

## Medical Home Telephone Conference February 28, 2006

Lisa Samson-Fang, MD and Judith Gooch, MD (PCMC Rehabilitation Clinic)

PCMC has a lot of outpatient resources for children with special health care needs and today we are going to focus on what's available through the rehabilitation department.

Judith is speaking for the rehab medicine physicians but also the rehabilitation therapy services. Please refer to brochures that were mailed out. Will start with a little overview of the rehab medicine services and then also the therapy services and then take questions.

One of the brochures that was sent out was the pediatric physiatrist or rehabilitation physician and that really summarizes what the rehab physicians at PCMC do. Judy Gooch and Terry Such-Neibar are both full time and Nancy Murphy is part-time. Basically what we do as rehab physicians is to address kids functional needs, so we work with kids with neurologic impairments or muscular skeletal impairments such as back pain that has been limiting their functions and the goal is to help them be as functional as possible. We might work in the motor area, kids with cerebral palsy or brain injury or spinal cord injury, might need to work to manage spasticity that's keeping them from being functional, might involve them in therapy, might refer them for orthopedic or neurosurgical intervention, we address their functional related medical issues as well as addressing these functional issues. As it says in the brochure improving function means maximizing walking or getting around however you can, hand use, communication, thinking, eating and behavior. So we work not with just motor issues but with cognitive and behavioral issues. The behavioral issues would be in kids with neurologic impairment such as cerebral palsy or traumatic brain injury as opposed to a psychiatrist who is going to work with just the kids with behavioral issues. Judith's favorite area is working with motor issues, she does a lot with spasticity management and another one of the brochures that was sent out is managing spasticity and it talks about the different treatments they use such as oral medications, botox injections, phenol injections, and an intrathecal baclofen pumps. Judith and two other therapists make the decision whether a kid is a good candidate for selective dorsal rhizotomy, and then refer the mom to neuro-surgery. Judith likes to manage spasticity and optimizing the kids motor function. Terry Such-Neibar's favorite area is the cognitive and behavioral area and she is really knowledgeable on working with kids who have had brain injury, for instance, and have attention difficulties related to that, behavioral difficulties and managing that with medication and different therapies. Nancy Murphy is most interested in the kids with lots of complex medical and functional needs. She has a special expertise in eating and behavioral feeding. All of us do a little of everything even though each of us has our favorite areas.

A couple areas where we could probably see kids a little earlier are mild traumatic brain injury. We have a pretty good system set up here in the hospital now where we're getting people information on that but there's been a number of cases where we have a child with a mild traumatic brain injury, or they've lost consciousness and they come to ER and they are admitted briefly and they look ok but they have cognitive and behavioral difficulties that lead to difficulties at school and things can kind of spiral out of control so we like to make sure that people are educated about the possible sequelae of mild traumatic brain injury and we have information on that. Also I've seen with the kids with a lot of spasticity or motor disability, the earlier that you can work with these kids the better because we really want to prevent deformity that can come with that for example getting a kid into the office who is 14 with massive contractures that we could have done something about if we had seen them earlier, and most kids we're seen pretty early but it's good to be on top of that early.

A few words about the therapy programs. So we're the rehab physicians but we work within the rehabilitation department at PCMC and also within that department are the therapies, the speech, the physical and occupational therapies and also in-patient services. Out-patient services in Sandy, Taylorsville and Bountiful. There are speech, physical and occupational therapies through each of those outreach centers. The physical therapists work with getting kids up and moving, the occupational therapists promote hand use and improvement in self care, the speech people work with not just speech but also with feeding, they have a great behavioral feeding program now and also with cognitive deficits like kids who have had brain injury and have cognitive problems, the speech therapists would work to improve those.

The therapy world has been changing and this group here has really been in the forefront nationally. It used to be that kids would go to therapy twice a week until their insurance ran out or people got sick of the therapy, now we've changed to a system of models of therapy where there's a lot more therapy consultation and then maybe a little burst of some therapy while the child is trying to reach a specific goal and then time off for a while and so it's more geared at the efficiency of service and also providing home programs for the family. We also have, some of you may have heard this, there's a big deal now going on of some kids going to Poland to get a special thera suit. They go to Poland and spend a month there and for \$10,000 they have an intense strengthening program and use this special suit. We've had a lot of calls from parents asking about this newest thing, we have here an intensive strengthening program, we don't have the suit at this point, this is a suit that is kind of like a rubber band, the real deal behind this is actually the intensive strengthening that works for these kids and the suit may or may not help, so we're trying to promote intensive strengthening to let people know this is really what is behind the success for any of these programs.

Lisa : Please comment on the role of occupational therapy in kids with sensory issues.

There's a lot of kids out there that have autism or are autistic like, some kids with the diagnosis of CP, which is a very broad diagnosis, have sensory issues. The sensory issues might manifest as hypersensitivity, maybe they're easily irritated by noise or over stimulation and then they can become very irritable. Some of the kids with behavioral feeding might have an oral hypersensitivity. Also kids that may not be getting around right well, not because of motor problems but more because of their sensory awareness of where their body is in space. This may be a hypersensitivity issue or maybe a hyposensitivity issue, occupational therapists can work with that in terms of methods to decrease that hypersensitivity or methods to help children understand where their bodies are in space more, not all the occupational therapists are experts at this but a handful of them are and have had special training. Also occupational therapists work with kids specifically with autism who have that sensory issue also.

