

Sept 3 2025 – CHAMP Action Team Meeting Transcript

Attending: ToniAnn Marchione, Kerry Moss MD, Jessica Pope, Barbara Cass, Eileen O'Shea, Jazmin Johnson, Eugene Rusyn, Piotr Kolakowski, Melissa Witthoft

MARCHIONE: Dr Moss, I don't know if everyone has joined the call yet but do you think we should start?

MOSS: I think we should get started. I think because I think we're going to be doing these meetings so routinely that we should just stay on point to give people back time when we don't need it.

MARCHIONE: Thank you. while we're doing that, I really just want to thank all of you for your willingness to be on this action committee which is uh a little bit different than the advisory committee. We've split this group into two. advisory will be meeting monthly with all of us but we will be meeting as you have seen more frequently because we really have a tight time frame and you know things that we've learned along the way have been that the people who really own being able to help either gather info, give insight, get things done really need to meet more often. and really are going to be the action behind getting this done in a in a timely fashion. So, I thank you all for your willingness to do that. And then I think Peter had sent out the PowerPoint earlier. So, if we can bring that up, look, it's like perfect timing as we speak. So, for those of you that don't know Melissa or if you're new to the group, Melissa worked with us last time we were working on this and she is just phenomenal at putting together what we're saying into like a PowerPoint presentation and puts all of our timelines and everything we throw at her in some comprehensive way to understand. So, this is pretty much what she has put together after we met last and Senator Anwar was able to join us and kind of fill in some blanks that I know I had. And I'm going to give her the opportunity now to present this and the very tight time frames and also some of the owners we have put on certain things. That being said, I don't want anybody to think they are the sole owner of anything. I mean, this is a team, but there are some that have, more flexibility and capabilities to gather certain things than all of us do. So, with that, unless Dr. Moss, you have anything to add, we'll let Melissa go on.

WITTHOFT: Okay. Thanks, everybody. *(slide 3)* I went back to the transcript of our call. with the full team and I added everybody's voices in there, but I pulled out what Senator Anwar summarized at the very end and that's this the script on the text on the left. Basically, what he said are our marching orders are he wants us to come forward when we present the report to the assembly proving the need for having a program and we need to have metrics and data to do that. Obviously, that's always very critical, he wants us to analyze the existing state programs to assess the needs for enhancements with them. And also proposed pilot costs for the assembly budget. So, that's kind of what at a minimum we have to meet.

(slide 4) When we've talked before, we've talked about adding on other things...really qualitative...we want to have a vision where we want to go what we want this program to look like even if we don't reach it in this first tranche, we I think we want to have the optimum vision of what we think a program should be. We need to bring in all the thought leadership we can other states existing best practices many of you and this team have already done a lot of these things you know we have the white papers the Solomon school. There are so many different sources we have to pull this stuff and I think we need to make sure we're tapping into everybody's information just to make sure that what we come up with looks and feels right and takes advantage of all the other work that everybody's done. So there's tons of information out there and tons of best practices, but we need to pull all those things in to analyze and come up with something we think is worthy of, you know, on a statewide basis. When we go forward with this report we need to create a best practice model. And also part of that - and I think it was raised last time - maybe it was Jessica talking about having individualized care plans for patients so that we could customize things. I mean you want to have a framework but you need to have things that work for the child or the family. So those are kind of some qualitative things (workforce development). We know that we're under-resourced, understaffed to help all the programs in Connecticut and even if we start with kind of a center of excellence approach through the pilot, we need to have enough staffing. And I know Eileen has done a ton of work to create a curriculum and a model for RNs specifically for pediatric hospice care. and we'll be working through the center of excellence just to do in-person training and handoffs. So, there's a lot of education that we can do, but I think Eileen and Fairfield University Egan School of Nursing have done a lot of work to tee this up and move this forward relatively quickly. And then there's the concept of you know having comprehensive education and communications for the audiences who need to know this – doctors, hospitals, hospice organizations, anybody who works with pediatric patients who have life limiting illnesses need to know there's something out there and we will probably come up with

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a variety of different communications but having something so that it's not a mystery that if someone needs this help, it's pretty clear what the protocols are, what the marching orders are. I mean doctors obviously get one version. but everybody we need to follow up with something that is comprehensive and it's there's an awareness across the state. So that's kind of the best you know best vision. Does anybody have any comments to add to that? Anything that we might have missed? Okay.

