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Caregivers Count! Support for Women and Families with Special Needs Children

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DARCI ESWEIN: Good afternoon. And thank you all for joining us for the third podcast coordinated by the Department of Health and Human Services Health Resources and Services Administration Office of Women's Health.

I would like to thank HRSA's Maternal and Child Health Bureaus, Division of Children with Special Healthcare Needs and the Division of Research Training and Education, as well as HRSA's Healthcare Systems Bureau. Their collaboration has made this effort possible.

I'm DARCI Eswein, a public health analyst in HRSA's Office of Women's Health, which is under the direction of Dr. Sabrina Matoff-Stepp. The Office of Women's Health is responsible for disseminating and promoting information related to the health and wellness of women throughout their life course.

Today's podcast Caregivers Count: Support for Women and Families with Special Needs Children has brought together three amazing women. Dr. Rosemary Johann-Liang, Jane

Moss and Lou Anne Jones, to share their stories as mothers with children with special healthcare needs and lessons learned.

It is our hope that today's podcast will provide listeners with an understanding of what services and resources are available to them. And that by taking care of themselves and making their health and wellness a priority, they will be able to provide the best care and support to their children and their families.

Thank you guys for tuning in. And I will turn it over to Rosemary.

ROSEMARY JOHANN-LIANG: Good afternoon. I'm very glad to participate in such an important discussion. Yes, the wellness of the caregiver is crucial in the care of children with special healthcare needs.

I can tell you this from the different hats that I wear in my professional life as a public health physician, pediatrician and director of a home health agency of children with autism.

However, it is the personal perspective as a single mother of three children, two of whom have severe chronic disabilities, that I want to provide this overview.

The breadth and scope of the responsibilities of a caregiver of chronically disabled children are overwhelming. In my case, my son, who just turned 15 years old this month, was born very premature and has cerebral palsy and autism.

In his young life, he has undergone three months of breathing through a machine, 11 blood transfusions, seven surgeries for his hips and legs, and countless emergency room visits, physical therapy, speech therapy, occupational therapy, hip therapy, aquatic therapy sessions, as well as tutoring support around the clock.

He's made incredible progress way beyond what anyone thought he would be capable, but he still cannot stand without holding due to the spasticity of all four limbs and low muscle trunk tone to this day. Thus, for the last 15 years my life has been daily infant care for him. He has to be bathed, brushed and dressed morning and night like an infant, except that this infant is now a handsome young man who is 5-5 and weighs in almost at 130 pounds.

Giving duress, much duress, to my neck and back. His younger sister, who is a beautiful 10-year-old girl with autism, seizure disorder and apraxia, she's still nonverbal, also needs complete daily living infant care due to her extremely delayed cognitive processing.

Aside from the unrelenting hands-on daily care giving, which never lets up, it is the primary caregiver's responsibility of accessing the medical care for the special needs children; that is, finding the appropriate healthcare provider, scheduling appointments, preparing the children to the appointments to avoid complete meltdowns, bringing children to the facilities, advocating for the children, equipment facilitation, and insurance negotiation.

Plus, the tremendous out-of-pocket expenses. There's also the multi-faceted advocating for appropriate placement and curriculum for each child's school-based individualized educational program, which can be, at times, all-consuming and frustrating, to say the least.

There is the researching and setting up therapeutic care access such as PTOTST and around-the-clock tutoring and home applied behavior analysis intervention programs,

where you, as the primary caregiver, have to act as both master scheduler and personality negotiator to teams of different people with different agendas.

This is in addition to making sure that your work is on track as well, to pay for the mortgages, health insurance, medications, food, so on and so forth, and meet all the demands of out-of-pocket therapeutic expenses.

Also not to be forgotten is the not disabled sibling and her physical and mental health and her needs as she's going through the tough teenager stages herself and needs her mother.

So I can say unequivocally that 24 hours in a day is just not enough for the primary caregiver of chronically disabled children. The overwhelming responsibilities are beyond what one can even articulate.

Personally, I feel that my tank is always draining. Draining and draining some more, as I'm asked to give, give and give some more until there is nothing more left to give.

