WEBVTT

1
00:00:07.510 --> 00:00:14.749
Hello, everybody, and welcome. We're just gonna take a couple of minutes to let everybody join us.

2
00:00:16.360 --> 00:00:18.990
And we will begin shortly.

3
00:01:25.060 --> 00:01:38.990
All right, everybody, I think we're good to start. Welcome, everybody, to this very special Ask the Expert webinar hosted by the CHARGE Syndrome Foundation.

4
00:01:39.090 --> 00:01:53.940
My name is Lulda Esquintana, and I am the Outreach and Engagement Manager for the Foundation, and I am thrilled to share today a very special webinar, very close to our hearts, because

5
00:01:53.940 --> 00:01:54.610
It's…

6
00:01:54.610 --> 00:02:16.269
The Ask the Expert for today is gonna be our families. It's gonna be about your stories. It's gonna be about your experiences, and we are really happy to have you today, live, and for those of you that are joining us later, through the video, we have a lot of great things in store for you today.

7
00:02:16.520 --> 00:02:23.719
But before we start, we wanted to go over, a couple of things regarding accessibility.

8
00:02:23.940 --> 00:02:32.690
We will be providing ASL interpretation, and Spanish interpretation.

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00:02:33.230 --> 00:02:40.090
ASL, you are able to spotlight your interpreter so you could see them.

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00:02:40.360 --> 00:02:52.660
And, now I'm gonna turn it over to our Spanish team so they could explain how you're gonna be able to access, the Spanish, channel.

11
00:02:53.880 --> 00:03:09.630
Hello everyone, good evening. My name is Jancy. I am one of the Spanish interpreters for today's session, here with my colleague Kenton, who will be my co-interpreter. This session will be conducted in English with simultaneous interpretation into Spanish.

12
00:03:09.860 --> 00:03:23.560
To listen to the interpretation, once the interpretation feature has been turned on, you can access it by selecting the three dots that say More at the bottom of the screen, selecting Language Interpretation, and choosing your language of preference.

13
00:03:23.820 --> 00:03:28.360
Please don't forget to click done to activate it. Now I'll be switching to Spanish before we begin.

14
00:03:28.610 --> 00:03:48.340
Hola tod el mundo, mini nombre es una de sus interpretes de ingles y espanol, hoy esta noche junto a mi colega aquenton, que sera amico Interpreter la session de hoy. Esta sesion sera en ingles y contra a con interpretacion simultania al espanol. Para accederar la funcion de Interpretacion, tan pronto sensienda el modo Interpretacion.

15
00:03:48.500 --> 00:04:02.800
Haga click en los trespass puntitos que dice mas en la parte trabajo de la pantalla, luego selecciones Interpretacion de idiomas, escoja el idioma de su preferencia, y no elvideo presionar listo para activarlo. Gracias, you may now begin.

16
00:04:03.900 --> 00:04:05.100
All right.

17
00:04:05.280 --> 00:04:09.350
We are gonna turn on the interpretation.

18

00:04:10.320 --> 00:04:15.800
And welcome again. Now we could officially begin our webinar.

19
00:04:16.040 --> 00:04:20.650
Today, we're gonna be talking about holding it all together.

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00:04:20.810 --> 00:04:25.079
Family life, Resilience, and Connection.

21
00:04:25.390 --> 00:04:45.689
We're gonna have our presenter, Megan Cody. She is a family and network engagement specialist with the National Center for Deaf and Blindness. She has over 30 years of experience providing support and technical assistance to our Deafblind community.

22
00:04:45.820 --> 00:04:50.200
We also have Alexis Ramirez.

23
00:04:50.850 --> 00:05:14.690
She is our family liaison from California, and she has a beautiful family of two girls and a boy, and that boy, very awesome boy that you're gonna learn about soon, has CHARGE, and is the one that introduced her to our community. And then last but not least, we have our wonderful Sharon Foster.

24
00:05:14.690 --> 00:05:34.890
She is the family liaison for Massachusetts, and she also has a beautiful family with two daughters. They're twin daughters, and one of them, has CHARGE. So, they're gonna be joining us today and sharing their stories. The presentation is gonna last around one hour.

