gmail.com <ul style="list-style-type: none"> • Consensus guidelines for starting propranolol, for choosing between propranolol and atenolol, etc 	
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7:45p Vascular Malformations Subgroup Update

Discussion	Action
<ul style="list-style-type: none"> • Subgroup leads Dawn Eichenfield and Bella Plumptre • <u>Ongoing Projects</u> • KHE Cohort Project <ul style="list-style-type: none"> • Led by Elena Pope; Dawn gave update on her behalf • Retrospective review of systemic therapy (MEK, PI3K, mTOR inhibitors) use for vascular anomalies <ul style="list-style-type: none"> • Led by Joyce Teng; Dawn gave update on her behalf • Seeking additional sites (18 sites currently, 10 have IRB). Aiming for 200+ patients on any targeted therapy (especially sirolimus, trametinib and alpelisib) • Contact students Carolena Estee Steinberg (cesteinb@stanford.edu) and Jordan Kim Uyen Bui (jkbui@stanford.edu) if interested in participating • Vascular Anomalies Genotype-Phenotype Project <ul style="list-style-type: none"> • Led by Beth Drolet • Seeking additional sites (12-14 sites), still enrolling patients (>500 patients enrolled)- in particular verrucous venous malformation cases and those with double hit mutations • Contact Ellen Bruhn (ebruhn@dermatology.wisc.edu) if interested in participating • CM-AVM Syndrome Consensus Guidelines <ul style="list-style-type: none"> • Study lead Lara Wine Lee provided update • Presented at ISSVA 2024 • Manuscript preparation underway – hope to submit in next few months • <u>New Project/Ideas</u> <ul style="list-style-type: none"> • Retrospective study of CM-AVM (Lara Wine Lee) <ul style="list-style-type: none"> • Including imaging, genotype/phenotype, and natural history 	

<ul style="list-style-type: none"> Lara (winelee@musc.edu) is seeking interested sites to participate – goal to start project in Fall 2024 	
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8:03p Lasers Subgroup Update

Discussion	Action
<ul style="list-style-type: none"> Subgroup leads Deepti Gupta and Yakir Levin shared the first faculty call will be on June 3 – email Katherine (Katherine.devenport@pedraresearch.org) to participate 	

8:05p Open Discussion

Discussion	Action
<ul style="list-style-type: none"> The group discussed treatment trends of ulcerated hemangiomas <ul style="list-style-type: none"> Propranolol dose and timeline of dosing, lasers, ‘white flag’ signs, etc. Potential survey study Email Katherine (Katherine.devenport@pedraresearch.org) or subgroup leads if you’d like to join a subgroup Upcoming Birthmarks Meetings <ul style="list-style-type: none"> Lasers Subgroup: June 3 All subgroups: August/September Full FSG breakout session at PeDRA: October 24-26 Upcoming Conferences: <ul style="list-style-type: none"> PeDRA Annual Conference: October 24-26, 2024 – Phoenix, AZ ISSVA: April 23-25, 2025 - Paris 	

8:10p ADJOURN

Minutes prepared by: Katherine Devenport