When the tank starts to dry up, the physical aching of the body, the mental fatigue, and the psychological despair and hopelessness can set in.

It is, therefore, so extremely important that this crucial point person, the primary caregiver, be supported to keep the tank filled. It is preferable that the tank does not get to the empty point, the E, because when the health of the caregiver suffers, and he or she has nothing more to give, it's the children who also suffer as a consequence.

Remember, the healthier the caregiver, the healthier the child with special care needs. How do I fill my tank, I'm often asked. This has been a gradual learning process, too. Over the years I've had many dark times where my tank went to E to double E to triple E.

It is much more difficult to get out of the E than not letting the tank go to the E in the first place. Now, I know to some extent how to fight off the guilt of not being the hands-on person to my children 24/7. I have learned over the years that it is okay to let go sometimes.

It is okay to delegate some of the daily hands-on to either hired help or to a caring network of friends. I tried to keep my tank filled by making sure that I go through a mental

checklist for my own health needs. This checklist is practically based. And it's treated with as much diligence as my children's to-do checklist.

For spiritual and psychological fill to my tank, I found a church where there is a special needs ministry. The children can go to this special needs Sunday school with qualified personnel and I can get spiritual feeding away from the children at the worship service.

I also carve out personal daily quiet time and bible study time weekly with my faith friends. For physical fill, I make sure I get exercise in during the week whenever I can, with dance classes, time at the gym and walking with the dog.

For emotional fill, I make sure that I find time for date nights and short get-aways with my fiancée, and time for that all-important therapeutic massages for my aching neck and back before I get to a point where I just can't move.

In addition to these feeds into the tank I know that one feed out also feeds my tank. This is helping and reaching out to other parents and children in similar needs through my home health agency and the after school program for children with autism that I run, which I started because of the needs of my two disabled children.

The extreme sense of gratification from this feed out especially fills my tank. Finding joy in small steps forward for all my children and taking the time to have many breakdowns for myself and release the frustration before it piles up also reduces the leakage from the tank.

I have learned that I cannot do it all by myself. I have learned to ask for and receive help. To survive I have set up a system both the environment and the personnel where my children can be taken care of in my absence.

The president may have inherited Air Force 1, but I have cultivated a Team 1 over time. I act as the leader of the team and am no longer struggling as the Lone Ranger. Team 1 allows me to have the time I need to make sure that my health checklist is taken care of as well.

Remember, the healthier the caregiver, the healthier the special needs children. DARCI, I will turn this back to you at this time.

DARCI ESWEIN: Great. I'm going to turn this over to Jan Moss. She's a HRSA grantee and chairs the Family Leadership Council. Jan.

JAN MOSS: Hello, everyone. I'm coming to you from Oklahoma, where the wind has been sweeping down the Plaine, I can assure you. I want to just kind of give you an overview, kind of the philosophy of where I am now.

I was so glad when someone spoke earlier about HRSA having the life span perspective, because my children are older. Jennifer is 41 and Jason is 31. And Jennifer was born with deafness, cerebral palsy, hydrocephalus. She has mild mental retardation. And she's had scoliosis. She's had a number of surgeries. But nothing was critical. Her health, in general, has been pretty good.

And she's someone who now lives in a rental, condominium rental, and with supports she's employed part time and she uses public transportation to and from work, and we also have her in-home supports through the Medicaid waiver.

But Jennifer is someone who really began school and all of her different therapies and related services and things about the time that public schools were being opened to children who had disabilities.

I actually was part of the testimony that was given by families across the country to implement Public Law 94142, is what IDEA is today.

So Jason comes along 10 years later. It's like having two only children. I don't recommend that split. I'll tell you for sure. Jason was born with a significant heart defect and a number of other problems.

A lot of physical anomalies, which he still has. And Jason would be said to be someone who would be on the autism spectrum, and he has an uncontrolled seizure disorder and he has mental retardation. And he's an absolute hoot. He can get around but he requires lots of navigation assistance, which usually is me.

