Early CP Risk Detection and Intervention Task Force Agenda/Minutes

### MEETING OBJECTIVE

**Draft Mission Statement**

*New Mexico infants at risk for cerebral palsy will receive timely, specific screening and if identified at “high risk” appropriate services will be available.*

**Vision / Mission Statement**

*All infants at risk for Cerebral Palsy should have access to opportunities, including quality healthcare, education, employment, etc., in order to optimize their function, fulfill their dreams and participate in their communities.*

### Notes

- Margaret Armstrong announced a new Carrie Tingley-produced brochure for newly diagnosed families. It is saved in the Google drive under Resources: “About Cerebral Palsy.” Will be useful for when family goes home, helps family remember what doctor said. Has links to good useful information. Families frequently search on the internet and find questionable information and someone trying to sell them something. Pass out but identify as CTH resource. There was a brochure before, but it was outdated.

- Marybeth Barkocy confirmed note in Meeting Agenda-- group will no longer review member news at meetings. Instead will send to members via email. At task force meeting, group will discuss highlights and relevant points.

- Marybeth B – Had hoped to have State Representative Liz Thomson come to meeting to answer questions, but she is sick and unable to attend even by phone conference. Some of the questions Marybeth wanted to ask:
  - Now that House Memorial 12 has passed and Taskforce formalized, are we responsible to move Taskforce forward? See questions on agenda.
  - To whom are we accountable?
  - What is time line?
  - Other questions about the bill which was approved to be heard, but was not heard. Should we assume we have to meet with interim committee? Short session next year.

Once we hear back from Liz Thompson, Marybeth will send email to group.
- Marybeth B – Upon recommendations, checked in with UNM HSC about Taskforce work/policy issues. She learned that the UNM process is long, like years long. The Memorial is not a UNM initiative.

- Marybeth, Erin, Margaret—Discussed need for help on legislative activities in the summer.

- Erin—Implementation of Early detection and intervention for cerebral palsy Conference (4/11-13, 2019) at Nationwide Children’s Hospital
  - Big takeaway--everyone in every state is struggling with early services to kids w/CP
  - To keep in mind--Difference between evaluative instruments. Discriminative vs. Evaluative instruments. The Peabody is both, good over time.
  - Existing accessibility in Apple device: there are many settings changes already there. More info at Apple.com/accessibility
  - Person with CP created the video via head switch for video editing on Apple re: apple accessibility – fascinating, inspiring person
  - When considering research into motor & development, focus on what is happening (the elements) in each intervention approach, rather than the name or acronym of the study. Researchers often use catchy acronyms to increase visibility and chances for funding.
  - Infants have to initiate and be involved in their movements. Are we setting up infants for success? Neurologically ingrained. We are not helping when passively stretching.
  - Zero gravity harness, supported walking—taking gravity out of the picture. Zero gravity harness still in development for pediatric px.
  - Give the child just enough support so that they can be active.
  - Creative parents finding ways to set up harnesses.
  - Gigi - gait trainers

- When we are not intervening, we are causing harm because we are missing the brain therapeutic window.

- Premature babies are spending hours in restrictive environments

- Helping parents—20 minutes 3X day equals 10 hours therapy a month.

- Bella’s Bumbo. Bumbo seat on tires. Child’s Mobility Chair is the Bumba seat on tires. So important for development to get little ones moving through space. Movement is about interaction.

- Delivering the Diagnosis--great course at CP Now.
  - Parents don’t really know what they should be expecting after discharge.

- Dr. Peter Rosenbaum – CanChild ([https://www.canchild.ca/](https://www.canchild.ca/)) involved with GMFCS Levels and Can GMFM research. Some ways he phrased the questions, when making dx, how to help parents get that:
  - When you see your doctor next time . . .
  - In transitioning between different types of services—warm hand off: what have you been told?
  - Like a drama with different scenes: super helpful language/scripts/questions/statements

- Diane Damiano, presenter- in EI, specifically in reference to movement disorders. Looking at outpatient debate, in-home less stressed parent, but treatment not as effective.

- Absence of fidgety movement and abnormal HINE usually spells CP.

- If you have a good plan in place, then you can be more effective, more cohesive approach is best.
  - In EI there needs to be a clear flow chart for how to get people help and information.
HINE and GMA trainings—Regular recalibration is necessary. You cannot just learn the techniques, you have to come back and relearn.
  - If everybody who is trained in the HINE maintains active recalibration, if anything changes, we can roll out / share with others, especially in rural areas. Maybe every 6 months, getting together, scoring.

