2024 Quality of Life Family Camp Information Session

You can watch the video of this presentation at: youtu.be/d9k1UdmVZNM

[00:00:04] **Rebecca Whitney:** Our annual Family Camp program is something that we are incredibly proud of and is one of our longest running programs at SRNA. And it's designed for those families who have children. And I say children and we use that loosely because the ages range. We also have some young adults who may join us as well with their families, particularly those who may be newly diagnosed. But we hold the Camp every year in the summer and really what it is meant to do is to bring those families and it's the children diagnosed, it's their siblings, it's their parents or their care partners who are coming in and getting to know one another.

[00:00:58] Oftentimes, it's a matter of they have never seen or met another individual who's been diagnosed with the same rare disorder that their child or that they themselves have had. And it's incredibly powerful. I can say from experience that with my son being diagnosed as an infant, we attended our first Family Camp when he was five years old. And one of the first things that was said was on behalf of all of my children, all three of them was we are not different here. And as a parent that was something that stuck with me, still gives me goosebumps, because they recognize themselves in the other siblings, in the other kids with the diagnoses. And we knew that we were not alone, that we weren't the only family that has had to go through so much in order to get where we were in that moment.

[00:01:58] So it's very personal for me and it's an honor and a privilege to be able to organize the Family Camp. How we structure it is main priority, have fun, enjoy the activities of the Camp that we're at, enjoy the company of others, and really just be a part of a community that you may not always have access to when you're home, you may not have access to in your school or in your hospital resources that are available to you. So that is the number one goal is to make sure that we are having fun. And the kids get to enjoy things that they may not have otherwise been able to enjoy.

[00:02:47] So this last year, we had attended Morgan's Wonderland Camp in San Antonio, Texas and they are fully accessible. All of their activities are accessible, all of their rooms are accessible and there were opportunities to do a ropes course and they can accommodate wheelchairs. So, a child in a wheelchair can do the ropes course alongside a child who may have full mobility, and no one is excluded from participating in those activities, including a climbing wall. And by climbing wall, I mean, a climbing wall. It is pretty extensive. Activities such as horseback riding, even swimming. Swimming can be difficult and dangerous sometimes. They have a zero-entry pool, a lazy river. They have a phenomenal gym where they even have adaptive sport wheelchairs. So, wheelchair basketball is an option or other sports where the kids can participate in that adaptive setting. So, it's really incredible.

[00:04:06] What also makes our Camp unique is the fact that we bring in the medical experts in these rare disorders. So, they have an opportunity to come. We have educational sessions with the parents or the adults who are attending and then we have separate sessions for the kids. We give one another a break from that parent kid-relationship and really focus on informing and discussing, and answering those questions that again, families may not always have access to in their hospitals or their resources that are back home. So, we really want to make sure that we give people an opportunity to learn, to ask questions, and to take that back with them as a means to advocate for themselves and their child in their own community.

[00:04:59] It's also really, really awesome to be able to see the kids and the clinicians, whether they're doctors, therapists, nurses interact outside of that clinical setting. So, it's really an opportunity for them to get to know one another on a different level. Sometimes I think we may often forget the fact that there's so much more to a child in a family when they've been diagnosed. We focus on treating those disorders and making sure we're managing symptoms. But there's so much more that plays into that—their family life, how they're doing at school, how they function, how they eat their meals, what does that look like? And likewise for families and children, when we see our doctors or our other health care professionals, we put them up on a pedestal, which we should, there's a lot of education, a lot of knowledge that goes into that, but they are still human beings and it's so awesome to be able to see when everyone can recognize the humanity in one another that there's so much more to them than just my doctor or just this child diagnosed with a rare disease.

[00:06:19] So that's something that we really, really are proud of is being able to have a community of medical professionals that are so interested in wanting to attend and be a part of Camp. And we host different sessions. We also have sessions for the kids to be able to talk with a neuropsychologist or other social scientists to be able to discuss those things that they can't otherwise discuss. They may not feel comfortable with their families talking about it at home or they may have questions that they're not sure who to ask. And we give them a setting in which they can feel safe and be open about talking about their diagnosis or their struggles.

[00:07:06] So it's been really great to also welcome families from around the world. In past Camps, we've had families from China, Norway, trying to think of others. There's been so many others and it's just awesome to be able to see that we can come together as a worldwide community in this manner and that it doesn't matter where you're from, what you look like, how you've been raised, these disorders can impact anyone, any child, any family at any time and we can all learn from one another and support each other.

[00:07:47] So we have an application process, and we also welcome volunteers from our community. Last year was one of our first years where we've been able to really get our community volunteers involved in Camp. And so, we had a number of them who themselves had been to Camp as kids return as counselors to be able to interact and talk with the kids, and really develop those relationships. And it's incredibly impactful for the kids and the parents to be able to see there are adults who are living their best lives, even though they've been diagnosed with these disorders, and they can still hold a job. They can still get married. They can still have children. They are thriving in their lives and it's not just the diagnosis that defines them.

[00:08:46] So it's been really amazing to be able to have them and have some of them returning for this coming session as well. So, this year we're actually meeting June 29th until the morning of July 4th in San Antonio again at Morgan's. And we're looking forward to an incredible time. Our applications are open on the website for both volunteers as well as for families diagnosed. So actually, we have a little bit of time. I'll go ahead and share one of my screens so I can just show where that is located. Let's go ahead and use this one here. This is the wrong screen. Let's see. Oh, are you seeing the home screen for the SRNA?