(slide 5) We talk about activity owners, and as ToniAnn said, an owner doesn't mean you're going to do all the work. It just really means we need people who have the footprint in this space, have the expertise, have access to different things, and are able to, you know, may have some time, but could be supported by others. I'm here to help everybody on the back end. So, whatever work that I need to do to help you move things forward, I'm here to help you. But we put some names on this slide and there's a couple of TBD and question marks, too, that we need to figure out what makes the most sense., and I think for obvious reasons, best practices consultations, ToniAnn and Dr. Moss kind of as a lead for this, but obviously we'll want to pull in the Solomon School their expertise. We'll want to pull in the state program. But in terms of oversight and organization around it might be best for the chairs to sit in this space to or to be the point of contact. There's a question mark of who would like to take on data & metrics collection. Peter mentioned that there's a nonpartisan working group in the state of Connecticut that could be a resource for some of the information that gets reported in statewide. So we would want to have Peter reach out to them and collect that. But we also know that there's a number of different organizations across the state already collecting their own metrics. So this is a big piece and this is part of our mandate from Senator Anwar. So we can not only know what the population is but prove the need. And then we have resource development and specifically are in education. Eileen, we kind of defaulted to you because it seems to be the natural person to at least for the first tranche for the pilot to take this on. Does that work for you?

O'SHEA: Yes, I have some ideas around that. Happy to go and share ideas or at a later point.

WITTHOFT: Okay, we'll want to follow up after this, and I can talk to each person individually, each owner individually to see how they want to move it forward. And my job is to summarize what we come up with too and to support you to so we can keep on track. So, but I don't know, ToniAnn or Dr. Moss, would you like Eileen to put some ideas out there right now?

MOSS: If she's prepared to do so and I mean, yeah, if you if you want to or if you want time to think about it, that's fine, too.

O'SHEA: You may be able to speak to it, Carrie. I've done a little bit of a lit review and came across Dr. Aglio's work in the reach initiative. U Dr. Aglio is a physician at CCMC and she in prior work has looked at educating hospice RNs. So those who take care of adults but via tele-education has introduced pediatrics, so she has had success. So there is evidence in a prior model that we may tap into.

MOSS: Absolutely. So she's doing the Reach project here a different version of the Reach Project here individually at Connecticut Children's currently with the hope of expanding to it. So her work was done during her fellowship at St. Jude. So it was Tennessee based which is a different hospice structure obviously infrastructure but that was part of what she did as her fellowship research and project and I think she would be open to allowing the Reach Project to be part of this and so we can certainly talk about that concept. So that's educating people that are within the community versus hospital wide education, right? So there's two there's two prongs to that, but the Reach Project is looking at people that are working in community-based hospices and which is some of what we've done as well alongside here in terms of the education that I've done for multiple different hospice organizations over the years, but not in a more formalized or research gathering platform. But definitely I think that that would be an opportunity.

WITTHOFT: And Eileen just to clarify, the Fairfield University Egan School of Nursing, you guys are moving forward with your curriculum for this fall. Is that correct?

O'SHEA: Not in regards to this project.

WITTHOFT: Okay. But you are focusing on pediatric hospice. Is that correct? or am I confused about two different things?

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O'SHEA: No, we had talked about potentially having clinicals begin, but we haven't done any work on that. Need some lead time.

MOSS: But you might be referring to the just the certification that you guys are supporting. I think that's what you're actually referring to, not a clinical protocol for training individualized nurses.

O'SHEA: Okay. Yes, we are moving forward on pediatric nurses in our state who are interested in attaining national board certification. We just closed our application window and we have eight pediatric nurses uh interested in completing that program. Ideally, they'll sit for the board certification by December.

MOSS: So that was a beautifully offered grant with the Kendrick Foundation that work with Eileen to develop it. It's more than just the I mean the package is quite beautiful for any So I think it's a model of I think we should include that as a model of excellence for training because the way that you put it together Eileen with full credit to you and Robin is that it's really not just helping support the education. helping supporting the motivation to get the certification done and really good timelines and great support along the way. So, as I looked into it after our last meeting, I'm so pleased and I will say just as a total aside that the people that received their emails that they were awarded this were so thrilled yesterday, I received three forwarded emails with real pride that they were chosen. So, thank you for providing that. You know, a moment of pride, a golden sticker is always a good thing. So, thank you.

O'SHEA: You're welcome. Thanks for the support and the outreach. And just to uh give a tiny bit of background, the faculty who are going to teach the education prior to going after the certification exam are from the hospice and palliative nursing association. So all of the nurses will meet some of our national leaders who have this interest in helping children and families.

WITTHOFT: Great. All right, just moving on. certification and licensure criteria. I think one of the things we'd like to do is develop kind of a standard model. And it sounds like some of what Eileen's working on might fit into this as a piece of information. But I think we on an organizational basis want to make sure because I think there's many organizations who want to provide pediatric hospice services may or may not be poised to do it quite yet. And so if we can help define what's needed by them. and it may be an issue of timing to get them to that point, that we have that and Barbara, we put you on this I think because you have the most expertise in this area...would you like to do it?

