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PHSG, Denver

February 2019

# Newsletter

*current topics >>>*

## Enrollment per center:

From last year, we have increased enrollment from 1956 patients to 2423 today (Figure 1).

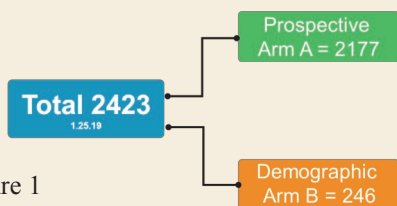


Figure 1

Of those we have: 2177 (90%) patients in the longitudinal Arm A, and 246 (10%) patients in demographic Arm B. Our enrollment visit completion rate is 96% (subjects completed OMT form/total enrollments). Enrollment rate per center can be seeing in Figure 2.

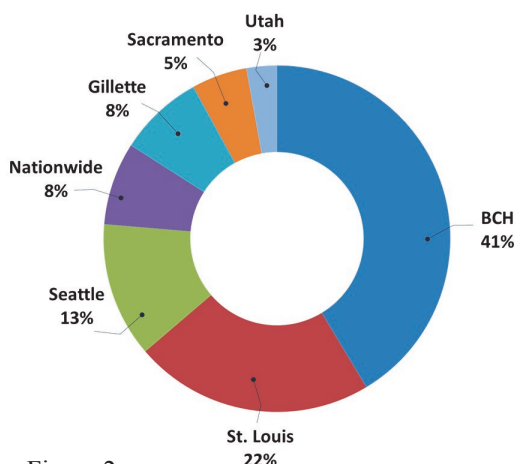


Figure 2

## Executive Committee Statistics

*Thanks to all CoULD members for another great year! With your continued hard work, CoULD continues to grow and move closer to our goal of understanding the effect of treatment on children with congenital upper limb differences.*

### Enrollment

From last year, we have increased enrollment from 1956 patients to 2423 today, with 2177 patients in the longitudinal Arm A, and 246 patients in demographic Arm B. Our enrollment visit completion rate is 96% (subjects completed OMT form/total enrollments).

### Surgery:

A total of 826 surgical procedures have been recorded in the CoULD database. 684 patients have had one surgery since study inception, and 142 patients have more than 1 surgery. Surgical rate 38%.

Table 1.

OMT 5 MOST COMMON Diagnoses	n=	%
Radial polydactyly	211	8
Ulnar polydactyly	192	7
Syndactyly	145	6
Radioulnar synostosis	140	5
Symbrachydactyly	138	5

### OMT

We assessed 2598 differences in 2423 patients. Malformations in the entire limb represent 33%, malformations in the hand plate 54%, Deformations 3% and Dysplasias 10% (see appendix number 1 for list of OMT diagnosis + syndromes). Syndromic associations were recorded in 13% of the patients The list of the 5 most common diagnosis is presented in **Table 1**.

### Follow up rate per main age group:

Patients of this age group that have completed follow up.  
 3yo: PODCI p: 71%  
 5yo: PODCI p: 70% ; PROMIS p: 63%  
 8yo: PODCI p: 61%; PROMIS p: 56%; PROMIS c: 51% .  
 11yo: PODCI p: 53% PROMIS p: 49%.  
 PODCI a: 41%. PROMIS c: 41%  
 14yo: PODCI p: 56% PROMIS p 54%.  
 PODCI a: 47%. PROMIS c: 49%  
 17yo: PODCI p: 43% PROMIS p: 33%.  
 PODCI a: 42%. PROMIS c: 35%.

# CoULD v.2 –UPDATES & FUTURE

## Implementing v.2

-PROMIS: We updated all domains from v.1 to v.2, and we chose to use autoscoring short forms instead of self-scoring forms. Data collected in the original self-scoring forms are still stored in the original instruments, which are now hidden from view but still accessible through data downloads.

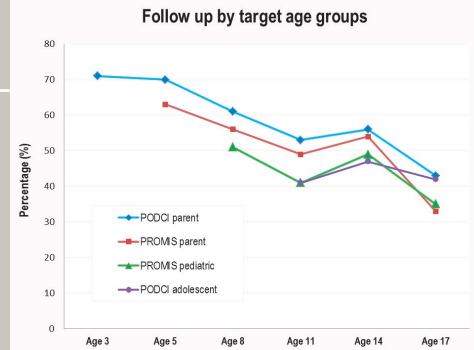
-PROMIS Normative scores (means 50±) for the item banks we collect are comparable regardless of whether they were collected with v.1 or v.2.