My husband and I were really a good team. We kind of passed the baton back and forth, so each one of us could have a career. I did stay home about five years with Jason after

he was born, because we were doing our catheterizations and heart surgeries and that kind of thing and his health was very precarious.

And it still is precarious but for different reasons now. So where we are by virtue of still receiving services and children still receiving care, and I am the primary caregiver now because Dale passed away on Father's Day of 2000.

So looking at what the future is for my kids, and then working with families who have very young children, my philosophy is kind of this: I feel like I'm driving through the rearview mirror. I'm constantly deciding where I'm going to go based on where I've been.

And it's very hard not to do that, because we're not given any road maps with these kids. And we're not given any road maps with our partners, our marriage partners either.

And it's very difficult to maintain a healthy relationship with your husband. And part of the wonderful benefits of having a husband, if you're fortunate enough, is a partnership, and it doesn't mean that you're dividing up the chores, necessarily, evenly. We always looked at a priority list.

The number one priority was who had the best insurance. And so we made a lot of decisions about jobs based on who had the opportunity to have the best insurance.

One of the things that was brought to mind, as I heard Rosemary speak; and, of course, I would have to ditto everything she said. And it was refreshing for me to hear from a primary caregiver that she had an understanding of the complex and multiple issues that families have.

And it is hard when your tank is drained. Now, our family philosophy kind of has been I have a short attention span and therefore I can't stand to be sad or upset for too long at a time. And so we practiced over the years humor therapy, and it's been very helpful for Jason, because he is someone who has a lot of meltdowns.

And so we have key phrases that we use with him kind of therapeutically that we know will divert him from what he's being anxious about. And then we kind of can come to grips with that and self-regulate a little bit.

What I've learned from Jennifer and Jason is that our family experience is really the contribution to how we operate today. I call kind of encapsulate the way we've been able

to operate as intuitional navigation, you just have some things, you just have feelings about some things.

And, actually, there's some contemporary research that Malcolm Gladwell has done it's a book called "Blink". I grabbed it the moment I heard about it and read it because through life I feel like, and then I've known many people who say I can't tell you why, I just know. And I know that's kind of the way that we have negotiated services.

Certainly when Jennifer was little there were none that were organized in the way they are today. And I'm so grateful for the Family to Family organizations and I'm grateful for the parent and training information projects, and I'm grateful for the Parent to Parent organizations, because informally that is really how I began to develop survival skills.

Having the perspective of having much older children, one of the things I feel that is really important. We have 20 years of alumni now who have graduated from public school services and from current medical services. And so if we're looking at ways to support families, then we have the opportunity to interview both persons with disabilities and their family members to say: Oh, gee, what would have helped? What would have been

better? And I hope we don't miss that opportunity. As I get older I'm thinking I could croak tomorrow and I certainly haven't written a diary of any kind.

But I would hope that part of the work that HRSA could do would be to kind of tie in recommendations that the beneficiaries and recipients of services have regarding the way services are delivered and how families are supported.

I'm looking at my time here. One of the things that is improving, I think -- and certainly Rosemary is a part of this because she's a physician -- and that is how we can explain to families that their children have disabilities.

When Jennifer was diagnosed, Jason was diagnosed, too, it was all an apology. I think that was fine. And it was courteous and it was thoughtful, but it left me kind of limp. And I would have greatly appreciated, someone being able to share with me the resources that would be available to me and to tell me that I was not going to go through this alone.

One of the things that I think we can look at in improving that initial experience for families would be to maybe do what Maternal Child Health is recommending in their Medical Home Improvement Act, which is Partners in Practice.

And we're fortunate enough to be able to get some Title V funding, so that in one of the clinics that we have that assesses and diagnoses children, very young children with autism and developmental disabilities, is we have a family member who is with them all that day and who contacts them before, during and after. So that there's somebody who is in the same boat that is willing to row with you. And I have found that from the follow-up interviews for the families that have gone through the clinic to be real rewarding to me personally to know that we're able to begin to put some of these things in place.