CASS: Yeah, absolutely, Melissa. Thank you. And I just wanted to comment that timing is everything and we are currently we have separated the plan is to separate our home health care regulations from our hospice regulation. So that it would be two separate licenses. Currently you have to have a home healthcare agency license and with the service classification of hospice. So the plan is to separate them so that hospice is a standalone license and we are in the throes of developing those regulations right now. So, I think all three of those top tiers' best practices, data, and Eileen, the work that you're doing, will help inform decision- making as we move forward with those regulations. And I we actually have our weekly home health hospice reg meeting. And I sent an email or a chat to the group that I was meeting here and to put a placeholder for us in the hospice regulations for this so we could do a special requirement and then identify what the regulations would speak to or address. So the timing is perfect.

MARCHIONE: Thank you. Yeah, I think that's I think that's really exciting to hear, Barb, because, you know, I think it's really important to separate it because, you know, just because you have the home health license, you should still have to have the hospice to in order to do the hospice. So, I think that is I think that's great.

CASS: Good. and I will certainly welcome discussion from this group regarding what we need to address in the regulations. What is going to be and again acknowledging that it is the minimum standards. Well, I would love to say we all aspire to best practices and the gold standard. It is the minimum standards but exciting times for us.

MARCHIONE: Oh yeah, absolutely.

WITTHOFT: Barbara, I think you can attest the fact that not everybody even meets the minimum standards, but they'd like to, but they may not know what's expected of them.

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CASS: So, no, I agree. If we give if we give entities the rules of engagement and communicate well, then they can achieve them.

WITTHOFT: Fabulous. Great., and then project management, as I mentioned, I'm just going to keep track of everything on the back end in supporting everybody. So, I might be reaching out to you one-off to say, "Hey, where does this stand?" Or, "Do you want to talk about this?" Or, "Can I ask you a question about this?" I don't I don't want to overwhelm people with emails because everybody else has full-time jobs that take up lots and lots of their work time. So, the other thing, talk about communications planning. We may not need this immediately, but it is something that we probably need to focus on as we move forward especially if you know we're approved to go forward with a pilot next year. So I think there'll be some work on that on the back end and we may borrow some people from different places but I think there's some there's some best practices out there we can we can take from. Anybody have any comments or questions? The other I think the big hole right now is collecting data, just managing metrics.

MARCHIONE: Yeah. And I think it would be really good to be able to present data. I think it's, you know, it's so hard when you're sitting there testifying and you're kind of doing it from your ideas and what you think collectively you have come together with, but to actually have the data and show you know numbers or graphs or charts or really what the situation is in our state from that perspective is you know I think makes a total difference.

WITTHOFT: I think also to gather to get funding information, knowing the numbers, also cascading down the level of services/the tiers, there are a lot of numbers that flow behind that and there may be people in this team who should be doing this who have access to that data you know we can certainly get them help to figure out how to make the story prove out but I think it's we got Jazmin I see.

JOHNSON: Hi, you guys may have already discussed this but you know last time we were trying to collect data and it was a bit it was a bit difficult. I'm wondering if we've considered testimonies from families who've received these services whether in Massachusetts or throughout Connecticut because some families have had access to these services to make an impact.

WITTHOFT: I think that's great to tell the story. In addition, you know we know that there are organizations - whether it's hospitals, hospice organizations, medical providers, medical practices - who actually do this. I used to work for an accounting firm and footing numbers is an art unto itself. So, it's rather extensive and I think we probably just need to figure out how best to get this information because I think it will take us some time to get that done. So, to your point, Jasmine, you absolutely the last time we just struggled to find information and things get reported federally, we don't know if that data will be available to us within a couple of months. Some I think some sites have been pulled down. So, there's a little bit of tricky footwork we're going to have to have just trying to find who's out there getting information so that we're all on the same page. And whatever we put on paper, we have to be able to prove. Jessica, I see a hand.

POPE: Yes. I just wanted to make sure that you all were aware that the Alliance for Care at Home is going to be releasing their pediatric statistics, their national facts and figures should be by end of year is their goal and that will give us a really great jumping point for the programmatic resources that are currently being logged or at least based on the responses nationally and might be a good place for us to start just from a reporting standpoint.

MOSS: I think we also need data metrics from the hospitals like who are servicing in Connecticut because that's and that's a part I can help with is better numbers. But I do think part of our written report should be testimonials from both providers and families. I think we should focus on Connecticut unless we're really trying to make a case of what Massachusetts does. But I think the bigger case with Massachusetts is just the funding amount, right? the 10 million to one is really the big the big boom on what's going on in Massachusetts. But I do think we can gather providers in the community and patients in the community as well as hospital-based providers to just give a written testimonial that we can include in the documentation in in that section of our report. But in terms of getting numbers from the hospital, I can certainly do that. I can help get them from Yale as well, I believe. and we could come back with our data and then figure out all our resources of data and put it together collaboratively. Eileen, sorry, I'll hand it to you.

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O'SHEA: Just wondering, is it possible to get the number of families that are being serviced with the Katie Beckett waiver and then the exact numbers of those who are on a wait list. I think that may be impressive data.