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00:05:35.150 --> 00:05:49.530
And the last 30 minutes, we're gonna leave it open, so you could ask any questions, or share any encouragement, or have just an interactive, session with everybody. So, without further ado…

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00:05:49.830 --> 00:05:53.650
I'll give you Megan, and I'm gonna share this screen.

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00:05:57.700 --> 00:06:16.510
So, hi everybody. I'm really happy to be here with you guys tonight. As Lourdes mentioned, joining me are two mothers, Sharon Foster and Alexis Ramirez, both parents of children with CHARGE Syndrome, who've bravely committed to sharing their stories with you this evening.

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00:06:16.510 --> 00:06:29.769
For parents of children with complex healthcare needs, raising your child comes with increased demands. Families are often thrust into a world of medical appointments, therapies.

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00:06:29.850 --> 00:06:37.290
You name it, and services while simultaneously learning how best to meet their child's unique developmental needs.

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00:06:37.600 --> 00:06:49.630
And amid these responsibilities, caregivers may have little time to pause, reflect, and process the stress and the emotional impact that can accompany this journey.

31
00:06:50.010 --> 00:06:56.610
Which makes holding it all together on some days more challenging than others. Next slide, please.

32
00:07:02.110 --> 00:07:09.759
So, our session will explore what research tells us about stress, resilience, and our ability to cope.

33
00:07:10.210 --> 00:07:20.369
Factors that can increase stress and affect our capacity to manage challenges, and the importance of recognizing personal needs.

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00:07:20.920 --> 00:07:25.969
As part of sustaining long-term caregiving and family well-being.

35
00:07:26.100 --> 00:07:38.219
At the end of the session, we hope that each of you will feel validated for the real truth that is the journey of resilience and growth. So let me dive into what research tells us. Next slide, please.

36
00:07:39.600 --> 00:07:55.409
Research from Jackson tells us that the relationships between parents and their children may be the most intense life can generate. And when a family has a child with complex needs, the impact can be even greater.

37
00:07:55.410 --> 00:08:01.419
Why is this? Because oftentimes, there's no time to process the shock and grief.

38
00:08:01.520 --> 00:08:03.120
Next slide, please.

39
00:08:04.660 --> 00:08:15.209
And theoretical models of family stress and their ability to adapt stems from a few things. The type of stressor or the event.

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00:08:15.500 --> 00:08:30.100
The support systems around the family, the family's perspective of the impact of that stressor, and prior crises, and how those situations manifested and were internalized.

41
00:08:30.340 --> 00:08:31.760
Next slide.

42
00:08:32.809 --> 00:08:45.340
Research also tells us that when families have the resources they need, they're better able to adapt to adversity by coping with the stress. Thus, no more fight or flight.

43
00:08:45.720 --> 00:08:46.980
Next slide.

44
00:08:50.560 --> 00:09:02.269
And parents whose children have any type of disability or illness report higher levels of emotional and physical stress than parents of children who are healthy.

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00:09:02.270 --> 00:09:11.009
So this begs the question, how many of our families of kids with complex healthcare needs are functioning in a state of chronic stress?

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00:09:11.350 --> 00:09:12.750
Next slide.

47
00:09:13.360 --> 00:09:25.559
So this is a visual that I wanted to share with you all that represents how stress can compound over time if not dealt with, because our nervous system doesn't go back to a normal state.

48
00:09:25.560 --> 00:09:49.250
So, you'll see that the line on the bottom says nervous system activation over time, and then you'll see activations, or times where it spikes up, and then comes back down, and the goal is to reset our nervous system all the way to the bottom. But if we don't have time to process, then with each competing activity or crisis.

49
00:09:49.250 --> 00:09:57.169
Your… your panic and trauma keeps going, and so then you inevitably end up in a state of chronic stress.

50
00:09:57.630 --> 00:09:59.170
Next slide.

51
00:09:59.870 --> 00:10:09.309
So this leads to what Dunst found in their research, that family support ideally benefits all members of the family.

52
00:10:09.310 --> 00:10:25.379
Builds on existing social networks, enhances coping in response to adverse situations, and maximizes the family's control over services, since the families should be considered the expert regarding their child.

53
00:10:25.530 --> 00:10:30.009
So families need to be informed and supported with choice.

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00:10:30.130 --> 00:10:31.490
Next slide.

