Cerebral Palsy Task Force Minutes

Attendees

<table>
<thead>
<tr>
<th>NAME</th>
<th>DICIPLINE</th>
<th>AGENCY</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cynthia Applegate</td>
<td>OT</td>
<td>Presbyterian</td>
<td><a href="mailto:capplegat@phs.org">capplegat@phs.org</a></td>
</tr>
<tr>
<td>Monica Armas Aragon</td>
<td>SW</td>
<td>UNM NICU</td>
<td><a href="mailto:maaragon@salud.unm.edu">maaragon@salud.unm.edu</a></td>
</tr>
<tr>
<td>Margaret Armstrong</td>
<td>MD</td>
<td>CTH</td>
<td><a href="mailto:marmstrong@salud.unm.edu">marmstrong@salud.unm.edu</a></td>
</tr>
<tr>
<td>Marybeth Barkocy</td>
<td>PT</td>
<td>UNM/PT</td>
<td><a href="mailto:mbarkocy@salud.unm.edu">mbarkocy@salud.unm.edu</a></td>
</tr>
<tr>
<td>Elizabeth Brobst</td>
<td>OT</td>
<td>Lovelace Women's</td>
<td><a href="mailto:Elizabeth.brobst@lovelace.com">Elizabeth.brobst@lovelace.com</a></td>
</tr>
<tr>
<td>Gerri Duran</td>
<td>OT</td>
<td>UNM</td>
<td><a href="mailto:gduran@salud.unm.edu">gduran@salud.unm.edu</a></td>
</tr>
<tr>
<td>Sandy Heimerl</td>
<td>PT</td>
<td>CDD-LEND</td>
<td><a href="mailto:sheimerl@salud.unm.edu">sheimerl@salud.unm.edu</a></td>
</tr>
<tr>
<td>Karen Lucero</td>
<td>PT</td>
<td>Inspirations EI</td>
<td><a href="mailto:Karen.lucero@inspirationsabq.com">Karen.lucero@inspirationsabq.com</a></td>
</tr>
<tr>
<td>Andrea Maddaleni-Denison</td>
<td>OT</td>
<td>Pres-NICU</td>
<td><a href="mailto:amaddalenie@aol.com">amaddalenie@aol.com</a></td>
</tr>
<tr>
<td>Sydney Marable</td>
<td>OT</td>
<td>UNM OT student</td>
<td><a href="mailto:samarable@salud.unm.edu">samarable@salud.unm.edu</a></td>
</tr>
<tr>
<td>Erin Moody</td>
<td>OT</td>
<td>ExplorAbilities</td>
<td><a href="mailto:erin@explorabilitiestherapy.com">erin@explorabilitiestherapy.com</a></td>
</tr>
<tr>
<td>Kathy Romero</td>
<td>RN</td>
<td>UNM</td>
<td><a href="mailto:KRRomero@salud.unm.edu">KRRomero@salud.unm.edu</a></td>
</tr>
<tr>
<td>Angelynn Zimmerman</td>
<td>OT</td>
<td>Inspirations</td>
<td></td>
</tr>
</tbody>
</table>

MEETING

Introductions: New member Angie Zimmerman, from Inspirations

News/Announcements:

Sandy handed out 1. Kellogg Foundation Grant, 2. change process info; Sydney handed out Parent Tool Kit and data compilation using data from Kids Count. She would appreciate feedback. Sydney invited friends, some of who have CP, to come to CP Taskforce meetings.

Dr. Margaret Armstrong--reported that she had conversation with director of Carrie Tingley Foundation. They are receptive to support with money for training. Will need description of proposal. Marybeth suggested that the application wait until the work of the task force is clearly developed.

Kathy Romero--reported positive reception from Dr. Tara DuPont to include topic at Amazing Newborn conference Nov 8 & 9, 2018. Two options on how to go about it: Do it as a breakout with demonstration; or get into main session with talk about importance of early identification of CP. Dr. Armstrong suggested to do both.

Kathy—his group needs to decide which they would prefer. OT/PT continuing education credits offered. We get about 20 physicians, not all neonatologists.
Sandy—I think we need to go over guidelines, in General Session.