MARCHIONE: Yeah, did we get that already? I'm trying to think if we have that from last time or not.

JOHNSON: We did meet with the folks at DSS who oversee the Katie Beckett waiver and they at this time are not really like tracking and keeping data., but they were able to give us like common conditions that they see and so on and so forth. And we suspect that a lot of the children who are on the Katie Beckett waiver could benefit from these types of services, but not everyone. So, we can also I mean, we can try to circle back around and see what we could get if anything has improved as far as data collection since then, but at the last time we checked, we weren't able to get any information. And I can find the email that we sent to you, ToniAnn. And to refresh my memory.

MOSS: Okay. I think it would be interesting to look at the weight list and the time people are on the wait list. If you can add that to your data questions, Jasmine, I think that would be really helpful to know because there are families that have waited years for the Katie Beckett waiver, like 5 to 10 years for the Katie Beckett. So, right, since its inception, there's people that are still on a wait list. And so I do think there is something to be said for that weight list data as part of our plea.

JOHNSON: Yeah, I believe I have that information too, but let me double check in the email.

WITTHOFT: Eileen, was it you who talked about the Alliance for Care at Home?

MOSS: No, that was Jessica. I think what might be interesting is because we're going to meet again in two weeks, right? before we go back to the big group is that if we each independently and thoughtfully brainstorm what data we think would be the most helpful in this and then came back look back to our emails to see what data we have collected and look and see where the holes are and what we need for what we think numbers and then see what we can do to obtain some of those. I think that might be a resourceful because I think all of us can view data points differently for this but really the key would be to put it all together.

WITTHOFT: Dr. Moss, what do you think? If everybody sends it to me, I can summarize it in advance of our meeting so we have that information in front of us.

MOSS: I think if you have the time to do all of that, then I would time is a gift that I always say thank you for.

WITTHOFT: Yes. Okay. So, if everybody you can send it to me a couple days in advance of our next call. I'll be able to turn that around. You can shoot me an email.

MOSS: Even if you don't have the numbers, if you say I really think what will add merit to this is data about home versus hospital deaths, right? like what are the data points that you think build the biggest case for what we're trying to do here? how many children are dying at home without resources of hospice or hospice and palliative care expertise because we have a lot of those kids. are do they have home services like right what's that demographic look like? Do they have other home services? we won't be able to tease into why like was it because of concurrent care was not followed and they had to stay with their homecare nurses for continuity like what we won't be able to probably get into all of that data but because it's not collected well but I think there's a lot of data points we can all talk about and put into this.

WITTHOFT: *(slide 6)* This is the hard one. We owe a report to the assembly - Peter gave us a little bit of a wiggle room on this one. By Thursday, February 6th, I will likely need a week or so just to pull together a report, revert it to the team, get everybody's input. So essentially what we're asking is everybody conclude your information your areas of topics and we'll refine this as we go on so it looks a little generic by now but by mid- January. So we have a very short time frame on this. I kind of put December 20th as an end date for a lot of these different things. Just it there's no magic to that date. It just gives you a week before the holidays and gives us a couple of months to strive for. but and for the certification thing, I figured if we defined it but we also need to analyze agencies. There's a kind of a two-tier approach to that. So does anybody have any comments? And Eileen, I put the RN education in there because I thought this focused on the program that you're delivering at Fairfield University, but that

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may have to change depending on the fact that you're doing with the clinical certification. So, we can rename that. But bottom line is we have a very short time frame. So, but I think we probably have a lot of information Anybody else panicking? No. Okay. I think that the consultations are going to take a fair amount of time and I think if we get that list from you from everybody we can start scheduling out various meetings for ToniAnn and Dr. Moss either together or separately, whenever there's availability. And we may ask some of you in this team if you have an interest in participating in some of these conversations where you have people that you'd like to gather information from, we just need kind of a core dump of information from everybody so we know we have a best we have a comprehensive framework to work from. Does that make sense? I think that's all from a PowerPoint perspective. Thoughts, comments? Does this make sense to people?

MOSS: It does. I wonder if when we think about because I still think the testimonials have a good a good role in this., I wonder if there's a way or if anyone and I want to say I have the time and I know I don't, but I feel like we should do consistent interviews with these parents that are not, you know, not scripted interviews, but like say because what I'm thinking about is like how much information we can get from some of these testimonials and I know that's Eileen's project that she's working on too is doing some of this work. But I think for the purpose of our time tight timeline, I think some of the questions are is you know what resources were most, you know, just specific questions about did the end of life process go well for that and those pieces and being able to put those together because I'm thinking of some of my most amazing parents would will not sit down and write a testimonial because they just won't. And you I feel like we could get some really great information from finding a way to interview them. Eileen, you had your hand up.

O'SHEA: I was just going to say I am doing research but my focus is on the parents who have children living right now. So I'm not interviewing those who have uh experienced the loss of a child.