Question: Do you feel the data for the evidence of effectiveness of the sensory issues is convincing?

Answer: There is not good data on it. I think that needs to be done is, first of all, it's very hard to study this group because all the kids are very different and the interventions are very different. Given that, the sensory area in particular is difficult and the data does not, there's not good data backing it. Not good controlled trials. For that reason you don't want to get into one of these, we're going to do therapy for 2 years twice a week deal and work on this, I think that's where a child might see a therapist for a few times, see how the kid responds, and then do some home programming, that way you can see if it works and you can do some home programming which is a cost efficient way.

Question: How to know whether to send a kid to Judy or speech, OT/PT? When a parent comes in and states they want their child to work on this goal of walking or I am worried about my child's speech.

Answer: A lot of pediatricians are familiar with our system and they would know where to send them. One thing you can know is that if they go to a primary therapist, we have pretty good connections and communications among one another. If you send a kid to physical therapy and the physical therapist thinks, maybe he/she would benefit more from spasticity management or maybe he/she should see the rehab physician for some other reason, they're pretty good at calling the primary care physician and asking about that, so that's one thing to know. Some of it certainly depends on the complexity, if it's straightforward little speech problem we wouldn't need to see them. If it's a straightforward problem you can send them to the physical therapist, you can see them back and see how it's going, if you have a simple problem and it's really cleared up, then they may not need to see us. One thing we offer as rehab physicians is life long management of these problems. If they have an underlying neurologic condition to any degree, it's reasonable to have one of us see them. We might send them to therapy for a while and then come back for a follow up in 6 months to a year, I also do an adult clinic at the University and see adults with Cerebral Palsy every Wednesday and so there's pretty good continuity. A lot of the problems we see

don't go away so we offer a continuity service so that can be an advantage of sending them to us.

Question: Other diagnoses that a rehab physician might be helpful?

Answer: Muscular skeletal pain, pain that seems to be interfering with them going to school or getting out and doing what they want a lot of times we'll kids round about and there is certainly a group we can help if it's substantial pain that is limiting. Neurologic or muscular skeletal problems, and those that do limit functions. If it limits how they are getting around, limits how they are doing in school, limits how they are doing their self care skills, limiting them cognitively. Possibly the one that gets missed the most are the mild traumatic brain injuries but sometimes that's even hard to diagnose or know it's there. Conversion disorder, we love seeing these kids because we involve them typically in a therapy program, a functional program, and give them a reason to get better, a reason for their initial loss of function and methods and reasons for getting better and they improve.

Question: A lot of times it seems that patients and their families get caught in the cross fires between different opinions say between a physical therapist and an orthopedist having different ideas of whether surgery is necessary, etc... Is this as common as I perceive?

Answer: Yes, this is very common issue. One way that we've tried to deal with that is first of all, people need to know that if you're talking a population of children with cerebral palsy it is a very complex condition and at one point a few years ago I called some of my colleagues across the country and gave them a scenario of a specific child that had spasticity that was weak and was walking with a walker and so on and asked them what they would do and you can get very different answers, so the one thing I do try to tell the family is that this is a very complex issue and if you do get varying opinions it's not that people don't know what they are talking about it's just they have different opinions. Beyond that we really try to get people to communicate with one another and we've developed a good relationship with the therapists and orthopedists and when I first starting doing botox injections that was first suggested by one of the orthopedists following my starting those the orthopedists would say botox is temporary, doesn't work and the child really needs surgery and over the years we've worked out that in certain kids botox is helpful at such and such as stage and in other stage orthopedic surgery is helpful. We've worked out better communication. With a parent I would ask people to communicate with one another and the other thing is when you are looking at, get the parent educated so they can know all the options, sometimes you are going to see a physician that favors or does one option and that's all they are going to talk about so it's good for parents to know all the options. And then for them to question so if somebody recommends a surgery, ask is it important to do it now and if it's not important to do it now maybe we can be a little more cautious and a little more conservative for a little while. It's very common.

Question: How does someone refer a patient to a rehab physician and how much does insurance fund?

Answer: Call PCMC to our office 588-3950, also we may be a couple months out but we're always willing to get kids in sooner if there is a special request from the physician or the family. Insurances are very good at paying for the physician visit It's kind of interesting but sometimes the hardest things to get covered by the insurance is the therapy. We've done well with insurance and we are conscious of trying to be cost efficient in what we do. This is one of the reasons we've changed to the models of therapy.

Attendees: Lisa Samson-Fang, Barbara Ward, Judy Gooch, Grace Baugh, Jessica Carpenter, Lisa Lee, Wendy Hobson, Robert Terashima, Darlene Pead, Val Jones, Kendra Tortalita, Gladina Yanito, Donna, Fred, Lois, Cathi

Next Conference Call: March 28, 2006.