

AMCHP 2007 ANNUAL CONFERENCE

HEALTHY COMMUNITIES

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HARDSHIPS AMONG FAMILIES OF CYSHCN

RALPH CONDO: Good morning. I'm from the Catastrophic Illness and Children's Relief Fund Commission. And, what I'm going to try to do today is offer you a possible solution. Just imagine that you're getting bills from doctors, hospitals, and your insurance company feels they've paid their fair share. What do you do? How do you get the bills paid or some of the other expenses that Amanda referred to? Well, if you're from New Jersey, we at the Catastrophic Illness and Children's Relief Fund Commission are here to try to help you, to fill that safety net.

Some of the questions that people ask us, how was it created, the purpose, so forth. Back in 1988, I consider him a very conscientious legislator, was made aware of a family in his legislative district that had some needs. Had a child with major medical bills, and had some concerns. Reached out across state government, federal government. And there weren't many programs out there at all back in 1988. And he decided to take some action. So what he did is he put together this package to try to help them. He wanted to create a safety net. And he didn't want to create some large bureaucracy either. His goal was that families would not have to make medical decisions based on their ability to pay. And when he found that nothing was available, he then introduced legislation that

created our fund. It was the first such program in the nation, and there was only, as far as I know, one other that is similar, and that is in the state of Massachusetts. Which, we take pride in New Jersey, saying they copied our fund pretty much. Since 1988, some statistics. We have helped over 4100 families in our state with over \$100 million in assistance. One of the things that I needed to point out to you, and I point out to every group that I speak to, that the definition of catastrophic illness is very misleading. And if we could go back to 1988, we would change it. But I don't know to what. Because catastrophic illness is a financial definition. Not based on a diagnosis. Over the years, we have helped families with a child with everything from a broken arm to someone with major cardiac surgery. Who did we help? And what did we help them with? Children 21 years or, who was eligible? Pretty simple. Children under the age of 21. Actually up until the day of their 22nd birthday. Your uncovered medical expenses must exceed 10% of your family's income, up to the first 100,000, and 15% after 100,000.

The family must have lived in the state of New Jersey for three months, immediately prior to their date of application. I want to pause here a moment to just make a very important point. As long as you've met those criteria, the expenses did not have to be incurred while you lived in the state of New Jersey. For example, if Amanda was to move to our great state of New Jersey and live there for three months, and she was there as a permanent resident, not as seeking medical treatment or anything, she would have the ability to fill out an

application, and we would go all the way back to 1988 if that's when she could provide bills for us and evidence of her expenses. So it's a very important key to our program, we think. We pretty much cover, as far as what is covered, anything that an insurance company will cover, an insurance policy. Whether it's physicians care, pharmaceutical, home healthcare, in or outpatient care in an acute or specialized hospital, durable medical equipment, disposable medical supplies. Some of the formulas that Amanda alluded to earlier, some of the special-needs equipment, as long as it's medically related, we will pay for it. In addition, things that may be covered that are not normally covered by insurance is, such as a telephone bill. Mileage, taking your child back and forth to a doctor for treatment. Travel expenses for treatment. What we defined as experimental medical treatment and experimental pharmaceuticals. Now experimental just means, or is defined as that it's recognized by national or international organization. And the other thing is, those performing the services must meet certain licensing requirements after filing a review. So in other words, you know, you can't have your sister come in and help you with care and, you know, then bill us for PT or something like that.

We also, and this again is something unique to us. We also reimburse for modified vans and home modifications, again, that are medically beneficial to the child. We'll reimburse you for that van, and you're responsible for the first \$15,000 of the van, but then we will pay the balance for the base van, and all the

costs of any modifications, which in many cases, that's 50, 60% of the total cost. And you own it. It doesn't come back to the state of New Jersey. It's your van.

Some of the things that we don't cover, but many of us wish that we did, educational expenses. Cosmetic surgery, or those types of procedures, income replacement expenses, from providers without appropriate credentials. Or I'm sorry, or providers without appropriate credentials.

The reason that we don't pay for educational expenses is that is covered under the statutes that govern our education programs in our state. So if they do, if they're what we call individual educational program or IEP, provides, or requires, whether it be computers or whatever, that's paid for under a separate fund.

That's the only reason we don't pay for it. Let's see. How does someone apply? Well, it's not quite as simple as we wish it was. And we're working on that. But basically what they need to do is, they can look us up on the Web. We do advertising throughout the state. For the last three years that I've been executive director, I've tried to go around as many places as I can throughout the state, small groups and pediatric facilities and so forth, and just tell the people about us. We have an 800 toll-free number. And the other thing that we have is we have a contract of service to our State Department of Health and Senior services for county special health services and for special assistance. They're located in each county. And when a family comes to them, they screen out for just about any state or federal program that they may be eligible for. And we're one of those

programs. We also do the same thing. We act as a referral service. But a little over 90% of our applications come through those county offices.