WITTHOFT: That may be something ToniAnn you know regional hospice may have some of that information too?

MARCHIONE: Yes.

WITTHOFT: Does anybody in this group have - to Dr. Moss's point - a good list of questions that could lead the conversation with parents? Not that we want to script it, but...

MOSS: Oh, I have a good list because I've done a lot of these parent interviews. I just think it would be nice to say we reached out to 20 parents that dealt with hospice in the state of Connecticut in the last 5 years and here are the questions we asked and these are the responses we got. Right? that feels like clean, non-formalized data but good data points as opposed to the same stories of parents that can be very passionate but for the purpose of this I think it would be nice and I can I can put together something that might be easy for a script but because I do these interviews relatively routinely but I think just to get the data points for what we need here it's quick questions and it's us actually getting 20 people that we've done for this or whatever 10 people so it's new data that current data like we talked to parents that in real time have just experienced this in Connecticut and what could they what would have been more helpful where did they where were the gaps for them what was their experience does that make sense what I'm saying.

O'SHEA: It's pretty close to the I have similar questions that I've been asking for this research study. But again, with parents who are their ongoing challenges of resources that are lacking are fairly apparent. So, I could probably have something ready by the end of fall, but again, not capturing hospice.

WITTHOFT: Well, I think we're focused on the needs of families and children. And so, it doesn't have to specifically be hospice. I think it goes to the interviews you're doing. You're learning probably the same things that Dr. Moss has done has learned after families have lost a child. So whether it's current state or you know past I think both of those are important messages to bring forward.

MOSS: Well I think they answer separate questions to be to be honest I kind of respectfully disagree that there that I would have the same information in that experience because the death of a child is so different than living with chronicity of a child. So I think there might be different information but I think there's room for both. And this I think the data that you will have is

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really formalized data that's publishable. So that's really poignant someone in our state doing that and I'm looking for more anecdotal data that's collected in a streamlined way. So I think those bring out very different points of power in this if that makes sense. So I think the work you're doing would be really helpful and beautiful to add to this especially if it's part of your project's completion and that will look good for you and for you know there's a win on all of that. And then I think what I'm looking for is a little bit more of the heart and soul of anecdotal data of people that have gone through the loss of a child that gives us honesty about our shortcomings and how we do it in the state or the resources in the state because I think there's some power in that information for the heartstrings of the people that are looking at this.

POPE: I was just going to say I think that that data as well Dr. Moss is very important to quantify in a way because I mean we think of cap scores, we think of star ratings like these are the questions that are being asked in the adult world as well. It adds that credibility to us being able to formally introduce how they are now perceiving all of that support or lack of support when they are reflecting back on the care that was provided. And I think that can be provided both with or without hospice's involvement because it does paint the picture of where did you feel your needs were met which really is the heart of everything that's being done here. So I want to give credit to that as well that I think that will be extremely valuable data that'll be very easily shared and received because it's already in line in a lot of ways with what's being done in the hospice world.

MOSS: I feel like Jessica, you could work with me on that. I feel like you just found your name on the sheet.

POPE: It would be my honor. It would be my honor.

MOSS: I think I need to put you on that. I think we're going to collect you right in there.

MARCHIONE: I have such a comment to make about Jessica and I'm going to hold off till the end of this to make it, but you're so right, Dr. Moss. Barb, you have your hand up?

CASS: I just wanted to piggy back onto Eileen's comment about have families or did families it was about resources and how do you find resources and I also want to honor the family member who was on our large group that she indicated that she hoped that one of the goals of this group would be able to develop some kind of resource or guidance document that would help families when they find themselves at this point in their lives. And is that something that we can still do? Because I think there's great utility and incredible value to that. Families don't know I think for the most part where to go and I think pediatricians if that's not Dr. Moss, you do amazing work. but if that's not your specialty, it may be a struggle for a general pediatrician. And here's where I would say pediatricians' hardest job. They have to know everything. But in my conversations here with some of our physicians who are pediatricians that there's a knowledge gap there for them as well.

MOSS: So we have so it's interesting because we've our bereavement group and so some of these resources are on the web and some of them are not but we have just recompiled our list of resources and I think that the coalition has great resources and so I think what it is bringing all I think there's a lot of fabulous resource lists. I think that none of that that they are escaping some of the people that need them. And that that is part of our that's part of it is not so much about developing the list but just finding a way to centralize it so people are getting it and bringing together the resources and that's you know unfortunately Yale and we have been very collaborative together with Yale and Connecticut Children's but we've been forced to practice in silos because of the areas we're trying to cover desperately and so our resources are disparate because of where we are located simply and because there hasn't been all the bridges that we're now building to collaborate with all these organizations. So I think that that's our list may not look the same but should ultimately because all the resource should be these opportunities should be statewide

CASS: I think there's an opportunity then Melissa for your communications block. There's a job for that individual right there. How do we get this this all these an inventory of all of this incredible work that's out there out to the real people who need it? Right?