Kathy—If we need more time, we could move this forward and have a weekend conference.

Dr. Armstrong. It would be nice to keep people from Roswell, Deming, etc., in the loop.

Kathy—Need to work on how to introduce to neonatologists. Have person who knows how to contact neonatologists. Beatrice Stefanescue from New Mexico Neonatal collaborative. Someone like Ann Winegardner who is in contact with community physicians, is already maintaining those contacts, who know how to get info out to them. Craig Wong helped set that up at UNM. Interested in getting people involved through Envision.

Sandy—The Director of Envision is on faculty with LEND.

Gerri—Conversations indicate that pushback when you use term “CP”, we might need to work on terminology: “Early indicators of high risk of motor/movement . . .”

Erin – when you get into the treatment stage, you really have to use language that describes the condition.

Kathy—How do we get community physicians on board with diagnosis terminology?

Dr. Armstrong—using term “at risk of”, at risk of CP.

Angie—This is important, that we talk about the real issues

Dr. Armstrong—we need to talk about neuroplasticity.

Gerri—Just Googled movement differences, use that and then go on to talk about disorder—lack of normal physiological development

Gerri—It is possible that this will come up on a discussion. . .

Kathy—Once that is on their record,

Dr. Armstrong—Insurance usually wants a Dx, especially if more intensive therapy is prescribed.

Kathy—It comes down to money. Getting therapists trained.

Dr. Armstrong—Spina bifida has been pushed forward by (insurance co?) It is not going to cost a lot, just training. They might be willing to move forward.

Sandy—The process of change- Kotter’s theory. We have to do is create a sense of urgency. This group has sense of urgency, but we have to spread this sense to communities and providers. Envision maybe one of the ways to educate providers?

Marybeth—What does Carrie Tingley Foundation require?
Dr. Armstrong—I can do proposal. We’ll need to know how much, who we want to educate.

Erin—Seems important that we have a resource of evidence-based articles. If we have say 3 top notch articles.

Sandy—We have that, but we need to have them summarized.

Marybeth—We have students doing some of that work. ____

Dr. Armstrong—There is the inertia of change. But I don’t know that it needs to be a long-standing permanent thing. It is just dealing with the change.

Erin—We haven’t really articulated the type of organization we need.

Sandy—Yes, all of that would be required for a grant.

Discussion about conference

Angie – We can use the conference to create a buzz.

Karen—The question is what resources we have to use. EI works with anything and everything the child needs. CP does not affect that many kids.

Monica (Social Work)—The question is do we have the resources.

Karen—And is there a therapist there who can do it? The families have to decide what they will do. Erin—We have to design a plan that is the best

Dr. Armstrong—There are studies showing that parents can be trained to provide the therapy. Not all parents are able.

Karen—The Fit philosophy is that everything you do is therapeutic.

Marybeth—Once a month is not moving us as fast as we need to. After the training, could we do like a retreat. I’d like to take the momentum of the training, and get some of the details worked out. I would rather spend more time up front, and roll things out well. Things take a lot longer than you would think.

Sandy—Karen, does FIT have a there a list of therapists who work with EI? Yes

Karen, Gerri, Erin, Marybeth, Sandy—focus group for grant.

Training is April 5,6,7

Gerri—I thought it was about early identification, . . . all on board with the umbrellas,

Dr Armstrong—We could do a retrospective study on age of diagnosis.

Marybeth—Sounds like IRB.
Dr. Armstrong--We should do it as QI quality improvement. Age of diagnosis, what kind of services did they receive and when did they start receiving.

Erin—If the diagnosis is “at risk” and not “CP”.

Dr. Armstrong—They need to get the services.

Angie—Also need to get something for the family.

Time for the Grant Group to meet: 1/29 4:30
Next meeting 2/5 at 4.
April 14 for a possible retreat date

<table>
<thead>
<tr>
<th>NEXT MEETINGS</th>
</tr>
</thead>
<tbody>
<tr>
<td>DATE</td>
</tr>
<tr>
<td>Grant Group- Monday 1/29/18 4:30</td>
</tr>
<tr>
<td>Big Group- Monday 2/5/18 4pm</td>
</tr>
</tbody>
</table>