[00:09:49] **Amber:** Yes.

[00:09:52] **Rebecca Whitney:** I just want to make sure, because it's not showing that one for me, but let me go and see if I can -- there we go. Now, I can see it. So, for this here, our Camp information is under our "Programs and Services," under "Individuals Diagnosed and Their Caregivers," "Quality of Life Family Camp." So, this is where we have more information. All of these photos here, these are all kids and families, and volunteers who were at Camp last year and I hope to see every single one of them back again. We had such an amazing time.

[00:10:35] **Amber:** They look so happy.

[00:10:37] **Rebecca Whitney:** Yes. Yes. And I think the smiles say it all. They really did have a great time. It was incredible.

[00:10:45] **Amber:** Wait, I’ll hold back the tears. That's crazy.

[00:10:49] **Rebecca Whitney:** It was beautiful. So, we have our Camp application. We outline the process of the Camp application and how it works here. We do require some medical information for those who've been diagnosed in order to complete that application. But it goes directly to an online application that is filled out and then that information comes directly to us here at SRNA.

[00:11:23] So I think I said that June 29th would be when volunteers begin at Camp. Families arrive June 30th, and then our departure day is July 4th. So, the morning of July 4th is when everyone would leave. But we also connect to information about our previous sessions. There's a blog here where we have recapped our 2023 and of course, we're open to any questions that anyone may have or if there are any issues at all with completing the application, we welcome them to email us at camp@wearesrna.org or call or text this number here.

[00:12:08] But here again are some more photos of families, volunteers, children that have been diagnosed, their siblings that attended last year. And again, I think the smiles say it all. It really was an awesome time. But a bit more about Morgan's is located here and you can see this is the gymnasium that we have access to. They host different activities in there throughout the week that we're there. This is one of the arts and crafts room that they have open. This is the medical center. So, there is a dedicated medical station, and this also would house volunteers that attend. And this is just a photo of one of the medical rooms. It's more stocked than the photo shows at the moment. And this is a photo of one of the cabins. So, the cabins, most families can expect to share a space with another family.

[00:13:12] However, that said there is so much room in the cabins. These bunks are specifically designed so that if anyone has to transfer from a chair to the bunk, they're not hitting their head on that bunk. And every single restroom that is in the cabins is accessible and there are 3 to 4 showers as well that are accessible too and they differ in the type of accessibility. So, there is one that is an accessible bathtub. So that was something that we didn't know was going to be such a defining piece of Camp. And there was indeed one family who said, I have not been able to give my child an actual bath since their diagnosis and I was able to do so here.

[00:14:10] So Morgan's has certainly built their premises on accessibility versus considering it after the fact. So, it's an amazing place. This is one of the common rooms, so a couple of their cabins are shared. So, there's the shared common space within the cabins and obviously you can see that there's a full refrigerator. Some of them do have coffee makers, not everyone, but there is a place to gather as a group and also maintain some of those items that you may have to have refrigerated, whether they be meds or special diet details.

[00:14:54] You can see that there's a whole list of different activities here. This is just some of the activities that Camp offers that we have access to and a full map layout of Camp. But Camp is within 20 minutes’ drive from the San Antonio, Texas airport. And so, it's not too far out where we can't be reached. And there are certainly a lot of different amenities that are located within that area of San Antonio as well. But it is an amazing time. We love it so much. Even my 16-year-old was telling me yesterday that he wants to go to a basketball camp, and it ends the day before. So, he can still go to SRNA Camp, and he wants to know how to get to both. So even though he's 16, he's been there multiple times. He can't wait to go back.

[00:16:02] **Amber:** He has the energy too. I'm like, “Do it now. You're prime for this. You can do this.”

[00:16:10] **Rebecca Whitney:** Yes, exactly. So, it's an amazing time. We absolutely love it. We love welcoming our families and our medical professionals, and volunteers at Camp. I can honestly say the last day, last year, I didn't want to leave, and it was hard to leave, because well, I think as you know, too, we become extended family, right?

[00:16:38] **Amber:** Yes.

[00:16:40] **Rebecca Whitney:** So, for anyone who sees this after the fact, if there are any questions whatsoever and if you have any questions too, Amber, please let me know, I’m happy to answer them. Or if you have anyone in mind that you think would love to be a part of Camp, send them our way.

[00:16:59] **Amber:** Yes, I surely will. Whoever watches this, they're going to be blown away like I was. I didn't know what to expect. But man, I'm so glad I joined this one. I was like, “Family Camp?”

[00:17:13] **Rebecca Whitney:** Well, thank you so much for joining. I really do appreciate it.

[00:17:17] **Amber:** I will reach out to you for sure. And I screenshotted everything.

[00:17:21] **Rebecca Whitney:** Oh, did you really?

[00:17:23] **Amber:** I sure did.

[00:17:25] **Rebecca Whitney:** Oh, well, thank you so much.

[00:17:29] **Amber:** You're welcome. And I just want to say your personal story is so moving and I'm so glad that SRNA has you.

[00:17:48] **Rebecca Whitney:** Thank you Amber. That means a lot to me. So, thank you very much.

[00:17:43] **Amber:** Yes, ma'am. We’re going to get through this together. We'll do it together

[00:17:48] **Rebecca Whitney:** Yes. Thank you.