Appropriate service models, I think, in working in the LEND programs, they have what they call the LEND principles which are inclusive practices. You need to be including the families and you need to be looking at how to behave in ways that are sensitive to the individual family's culture and interdisciplinary. I would have to say I begged for interdisciplinary services. I bidding for them, because Jennifer and Jason's needs are pretty complex.

And it's rare that you get a physician, a single physician or a pediatrician, that has all the knowledge that someone really needs to have. And I'm invested and passionate about the ability to receive interdisciplinary services.

I'm passionate about the fact that we should be consistently asking families how we can do it better, how do you define help.

I have a little truism, I call, and that is that help is not help unless it's what you need and when you need it. So that's often shocking to service providers, because people who go into direct services go into it certainly not because it has glorified hours or pay, but because genuinely they want to be helpful. But I found over the years that sometimes some of the things they recommended were not helpful at all but nobody ever asked me. And I would have to confess that I have sure lied to service providers when they recommended things I had no more intentions of doing than the man in the moon.

When Jennifer was very young, with her cerebral palsy, she has lots of chewing and swallowing issues. And one of the things they were going to have us do that they suggested was to tie some gristle on a string. And when she choked on it, I could jerk it back up, that that would improve her chewing. Well, it just made her throw up. And so

when they would ask me had I been doing that to work on her chewing, I would say, oh, yes, yes, I have but in fact I had not, nor was I going to.

So some of those things that are recommended to family members are not going to happen unless we really ask the families is it appropriate, is it something that you have some value in, and where do you want the most assistance.

Respite is something I find that could probably eliminate a lot of secondary conditions for families. And all too often it's not available, either it's a duplication of some other kind of funding or there's no respite providers or that kind of thing.

Once when I was going to pick up Jason at a daycare, and he didn't do all that well in daycare, but we had found a place called Special Care, and it was an integrated daycare setting with siblings and children with disabilities. And so we were very pleased with the services there.

And I went to pick Jason up. And one of the moms that I had known for a long time who had a daughter with cerebral palsy, and she had considerable involvement and required a great deal of physical assistance.

And I ran into Stephanie. And both of her arms were in casts from the elbows to the wrists. And I said: Oh, my God, did you fall? What happened? And she had stress fractures in both of her arms from running her arms through the wheels of the chair to pull that chair out of the trunk of the car to take it in to pick up Stephanie.

And, you know, she was about 36 years old. And I think, gosh, that is a pretty significant problem that she'll have forever. And I've always thought, the advocacy part of me has always thought: You know what, with the secondary conditions, some of the falls, some of the anxiety disorders, some of the stress-related issues that families have, that if insurance companies had any idea of what those secondary conditions were causing, they'd be very pro respite and maybe divvy up some support and maybe even some money. Haven't seen that happen, but I certainly have thought it.

The rules of engagement for families. Every family defines themselves differently. None of us want to be called one of those families. And none of us want our kids to be called one of those kids.

And good manners, please and thank you, and asking the family what they define as helping and what the kind of services they need comes a lot closer than some kind of certificate in cultural competence, which I know is a big issue.

In looking at my professional side, working with other families, I cannot separate my own experience. You know I can't. I understand what it's like for those families. I sympathize with them.

I go home and care for my kids, yet I still think about families that don't have any service providers. And so it's nothing for me to visit with someone like Joanie Bruce, who is head of our Family to Family. She's in on this podcast today sitting in my office. And she's also the executive director for our Oklahoma Family Network, which is our Parent to Parent. Sometimes we're on e-mail discussing how we can support a family or how we can get some information out and sharing that knowledge.

As Rosemary said, there's no way you can do this by yourself. There's no more reliable resource than other families. We say things to each other that probably some professionals could not say to us. And we do this with that kind of love and understanding that therefore but the grace go I.

I've practiced over the years a little advocacy model, and that is I think, gosh, this is a big issue for me. And my current one is diapers. And that is for families who need diapers and who are receiving those diapers through Medicaid.

My gosh, they're crummy. And I keep thinking: How in the world can we keep furnishing families crummy diapers. So I think if it's true for some families is it true for others. If it's true for me, is it true for others. And if it's true of others who are they and where are they? And how might we contact them and how are they represented and are they being represented? And who else do we need to consider that is part of this constituency.

