

## Families of Spinal Muscular Atrophy

### Transcript of SMA Questions Chat, October 27, 2004

**This transcript has been somewhat edited and revised to match questions with answers, to correct typos, and to remove extra remarks. Please note there may still be errors and omissions.**

**Our expert this month is Jo Anne Maczulski, Occupational Therapist.**

<i>administrator</i>	Hi everyone and welcome to the new FSMA chat room. Today's chat subject is Occupational Therapy and SMA our guest expert is Jo Anne Mazculski, Occupational Therapist. We expect many people to log in today so we ask you not to chit chat too much before or after you ask your question, so the expert has space to answer. If you miss anything, a transcript will be available later. If your question isn't answered during the chat, we will try to get it answered later.
<i>kellydy</i>	I'm just curious if OT is really useful - do you see results?
<i>jmaczulski</i>	<b>Yes, I think OT is useful. Of course how much depends on the goals of the family and the needs of the particular child. OT focuses on the arms, hands, adaptive equipment as well as visual perceptual development and self care.</b>
<i>kellydy</i>	Our daughter is 8 months - and we are doing OT and PT. We have seen some results, just wanted to know expertly if it's worth it. Thanks!
<i>adoebbert</i>	Do you have any suggestions for arm support for the side-laying position, something that would enable independent play? My daughter is 15 months old, type-1, and we play a lot in the side-laying position. I have tried the arm sling, which works ok, but I am forever looking for other solutions...like a flexible, under-arm support pillow that doesn't require too much "harnessing". Once her arm is supported, she can move it from side to side. I would like her to be able to play independently with the aid of a support. Also...the other hand is always flat against the ground – have you ever seen anything that facilitates the use of both hands while in the side-laying position?
<i>jmaczulski</i>	<b>No, I have not actually seen anything that supports both hands. There are a number of different kinds of arm supports that allow the arm to move across the body and move the forearm up and down. I will research the pillow for you and get it on the website</b>
<i>naomi</i>	Hi, Joanne. We are seeking an adapted car seat for our 12 month, 20 lb, SMA Type 1 child. He can no longer tolerate sitting upright in a regular toddler car seat, even when it is reclined as far as it will go, and so have had to (unsafely) use the infant one he's grown out of. Please provide manufacturer's names, brands, contact information & whatever else is relevant. Note that we do live north of the border outside of Toronto. Thank you.
<i>jmaczulski</i>	<b>Naomi, Kristin (the PT) and I are constantly trying to stay on top of the</b>

	car seat issue. Your point is well taken about the safety. I will get back to you with some specific vendor names.
<i>kellydy</i>	May I ask a question of Jo Anne and other parents in the room - are your children able to hold their bottle/sippy up? That's something we're working on - can it be successful and any suggestions?
<i>naomi</i>	Our 12 month old is not able to hold his bottle. We do it for him :-)
<i>administrator</i>	Kelly, we designed special handles for Bernie's and Daniel's bottles and cups.
<i>jmaczulski</i>	I think a lot of kids have difficulty holding their sippy cups, especially to get the last drops. I would recommend getting the lightest weight cup and if it does not already have a non slip surface on the handles gluing some of the non skid material on it to improve the grip and prevent slippage. I frequently buy the non skid mats for under rugs and cut it to fit all kinds of things.
<i>adoebbert</i>	Do you have any creative suggestions in using a Versaform pillow for a type-1?
<i>jmaczulski</i>	I'm sorry I don't have any specific experience working with the Versaform pillow. May be if you could get me a picture of the pillow and your child I could come up with some ideas. Does your daughter have an OT?
<i>Adoebbert</i>	Yes, she does, but we have not used the pillow in our sessions yet. I will send you a picture
<i>bqtrinh</i>	I have a 10 yr old niece with type III and attending regular school. As she grows, she gets heavier and requires more physically capable assistants for things like going to the restroom etc both at home and at school. My question is how is that issue dealt with? for parents and those who live in the US, is there any Federal or State assistance for parents of children with SMA?
<i>jmaczulski</i>	I would refer you to someone who is an expert to dealing with the state and fed rules and regulations. As far as school however the federal law 94-142 provides therapy and necessary assistance for kids in school.
<i>bqtrinh</i>	I would appreciate the contact info. Thanks! I am concerned about my niece in her coming years. For teen age SMA girls in school, how do they cope with the needs of more then one personal assistants? or do they have to do home-schooling instead?
<i>jmaczulski</i>	I think you should consult with your niece's local school. They should be able to give you an idea of what kind of aide they might provide your niece. Many schools hire aides for kids with these kinds of needs. I think home schooling is a personal choice. I would recommend talking to the school district so you are aware of all your options.
<i>irresistible</i>	Hi, I'm from Turkey. What is occupational therapy?
<i>jmaczulski</i>	OT is another rehab profession. As PTs (physical therapists) we work with all ages and diagnosis. Pediatric OTs and PTs work very closely and have a lot of cross over. OT addresses the arms, hands, fine motor and visual motor areas. We also work with any kids that might have sensory problems. Depending on where you went to school and where