- On the MRI, if there is a risk for CP, then it might be best to get imaging when they are small and sleepy.
- Dr. Armstrong - It would be good if we had the incubator equipment for MRIs. One speaker said optimal time is early after feeding—with compatible gurney. This is potentially something donors could help with. There is donor appeal to purchasing a piece of equipment.
- Maggie -- When looking at the planning piece, looking at the process of determining when MRI would be done.
- Marybeth--There is an issue with pediatric neonatal radiologist
- Dr. Armstrong--There is a protocol not being used.
- Erin—Constraint induced and bimanual—there is not much infant research. Constraint is frustrating. Importance of having the sticky mitt—now you know you have a right hand.

- Increased parent training:
  - 3 hours/day in 20-minute increments
  - Younger than 2: 5X week . . . followed by all bimanual.
  - This approach has been used in the past with older children. With infants—-we don’t know.
- Marybeth—Met with Rachel Byrnes, VP of CP Foundation. Please see folder in Google Docs. Got answers to HINE questions.
  - Big takeaway--We need to be using the Novak systematic reviews. Refer to Agenda. Optimality is where kid should be on curve. Answered our biggest questions.
  - Maggie—there is a chart in Novak.
- New HINE site that you have to register for. Has videos from trainings,
- Ordered 2 copies of books: GMA and Dubowitz (HINE basis) books; anyone can check out from Marybeth
- Notes from all Conference sessions Marybeth attended are in Google drive, including flow charts, data tracking, and
  - Family Talk—script by Peter Rosenbaum. Much good language and detail on how to talk to families. Also helpful about interpretation of HINE scores. Nationwide and Utah also have good info for tracking.
- Maggie--Has to be on both sides of body, busy small movement. Fidgety is good—9-16 weeks, up to 20 weeks.
- Marybeth—We can’t predict cognition.
  - Dr. A—All cognition tests are motor tests.
  - Marybeth—Neuroplasticity are highest in cog and vision
  - All in notes from conference — in Google doc folder
- Diane Damiano—Neuroplasticity is highest up to age 2.
- Marybeth--The way we get intensity is with parents. Frequency, intensity, time, volume, duration. Same principles they are trying to use.
  - Important to educate parents that their child’s neural development is dependent on the work we are doing.
• Getting parents into routines early.
  o Italy—Perception/action approach.
  o Natalie’s first talk about sensory stim in NICU. Recording of mother’s heartbeat in a bladder. Skin to skin, maternal and paternal presence. Recorded parent voices.
  o When surgery is decided. Hip is at risk—have to be super proactive about hip surveillance.
    ● Dr. Armstrong--Hip surveillance is controversial topic. Sweden and Australia are very aggressive. Control group is families that refuse. Other approach is having dislocated hip and child is not ambulatory and not painful, then maybe dislocated hip not so bad. One approach is monitor and let them know they are at risk. Depends on philosophy of surgeon. Dr. Silva tends to be less aggressive.
  o Dr. Armstrong--Dr. Bennett is leaving Carrie Tingley.
  o Dr. Armstrong—There are some things that buy you time—standers. As far as range of motion, doesn’t really prevent hip dislocation.
  o Marybeth—We are going to bring in Sarah Winter again for NMAPTA conference. Train the Trainer model being revised for reliability. On the edge of certification process.
  o Sandy working to get some training in south/Aprendamos
  o Gigi—Reported on Parents Reaching Out Family Conference—Presentation was scheduled at end of day with concurrent sessions. Only 4 attendees. No new information, did not learn anything or get any feedback from families on sharing difficult news. Would suggest to PRO fewer workshops. Sandy did tremendous amount of work.

### NEXT MEETING

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<tr>
<th>DATE</th>
<th>TIME</th>
<th>LOCATION</th>
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<tr>
<td>June 10</td>
<td>Monday</td>
<td>4:30-6:00 PM</td>
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<th>OBJECTIVE</th>
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<tr>
<td>Plan:</td>
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<td>o What are we doing well in each of our settings?—move that to another day</td>
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<td>o Date for next meeting? June 10</td>
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<td>o Future topic: Attendance, offering an option for a different time to open up to more people. Once a quarter, Zoom?</td>
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<td>o Baby Labs—Need to keep doing. Maybe pick a date in August. Use Inspirations?</td>
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**Notes taker:**
Angela Sosa