MARCHIONE: And that kind of brings me to because I'm going to throw in my Jessica Pope comment here, but I'm also going to frame it with, you know, the last time we were meeting we were kind of talking about a statewide program, right? And we know

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we have to handle a staffing crisis, right, in the state to even be able to do this. And that's where Eileen comes in. and we need the nurses and we need so there's work we have to do like to allow this to happen in the state of Connecticut. And I was really at first kind of sold that it's a statewide program and let the state run it and feed out the cases that that need help. And then I met Jessica Pope. And Jessica oversees and does such a beautiful job with running a pediatric hospice for a hospice. It's not state-run. It is run like you know just like regional hospice or other hospices that are around here and do such a beautiful job. So I think we need to entertain what both of those look like. And as we're understanding that there may be now, you know, licensing towards hospice and the regulations that are going to lean towards that, we can still lean on the state to help with like let's just say how do where do people go when they need help? There's got to be something, some place that the state can actually provide with that. But do we really do a state-run program or do we look at the other hospices that are doing it themselves? And that would lead me into Dr. Moss, your idea about the next advisory meeting that we're all on. Having Jessica present the first part of the meeting to talk about a hospice that does unbelievable pediatric hospice work and what that looks like and how there are relationships with other hospitals from that hospital. And I mean I think from that hospice and I think if you're in agreement with that I think Jessica would be a great first speaker on the next advisory meeting.

POPE: Well, thank you ToniAnn. I very much I think it's important to honor as well though that there is such an incredible partnership with our Medicaid office in in all areas that we're working with in Virginia. we have that Medicaid contact that we're able to receive immediate feedback as it relates to concurrent care in DC. We're the only provider and so in many ways that is almost as if we are state-run because we are very much following their recommendations for care and what they have outlined through their state regulation. So I'm blessed to have the example of both ways in many in many aspects of that where but in in both situations it is very much a partnership and I think that's really the heart of pediatric hospice and concurrent care is the idea that there's a partnership within the organization but there's a partnership with our insuring bodies there's a partnership with our regulation bodies. And then there's a partnership with those different medical paradigms. s that we're working within. It's not just the hospitals, right? It's also the home health agencies. It's the DME companies. It's any of the pharmacies that we're working with. And so the education...there's that clinical education piece of being able to provide all of that information to the practitioners that are meeting with these families, but there is also that global education of how we all work together. And I think that really from a state program perspective is going to be more effective because there can be a lot more consistency in how that's rolled out., thank you for that plug. I'd be happy to do that if everyone's in agreement, but I also if anyone is opposed, I understand., but I do think that it would it's probably helpful to have a little bit of that context if it would be beneficial.

MOSS: I think it would be beneficial to have you do that. And I think what ToniAnn was speaking to is I think that what and forgive me if I'm wrong, but I feel like the bigger meetings we sometimes there's not as much it's hard because there's so many of us and I think it would be really lovely if in the in the group meetings that we have that we kind of focus a little bit on concepts and help people understand...like Barbara and I talk about MOLST - right - like you do so much work with the MOLST and it's really such a tool that we need to be using more widespread in pediatrics and so what is that like, but people need education on that because not everyone understands what that is and so really trying to pick a topic that we kind of educate the whole group on briefly like this is what the MOLST is this is the work I've done with it and then I think we spend the rest of the time really letting our committee chairs with that have been assign delineated in this power you know in the previous PowerPoint kind of update on where things are and then we the last 20 minutes to open conversation because even then then it is what it is right then we've accomplished what we set to accomplish because I'm really viewing those meetings as more of a report out than working and getting stuff done and I feel like that will make those meetings more meaningful and kind of be our little report cards and check-ins. So, I think Jessica, that's great if you can start it off for the next time that we do it your information. And like I said, Barbara, I think at some point talking about MOLST and what it can do for people and how that document can be so helpful because it's really underutilized in pediatrics.

POPE: Absolutely. I also wanted to go back to the list of resources for families and just make sure you all were aware., our pediatric ejournal committee just released two issues that specifically talk about the community bridging of support and in within that I have a list and so they were able to publish a list of resources that are available to families not only from a hospice

management side but also just from a connection side of knowing I just got diagnosed with this rare genetic disorder. Where are my options for support? Where is that community resource? Where can I get financial aid? Where can I get community? Where can I get direction or second opinions? And so we were able to compile that list and we it was published and that might be a good place to start with some options. Of course, those are for the most part going to be more nationally based since we wanted to make that something accessible to any reader. but I think that we could take a very similar approach in looking what's available within Connecticut to also add to that and formalize and I think it's good to separate out here's the national resources and here's your local resources right these are your Connecticut resources so I think that tool because when we think about all the resources that connect courageous parents network provide like putting all of those together right those are national resources that are incredible for people but then also looking at the more localized groups that are doing pieces I think would be really helpful. And that resource list is comfort. There's a lot to it, but I think grief resources, all of that. It's experience camps, you know, for grieving children. All those things that are that are out there should be included in that resource list.