So that little formula: Is it true of me? Is it true of others? Who are the others? And defining who might be the best representative has really assisted me in becoming an advocate for other families.

I think I'm right at my time, so I will turn this over to Lou Anne or whoever is supposed to take it next.

LOU ANNE JONES: Thanks, Jan. This is Lou Anne. And I took notes on everything you said, because that was such valuable information. And I'm going to refer to some of the things that both Jan and Rosemary said as I share the information that I've prepared for today, because we all have some similar experiences.

I have three children. And my husband and I, when we were preparing to have children, certainly had an image or an expectation of what it was going to be like to be parents. And I think most people do.

Most of the time that image does not include becoming a parent of a child with special needs. And I actually recall one conversation we had before we were married. We were sort of, I guess, in the interests of full disclosure, talking about some of the expectations that we had of what our home like would be like and what challenges we thought we might encounter in our marriage.

And we discussed certain expectations that we had, and we discussed things that we wanted to have in our marriage. We wanted to have regular meal times and we wanted a home that was going to be neat and orderly and we wanted our children to be disciplined in certain ways. And we discussed how we were going to handle holidays and in-laws

and all of those things that you know, the things that you need to discuss before you get married.

And I even remember we discussed the possibility of not having children, which would have been a challenge for us, because we both have siblings who do have children.

And we discussed an even bigger possibility that we might have a child with a disability and what a challenge that would be for us. And we both agreed that it would be more challenging if we had a child who was intellectually challenged rather than physically challenged. And having set ourselves up so completely and opened ourselves up to fate, it really should not have come as a surprise to us that our second daughter was diagnosed with autism at the age of two.

It has been a challenge for our family, but we decided early on that we wanted this challenge to be something that really brought out the best in all of us, that it was something that we wanted to be a positive experience for our family and something that we wanted to learn from, and something that we wanted to be able to use as a positive learning experience.

Well, at the age of 12, then, our daughter was also diagnosed with bipolar disorder. So we are now in the category that is known as co-occurring disorders. And we overlap into so many services. We have medical services and health and human services and we're in the mental health field as well.

And as Rosemary mentioned, our entire life seems to be just appointment after appointment and trying to coordinate all of her care.

In addition to that, my 11-year-old son has some health conditions that we're still in the process of diagnosing. He has some irritable bowel disease issues that we're trying to get diagnosed.

And so having one, as both of these other moms have talked about, having a child with one disability or having one child with disabilities does not exempt us from having other issues in our lives. That is often not the only challenge and sometimes not even the biggest challenge that we have in our lives.

Before I had children I also knew I had health issues. I had already been diagnosed with fibromyalgia and knew that I had some immune system issues as well.

So we often do find that there are other things in families, other issues in families that they have to deal with. Even when they have children with disabilities. And having a child with a disability doesn't cause these issues, it just contributes to them or sometimes can worsen them if we aren't taking care of ourselves.

By the time we were discovering that our daughter had developmental issues when she was two, I was already in motherhood fog because I had my two toddlers, my two girls, and then I had a newborn and sleep -- the stuff I mentioned having with my husband, about having regular meal times and the clean house and all that, that was a thing -- that was a fantasy.

And sleep was a luxury I had long forgotten. My house would never and has never been clean again completely. And every relationship in my life had changed. I had forgotten what it was like to have friends.

My relationship with our siblings had changed. And I had no idea that I was then going to be embarking on a completely new career path for which I had no training or formal skills. And there was a grieving process that I and most parents do experience when we have a

child who is diagnosed with a disability. And I became a disability mom. And that's a title that carries so many varied and different functions.

And there's no written job description. We just live it a day at a time and deal with whatever comes our way.

I've taken to calling this now extreme parenting. We just deal with things that are so intense. And it also is -- now we're finding out, as Jan has had the experience, it is long term. And what I used to think of as a sprint, when we were in the early days of our daughter's diagnosis and we were throwing ourselves into every therapy and treatment and program that we could trying to help her overcome her disability, we now know is a marathon.