How long does it take to get help? The Commission now meets every 10 weeks. And our Commission is required by statute to review every single application. Review and vote on every single application that comes before it. When I first got on the Commission 10 years ago as a Commission member, as a family representative, I said, "Oh. You know, where do we get these stacks of applications? Of course they're abstracts. But still, they're very long and very confusing sometimes to read. And emotional, I might add. But, the reason that we do that is the Commission has the right, regardless of staff's recommendations, to modify that recommendation. For example, if there are unique circumstances, a family may come in and say, we have a cap, on home modifications of \$25,000 per year. But you can apply every year. But if a family comes in and they've spent \$35,000, staff will make Commission aware of it. They'll say the total expense was 35,000. However, by regulation, you can only spend 25. If staff can demonstrate to us in their narrative, why there is some particular outstanding reason here that this family should reimburse over the \$10,000, Commission has the ability to override staff. It's rare, but it has been done. We don't, our attorneys tell us not to do it too often because you set precedent and, you know, you start expanding the program without the structure behind it to do that. But it does. So it is important that they review each one.

As far as timeline, how long an application takes, it really depends. We try to get them processed and before the Commission in that 10-week. However, define a completed application. I mean, a family is going through so much at this time. They submit their application. We need copies of bills, we need the copies of their 1040 or proof of their income. And they just don't have the time to do it. And, so, but once we have all the information, it's definitely well within that 10-week time period.

A little bit about how we're organized and funded. We are administered by a 12-member commission, with seven appointed public members, and five representatives of the various state departments. Those public members are physicians and, at least in two cases, family members like Amanda. They are appointed by the governor with the advise and consent of the Senate. And they serve for five-year terms. The representatives of the various state departments, the Department of Treasury for example, or Banking and Insurance. Or Department of Human Services. And our new Department of Children and Families. And the reason they're there is a family has a problem, for example, and the insurance company turned them down. Or they felt that they were mistreated. That representative from the Department of Banking and Insurance will take that complaint, if you will, back, and make sure that her staff looks into it and tries to resolve the problem for the family. We try to stand in front of the family as best we can. Financially we're set up is a revolving, non-lapsing trust fund. Now, that may sound like a lot of gobbledeygook. To us in the bureaucracy

that means something special. And what it means is that we're not subject to the ups and downs of budget shortfalls or budget surpluses.

Any funds that are not used in the current fiscal year for our program automatically roll over to the next. Some administration can't take our funds and use it to pay potholes, and say, "Well, so that was so the children can get to their doctor on a smoother road." There are a lot of other funds in our state that they do do that, but they can't do it with ours. And what this does for us is it allows a more stable funding and financial footing, and therefore better planning by the Commission. How do we receive our funds? Where does it come from? We receive them from an annual surcharge levied on all employers subject to the New Jersey Unemployment Compensation Law. Every employer pays the state one dollar for every employee that they have on their payroll. The employer cannot pass this cost onto their employee at this point, although there's legislation proposed to do that.

And there are, and I think this is very important. And I know I use it when I speak to new governors, and when I speak to legislators that are trying to rate our fund, there are no federal or state dollars involved at all in our program. The employers pay for the operation, including the administration of this program. So, they can't, again, it's a little difficult for them to take our money. And, and I think it's important because, we're about, we have legislation that is probably being introduced today, today or tomorrow, that will increase our fee from a dollar to a

dollar fifty. In the 19 years that we've been in existence, it's always been a dollar. Costs have gone up, more families are aware of our program, we've used up all the surplus that we had, and we're to a point where we need a fee increase to cover the next seven to eight years. And when I was explaining that to some of the legislators who have to introduce these bills and pass them, they said, "Well, what's business and industry going to say? You know, your 50% increase," and so forth and so on. And my answer to that is, "Okay, a company like"—I don't want to name a company, but "ABC, that has maybe 10,000 employees, yeah, it's going to cost them \$5,000 more." But I've cut out the articles in the paper where those same companies have negotiated with their employees in some cases, or just forced increase in co-pays. So they've saved hundreds of thousands of dollars in premiums. So I don't have a problem telling that CEO, yeah, you got to pay another 5,000, but you just saved \$100,000 in insurance premiums. So, you know, sometimes you have to be a little forceful too.

In conclusion, I would just like to quote our current Governor, John Corzine. And he said recently at one of our public events, and I quote, "Our most important obligation as a state, and as a society, is to make sure that our children grow up in a safe, healthy, and prepared to succeed in life. The Catastrophic Illness and Children's Relief Fund provides an important safety net to help families cope with unexpected costs and focus on caring for their children." End of quote. I believe that the state of New Jersey is fulfilling this mandate, one child at a time, with each application, and with each dollar that we spend. Thank you.