WITTHOFT: Is that a searchable list, Jessica?

POPE: Yeah, it's for the is that if you just honestly Google pediatric ejournal, it'll be probably the first or second thing that comes up from the alliance the National Alliance for Care at Home. it's very hard not to say NHPCO these days. but it is from the National Alliance. So they did release that. I think they just released the last the last journal and then the one before that as well. We went ahead and split it into two issues because it was so comprehensive.

MARCHIONE: And that's why like Jessica just speaking about what she you know you speaking about what you were just speaking about and how the partnerships you know your partnership with your Medicaid office your partnership with your DME like we for me that's even new to hear like what do you mean your partnership with Medicaid the Medicaid rate is the Medicaid rate what do you like how are you how is that partnership benefiting you like to understand that better for us and to also like the things that you said that it kind of you are basing it on a state-run program yet you are one of the only you know providers. how does how does that work for you and how eloquently you talk about concurrent care as if that's the service you know like you we speak we me I won't say we I speak of concurrent care like well we have concurrent care so you know they shouldn't lose certain things yet you almost speak of it like part of the program with hospice and I think those are things that we need to take into consideration and re not even relearn, learn how it is that you do that because it does make such an impact when you're talking about hospice to a family., so that's why I think it would be really good to have you present and we can understand better about specifically your state partnerships and how that you know helps you make this a viable program for your hospice to sustain. Are there other things on the timeline that we have that we haven't touched on?

WITTHOFT: No...we have so many great ideas here and I'll try to synthesize them all in into some categories. But I think gathering all this information, letting people in this this group read what's out there, follow up on it, check it to see if there are best practices we can begin to integrate into what we want to do.

O'SHEA: Can I add one more concluding thought for consideration? So one of the intentions of the coalition was to be that warehouse of resources for different parts of the state. To me, it it's not to have separate resources but bringing together the two children's hospital resources and references to be in one place in addition to what you already do on the children's hospitals websites but to centralize information for families. That was one of the intentions of building a coalition is to be a warehouse for the state.

MARCHIONE: Well, there you go. There's our answer.

O'SHEA: We've been working for the last six months on looking at specifically community resources. We already have the many of the national resources uh through our partnership with Pennsylvania. However, we didn't have community resources. So, we've been working with both children's hospitals to try to capture that and we've made an interactive map so that families or healthcare providers could click on the links and to learn more information and to see where these uh resources are located. It's working in an ongoing initiative and we know that we'll continue to add, but we hope in September that we'll have live links to everything of the work that we've done so far over the last six months.

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POPE: When you mentioned Pennsylvania, I was glad to hear that because I was going to say, I hope you're connected with Betsy.

MARCHIONE: Well, we know who the 2nd speaker is going to be! Okay. Anybody else before we let you all go back to all the other things you do?

RUSYN: Could I jump in here with ToniAnn with a quick question for the group? So early on when the core guiding questions were framed for us - extremely helpfully incidentally...Melissa this is very structured - and the point was made that we should analyze existing state programs to assess need for enhancements and that seemed to kind of speak in some ways to how do we actually prove that some of the things that we might suggest actually work from our side at the Solomon Center we spent a lot of time looking at other state programs, other initiatives. How as a group are we thinking about what examples to draw in and how that information should slot into the various work streams?

MARCHIONE: Well, that's a good question. And like if you could see my eyes right now, I'm staring at Dr. Moss like how do we how do we actually answer that? And are we looking to show that the programs in Connecticut are very limited, right? Like, what are the resources? What are the programs? What are we are we looking to show what it's like in other states and then compare it to the state of Connecticut? I mean, I'm thinking that might be the way, but I don't know, Kerry, if you have other thoughts on that.

MOSS: Yeah, I mean I think the whole point of this is to express that we have motivated people and a paucity of resources that are active right now in the state. I don't think it's that we just haven't been looking I mean I think there are great resources, don't get me wrong, but the resources don't provide the care in the home that we're looking for, right? We're looking to build a hospice program that provides actual care or translates to actual care. So, so I don't think it's bad to shine light on all the great resources we have, but we have to go back to the baseline, which is we're trying to provide in-home care and opportunities for care for patients and families. That resources don't take away from what you actually need to provide in the homes, if that makes sense, or in the hospital, wherever they choose to be, but we need to be able to provide hospice care to children moving forward. And so I think that that's what the disparity, there is what they provide in other states with funding than what we provide here.