And her care is lifelong. And we now know that we have to be able to pace ourselves so that we can be able to give this care for the rest of our lives and prepare for the rest of her life.

I know that all parents feel stress and burnout. But in my experience, and from dealing with a lot of parents in the programs that I work with, and in associating with friends and

neighbors and my siblings, I know that the stress and the burnout and the things that we as parents of children with special needs experience is above and beyond that of normal parenting.

And I have come to think of this caregiving as a job. Like every job, it has its rewards as well as its challenges. Like every job, the person doing the job is able to function better and more effectively in that job if he or she receives adequate rest, scheduled breaks for physical and mental relaxation, vacation time, proper training and peer support. I mentioned that I've come to think of it as a marathon. I am not a runner, but I really do admire people who run marathons. So I read a little bit about the process of training for a marathon.

And just like those who run a marathon, I think we as caregivers can learn a lot from that process. There's training involved. People who run marathons have a support team. I love that concept that Rosemary mentioned that she's developed Team 1 and that she has those people in place that she can trust and that she can delegate and who will take care of the tasks that she can't and that she's able to hand off to.

There's also having proper equipment involved. If we have the proper equipment for running that marathon, then there are fewer injuries; there are fewer accidents. We're able to maintain our bodies for a longer period of time with less stress.

And these kinds of things would include just simplifying the things around our home, making sure that things that we can control are taken care of, making sure that our cars are maintained so there is less stress involved, making sure that simple repairs are taken care of so that the things that would otherwise cause stress for us do not cause stress for us.

If those are things that can be delegated to a friend or a spouse or to a neighbor or to an older child, then those would be the kinds of things that can be delegated.

Sometimes we just think of delegating the caregiving when we can think in terms of delegating some of the simple tasks in our lives that are also adding stress and burden to our lives.

And in training for a marathon, athletes take rest days. They have days when maybe they have to train really hard and they run a lot of miles but they don't do that consistently.

That's when the injuries happen. They don't do it day after day after day. They have a training schedule. So after a day of really hard work, then they take a rest day.

And as caregivers we sometimes forget that we have to take those planned unscheduled breaks. One barrier that I know that I have experienced in that, though, is that we are hesitant to ask for help. I've had a very hard time asking for help. And even asking for the specific help that I need, the more specific we can be in asking for help, the more likely we are to be able to find somebody to help us.

Although formal and state and federal funded supports including respite care or other in-home supports can greatly reduce our stress, especially in these tougher economic times, they can be much harder to come by, and all special needs children or medically fragile children are going to qualify for those eligibility programs.

So I always encourage parents to look for those programs and to apply for them even if there's a waiting list, because eventually the funding for those programs might become available.

But in the meantime there are other ways to access some support. Other ways that we might find help with rest might include trading respite with another family. Even a family who doesn't have a special needs child might be willing to trade baby-sitting for the experience of taking care of a special needs child.

We can also ask for volunteer help from our faith-based community. Often, they have youth groups who provide service hours and are very willing to help out. It just takes overcoming our hesitation and maybe our pride, I know that's been a barrier for me, and it just takes overcoming that pride and asking for the help.

We can also look in our communities for community family support centers. And in some communities there are family support centers that specialize in taking care of children with special needs. I have found that there are so many people who are willing to help, and they will even say: What can I do to help? But if I haven't planned in advance so that I know what I need, then I don't know what to have them do. If I can be very specific and say: I need two hours once a month on Saturday so that I can get my hair done. Or I need two hours on Wednesday nights so that I can sing in my community choir. If I can be that specific in my needs, then I can get my needs met.

The toll of caregiving adds up over time and we need to take steps to be proactive in taking care of ourselves and our family members before we start to feel those effects so deeply. Rosemary used the example of the empty tank. And I had thought of the example, too, of we can't get water from an empty well. It's that same concept of if we just let ourselves completely used up and drained, then we can't give anything to anyone else.

