CoULD Meeting

ASSH Las Vegas

Friday, September 6 11-12pm

1. **Welcome!**
2. **REDCap Enrollment**

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| --- | --- | --- |
| REDCap Enrollment ASSH | 8/2018 | 8/2019 |
| Arm A | 1974 | 2475 |
| Arm B | 223 | 303 |
| Total participant enrollment | 2197 | 2778 |

Arm A

Boston: 893

St. Louis Shriners: 424

St. Louis Children’s/Wash U: 170

Seattle: 286

Nationwide: 230

Gillette: 230\*

Shriners Northern California: 145

Salt Lake City: 97\*

1. **Site Updates**
   1. **Currently 7 sites.** WU and Shriners St. Louis officially separated this spring.
   2. **Site Coordinators Updates:**
      * New coordinators onboarded at Nationwide and Utah.
      * Seattle changing coordinator. Tressa Mattioli leaving on Sept 13th.
      * Shriners Northern California: Without a coordinator.
      * Gillette’s coordinator: Jamie Price is doing a great job, very engaged and communicative with CRC.
   3. **CHOP Update:** 
      * DUA fully executed.
      * IRB approved.
      * Personnel: Faris Fazal, new coordinator is quickly getting up to speed as our new hand and UE research study coordinator. Along Faris CHOP has 2 part-time research assistants who will be helping with the registry. They will start towards end of September.

CHOP is currently wrapping up heavy enrollment and data collection for another study group concurrently for UE research. Also, Dr. Shah will be on the POSNA-SLAOTI traveling fellowship this fall returning on 11/9. Timeline should be discussed based on these two factors.

1. **Committee Updates**
   1. Data Cleaning: Suzanne Steinman: RLD project served to clean this subgroup of patients. Pending discussion with classification committee to decide change status to VACTERL when patient has at least 3 signs. Changes were only made to RLD dataset not to CoULD database.
   2. International: Michelle James. Collaboration with Scandinavian countries.
   3. Classification: Lindley Wall: OMT revision
   4. Onboarding: Donald Bae: Pending onboarding CHOP (see above for details).
   5. Marketing & Advocacy: Goldfarb Website update.
      1. Kidshandregistry.com could2019
      2. Important: Website content must be submitted to local IRBs prior to sharing with families as some of the content will be considered recruitment material
   6. DNA Warehouse: Bae
   7. Research: Goldfarb: Update studies.
2. **Conclusion**

**Zoom Call Information**

Join from your computer or mobile device: <https://bostonchildrens.zoom.us/j/6179197752>

Or dial in from your telephone:

    Internally:       x28882

    Externally:      646-558-8656 (Primary)

                             408-638-0968 (If you are unable to dial into the primary number)

Or iPhone one-tap:

                             +16465588656,,6179197752#  or +14086380968,,6179197752#

EWS link: <https://zoom.us/wc/6179197752/join>

Meeting ID: 617 919 7752