WITTHOFT: Just from a historical project management perspective, we now have a world available to us. And I think there's so much information out there. I think as time goes on, we'll be able to refine further all these different activity streams all these initiatives so that we can clarify you know all these questions we need to answer. So it while it feels overwhelming, it also it's very hopeful and very inspiring because it obviously there's a lot of information out there and a lot of resources out there that as a group, we eventually will collectively know about but right now there's still some silos that we just need to put together. So, I think it'll it's just very heartening to hear all the different things going on and all the things that all the great work people are doing.

MARCHIONE: So, did that kind of help Eugene or did we just make it more confusing?

RUSYN: No, no, that absolutely helped. And Eileen, I see I think you had a thought to share too.

O'SHEA: I just for me reading your Yale the Solomon's white paper was very helpful because of the models that exist throughout the nation some really aren't a good fit with Connecticut and so I appreciate your work the Solomon all of your work because it put forward what could be a good fit. And I'm sure with all the like-minded people here, we would like to have one or two models to really delve into with all of our silos and uh services that need to be enhanced. if there are one or two current models that might we might be able to put forward as a group, not saying to the legislators, but as a group to sus out would this really be feasible and do we like it or and why? What is what is the rationale for putting such and such a program forward and to and to what cost? So I appreciate that white paper and I'm wondering if it makes sense for you to share your thoughts. I know it's on paper. I appreciate it's on paper, but to say this is a model that seems to that could work. And then maybe as a group we could say, 'hah...we like this but not that'. And in trying to whittle things down in the time that we have, what can we put forward?

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MARCHIONE: You know, I think that's I think that's a really good point. And you know, if Dr. Moss is in agreement, I think I think we meet again as an action committee as opposed to the advisory, the whole thing. So, Dr. Moss, if you agree, do you think maybe the next time we meet as an action group, maybe Eugene, I don't know if it will be you, but can summarize the white paper and what your ideas on what might or might not work and maybe then we could go from there.

MOSS: Absolutely. Okay, that's because I think there's some objectivity to that, right? There's some objectivity what you bring. I mean, I admit I'm so passionate about doing this that sometimes I lose the forest through the trees., I just want a magic wand and not hard work. But I recognize that's not a plausible answer to it. So, yeah, I think I'd love to hear from I mean, I think the white paper's so well done. I'd love to hear it. I'd love to hear an open discussion about it.

RUSYN: Well, thank you so much for the feedback and we would absolutely love to I say we because whether it's me or Elle or Jeremy, I'm sure in two weeks-time we'll be ready and happy to share our you know overview. and within that just two very quick thoughts mindful of time one is what we've been talking about internally as well is a menu of options potentially. So I think Eileen's point is excellent that you know we can zero in on let's say one or two models that seem to be particularly salient for Connecticut. But what we might also be able to do is if you have the two main courses you also have a range of appetizers things that we can kind of add in to the mix as we need them. So I think we'll try to think about the options from state experience from that perspective too., and then in our conversation, I think we can feel out what are Connecticut specific needs that might map well onto something from one state while not necessarily uh connecting with other parts of that state is doing., so it's a mix and match. But the second point is a question uh and the final question for me, I promise, which is Massachusetts as a model. It's come up in our conversation today. I think it it's come up in the past to the degree that we prepare material. Has there been a system have we had in prior months conversations with folks from Massachusetts or to what degree is Massachusetts figuring into our thinking and uh what would be helpful from let's say the Solomon Center in learning more about their experience if anything?

MOSS: So we've had conversations we've had presentations from people on the Massachusetts side. I would, you know, I don't know if it's the model per se. I do know it's the experiential model for us because I take care of children that live in Massachusetts. And so what I'm always struck by is the availability of resource at home for those children when I send them across the line. They get a very different hospice experience than children that live within Connecticut. Right? So they may both be housed at Connecticut Children's for their medical care, but they will have a very different experience dying at home if they live across the state line. So that's the point of comparison that's always been so important to me. Now we know that they grew out of a small program and we know that they ended up with they now have a \$10 million budget per year and those are the pieces that have really struck with me. But in terms of whether their model is one that we want, I'm not sure that I necessarily their model has some challenges too. It's an older model and so I'm not sure that that is the pinnacle or the way we want to approach it. But I just think it's a good point of comparison due to proximity of location and shared services from a hospital standpoint. That's my vantage point about Massachusetts if that helps.

RUSYN: That's very helpful. Thank you.

MARCHIONE: Well, I have to say that this was inspiring and very fulfilling this meeting and the conversation and I think the direction that we're going and I just feel that it was just the best thing that we did was to kind of to make the action committee and I couldn't be more grateful to all of you and we will I think we're on again. Peter, are you on? What? Our next meeting is two weeks from today. It'll be the because it's every other meeting, every other. Yep. Perfect. Two weeks from today., and we will basically go over the white paper. Like we'll send out an agenda, but your, you know, your summary of the white paper and then anything else that we need to kind of button up and then we'll just start going from there. How does that sound? Good. Okay. Everybody have a great rest of the day and thank YOU.