	you work, OTs may be involved in seating, splinting and feeding. But the bottom line is we do most of our therapy through activity whatever is important, appropriate and functional for the person.
<i>naomi</i>	Another question: For a Type 1 baby, is it important to lie him on his belly to prevent development of contractures, or is this even likely to become an issue? (we don't know how long he has)
<i>Person</i>	What are contractures?
<i>naomi</i>	Contractures are shortening or tightening of muscles that can lead to deformity.
<i>jmaczulsk</i>	For a type I baby tummy time is an option if his breathing is not compromised. Gentle rang of motion and positioning should help prevent contractures. You're right if may not even be an issue. Sometimes these kids do tend to flop out at the hips. If that is the case I would refer you to PT.
<i>naomi</i>	Our little boy does 'flop out at the hips'
<i>jmaczulski</i>	Noami I will forward your question to Kristin, the PT. But I do know one of the suggestions she has shared w/ parents is to use a clothes pin to hold both legs of pajama bottoms together so the kids do not flop out.
<i>nellie</i>	What should a preschooler-kindergarten student, type 2 be doing at school in regards to OT?
<i>jmaczulski</i>	As you know, these kids are so bright. Preschool/Kindergartner should have access to do what the other kids in the class are doing. The challenge would be to get the appropriate seating and mobility equipment to allow them this interaction. As far as toys, crayons, paint brushes and things like this there should be an OT in the school that would help adapt them to allow for as much independent function as possible. The website has a section on adapted ideas that the families came up with.
<i>administrator</i>	And we are always looking for new ideas to add to that - so send them if you want to share or use the Equipment message board.
<i>AlexZenz</i>	I am from Germany. I am 36 years old and have SMA type II. I can only put my hands a little bit in motion. What type of therapy should I do and how often?
<i>jmaczulski</i>	I would recommend you consult your physician and ask for an OT referral. It's hard to say how much therapy you need without seeing you. Sometimes just squeezing a wet sponge is a gentle way to exercise your hands. I lived in Wuerzburg for 3 years so I know that there are some great occupational therapists in Germany. Good Luck!
<i>naomi</i>	Another equipment question from Canada: where would I find an adapted pillow for head support, trunk support, and hip support - to use in a stroller or highchair or lazyboy (again, for a 12 month old type 1)??
<i>jmaczulski</i>	Naomi let me get back to later with more specific info. I will also consult w/ Kristin in order to cover all the bases.
<i>irresistible</i>	I'm 33. I have SMA type III. I can use only my right hand what should I do?

<i>jmaczulski</i>	A challenging question without seeing you. Do you have any use of your left hand? I would look at what you do and what you want to do and assess you for adaptive equipment or modifications to household items that would allow you to accomplish tasks with one hand.
<i>naomi</i>	Our son has developed an indentation on the back of his head from lying in one position - should we be worried?
<i>jmaczulski</i>	Babies that are positioned in limited positions frequently develop "molding" issues with their heads. I would suggest investigating pillows, head supports to try and prevent this. Again I will try and include some more specific info in a later email.
<i>naomi</i>	A question for everyone: from where do you glean hope??
<i>jmaczulski</i>	Naomi, I cannot answer this question from a parent's point of view, but these children are so absolutely delightful and wonderful to be around. I know this is not an immediate answer, but there is considerable research into SMA.
<i>administrator</i>	Naomi it's really different, depending on the type of SMA. However, we try to focus on the joys and challenges of each day and don't worry too much about the future things we simply can't control. There is hope for a cure, but I don't know if it will be in time for our son.
<i>administrator</i>	Thanks to everyone who came and participated today. Thanks especially to our OT expert Jo Anne Maczulski!!
<i>jmaczulski</i>	Everyone I have to get back to work. I hope I was able to answer some of your concerns. FSMA has my email address I would be happy to answer any other questions via email. Happy Halloween!
<i>many</i>	Thank you Jo Anne!!