Many of the parents of children with disabilities that I know, myself included, have health issues. My health issues are not caused by the fact that I have a daughter with a disability but the symptoms and frequency and severity of flare-ups can be caused by stress fatigue and tension. So I know when I start to have increased muscle pain because of fibromyalgia or chronic migraine pain or when I'm having a battle with insomnia, I'm not an effective caregiver to any of my children or to the parents who come to me for help.

So until I take the time to resolve those issues and get a balance back in my life, I can't help my children or other people be balanced in their lives either.

We often think that maybe because we have a lot, we are very blessed in our lives, so sometimes we think we should not ask for help when other people are so much more in need.

But we try to remember that we don't all have the same needs and we don't all get them met in the same way. And if we have our needs met, then hopefully we can reach out to other people and help them get the things they need. And that's something that we remind other families as well, is that if they get a little bit of help, then they are in a better position to help other families and people as well.

DARCI ESWEIN: First off, I want to say thank you all for sharing your stories and giving a little bit of insight of lessons that you have learned or are currently learning.

It seems to be, I think, a general theme in most mother's lives that they need to learn how to ask for help. And I think you guys definitely have to work harder with that, times two, just with what you've been through.

It's huge the support you can give to each other, that can make your lives just a little bit easier, so that way you can take care of yourselves to take better care of your child no

matter what stage the diagnosis or what age your child is or how old your child is and you'll do whatever you can to take care of them.

I don't know if any of you guys had any last minute things to say before wrapping up or any resources you wanted to make sure our listeners had to go to, if they're just getting diagnosed with a special healthcare need, anything you would recommend to them.

LOU ANNE JONES: This is Lou Anne. I did have one more thing that I forgot to mention in my presentation. I don't have a specific site, but I do recommend for parents who are hesitant to join a support group, or in my case I live in a rural area, and we didn't -- when my daughter was first diagnosed we didn't have a support group. So we eventually started one. But now there are so many online support groups.

And there are national, there are state, local groups, even on Facebook there are groups. One of the things that our parent group did on a state level is we started a private, membership-only online social networking group for both parents and professionals who could join that would be a safe and secure networking site to share information.

And I highly recommend this type of networking, online networking, to parents who are not able to access support groups in person, or who may be looking for a way of accessing information on the computer.

Especially if you go to a safe and secure site that has a membership and password sign-in so you know it's more secure, these are very good ways for getting information and of chatting with other parents and accessing support at any time of the day or night, whenever you can get to a computer. And we are finding, this is a way that parents, in this generation, the newer generation of parents, are really accessing support.

And it's a great tool to use. And we highly recommend that parents access the tools available there and the sites and resources that have been set up.

DARCI ESWEIN: It sounds like speaking with other families you guys are able to help each other navigate the whole healthcare system since you have so many providers that you're going back and forth between.

LOU ANNE JONES: The information on those sites is almost instant. There's almost always someone there. If you throw out a question, the information that comes back to

you is almost instant. Or if somebody has already asked the question, so the discussion threads are saved and posted. So they're great resources.

JANE MOSS: Am I on? One of the sites that I find very helpful is the National Dissemination Center for Children with Disabilities, and that is also run by a family member, which is really nice to know. But NDCCD has recently received the family support, funding for a family support, national family support center as well.

And they're building that site and already have many wonderful things on there. I would highly welcome that. And Family Village, Exceptional Parent Magazine. And the Family to Families, you can query that on the web. And every state has a parent training and information center. And just about every state has a Family to Family organization.

And then the Family Voices website. And if you have a state Family Voices chapter, that is wonderful. And those are resources available in every state.

We should have a running list of those to disseminate to families. I think pediatricians, it would be wonderful if they had a laminated card that had that information, so as families begin to have questions, there may not be any in the beginning, that they can give

families those kind of resources. I'm sure some do, but not all of them and not as many as we could have.

DARCI ESWEIN: That's a great idea. Again, I'd like to thank all of you for participating in this podcast and shedding a little light on what support is out there and what you have found works for you and also to kind of give us a better understanding as to what we here at HRSA maybe can do to help make things easier, just the availability and access issues that you guys face.

So thank you all once again for participating in the podcast and sharing your stories. We really appreciate it.