-We faced challenges setting up survey queue logic for PROMIS v.2 due to the autoscoring feature. One issue is that coordinators have found data entry to be more time consuming.

-We wanted to transpose data from PROMIS v.1 to v.2, but it is not possible due to the autoscoring feature of v.2. We will need to score our PROMIS v.1 surveys using the Assessment Center.

## Future Plans:

REDCap is still a work in progress. To help make coordinators' lives easier, we are in the process of setting up automatic survey follow ups at the main visit windows: 3yr, 5yr, 8yr, 11yr, 14yr, and 17yr. We obtained a central email address (kidshandstudy@wustl.edu), from which we will generate all automatic surveys. REDCap will also send three reminders if a survey remains incomplete. Coordinators will still have to manually send any surveys that do not fall in the main visit windows (i.e. those after surgery). Development is going on behind the scenes and no automatic surveys will be generated until we are 100% sure that everything works the way it should. Ultimately, we hope this will reduce coordinator burden and help us stay on top of sending patient surveys.



## Questions for PI and coordinators:

We created cover letter templates to be used when sending the questionnaires. In this letter, we might want to include questions about 1) past upper extremity surgeries, and 2) other surgeries in the past. This would help us obtain information required in the MD-clinic form visit at these time points.

## Questions:

- Do you think we can implement this change at your center?
- If yes, do you think that you will need to request an IRB amendment?

## Current issues>>>

# Subcommittee's Work

DNA WAREHOUSE (Dr. Samora, chair): No change. Next step: Determine charges and potential projects.

ONBOARDING (Dr. Bae): Waiting for onboarding CHOP and determine who will be next center.

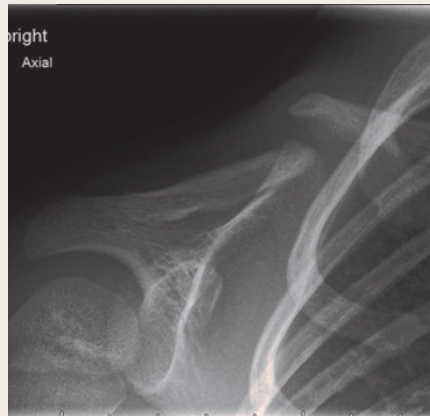
DATA CLEANING: (Dr. Steinman) Performed data audit of 10% of the records in every centers. It was time consuming to look for each record, the main problem encounter was missing data that arose from new questions added i.e., birth order, or OMT modifications.

CONSENSUS CLASSIFICATION: Have been classifying patients during in person meetings i.e, ASSH and PHSG, consensus building happening approximately twice a year. Pending proposal on how to modify OMT classification based on the cases that do not fit in the current scheme.

RESEARCH: (Dr. Goldfarb) Various proposals submitted. Needs to discuss authorship and publication rules.

MARKETING & ADVOCACY: (Dr. Goldfarb) Looking into website creation maybe under PHSG page. Next step: implement website or method for communicating results.

INTERNATIONAL: (Dr. James) Established a working collaboration with Dr. Marianne Arner who is leading a group of Scandinavian countries in an effort to create a registry for congenital differences with the potential for future collaboration.



## Research Dashboard

### Published:

Reliability of the OMT -JPO 2016  
Functional outcomes of the CoULD registry-JHS 2017.

### Submission:

Prevalence of congenital upper limb differences registry-JBJS.

### Current Approved Studies:

- Adoption study (St. Louis)
- PROMIS vs. PODCI validation (St. Louis)
- RU synostosis (BCH)
- Radial polydactyly I (Gillette)

### Proposals not yet approved:

- MHE (Sacramento).
- Triphalangeal thumb (BCH)
- Congenital radial head dislocation (BCH)
- Symbrachydactyly (Gillette)
- Radial polydactyly part II: (Gillette)
- Madelungs (St. Louis)
- Thumb deficiency: (BCH)