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00:10:34.280 --> 00:10:53.739
Families are called on to be experts in the systems they need to rely on to support their child, and each system is complex with its own language, professionals, and rules for engagement. This is a lot for families to navigate, in addition to the other demands in life.

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00:10:56.280 --> 00:11:07.580
Next slide, thank you. So, a researcher named Eileen Forlenza created a model for family leadership development centered around self-determination.

57
00:11:07.580 --> 00:11:26.609
It starts with the family at the center, which is represented in this white triangle in the center of the slides. And then, it's surrounded by family support at the individual level in blue, family engagement at the community level in green.

58
00:11:26.610 --> 00:11:33.530
And then finally, family leadership at the state and national level, represented with the blue circle.

59
00:11:34.160 --> 00:11:35.590
Next slide.

60
00:11:38.320 --> 00:11:46.299
And around each family are the systems, which are represented on this slide, as school, medical.

61
00:11:46.320 --> 00:12:02.579
financial, legal, and social networks, and these are constantly spiraling around the family as the child and the caregivers age and switch systems and spots for support. Next slide.

62
00:12:04.870 --> 00:12:25.749
And those systems evolve and change over time as the child ages, as well as the caregivers or parents, and as they evolve, there are highs and lows as families move through the systems.

There's relearning, there's new providers, there's new languages and systems, and it goes on and on.

63
00:12:25.910 --> 00:12:27.250
Next slide.

64
00:12:28.840 --> 00:12:35.680
So, this is why connection is so important. As families of loved ones with CHARGE are navigating a lot.

65
00:12:36.010 --> 00:12:40.759
Also, as teachers of individuals with CHARGE, you're navigating a lot.

66
00:12:40.960 --> 00:12:47.959
A quote from Brene Brown reads, Our most basic need in life is for relationships and connection.

67
00:12:48.080 --> 00:13:04.100
Connection with your child, connection with immediate family members, connection with extended family, connection with providers, your community, and most importantly, other parents and families. Next slide.

68
00:13:05.980 --> 00:13:21.419
So now that I've shared about the research and complexities, let me dive into self-care, what it is, and why it's important. And I know it sounds decadent, and you may not feel you've got time for it, but here's what I'm wanting to say.

69
00:13:21.540 --> 00:13:36.009
The self-care doesn't have to be a week away or a day at a spa, although that would be amazing, right? I would love to do that. But it really, truly is just taking time to do little things here and there when you can.

70
00:13:36.220 --> 00:13:39.699
A full breath, grounding your feet on the earth.

71

00:13:39.880 --> 00:13:44.419
Soaking up vitamin D outside, or even a cup of tea.

72
00:13:44.560 --> 00:13:56.510
Those little moments are acts of self-compassion that allow us to fuel our… or propel ourselves forward and regulate our nervous system. Next slide.

73
00:13:58.710 --> 00:14:03.060
Showing your self-compassion is part of post-traumatic growth.

74
00:14:03.220 --> 00:14:09.670
Which helps you move and be more resilient during challenging times, because they're part of life.

75
00:14:09.790 --> 00:14:18.230
And offers a chance for self-reflection. Without it, you're in danger of living in a state of chronic stress.

76
00:14:19.100 --> 00:14:32.870
So, as we move forward through tonight, my challenge to you, as parents and caregivers, who join this webinar, is to take time to acknowledge your areas of grief and trauma.

77
00:14:32.960 --> 00:14:43.209
Become aware of your own needs and triggers, and work on establishing healthy boundaries, because we have to help ourselves before we can help others.

78
00:14:43.590 --> 00:14:44.900
Next slide.

79
00:14:46.320 --> 00:15:00.190
Defining what responsibilities you have to others, and what responsibility we need for ourselves is key, and remembering to take time for both is important to endure the long haul.

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00:15:00.440 --> 00:15:01.800
Next slide.

81
00:15:03.940 --> 00:15:05.619
So, why is this?

82
00:15:05.920 --> 00:15:17.709
Because if you don't have healthy boundaries, you're at risk of burnout, compassion fatigue, secondary trauma, and even a trauma exposure response.

83
00:15:19.510 --> 00:15:24.979
Slide… Keep going, Florida's.

84
00:15:28.010 --> 00:15:35.239
Yeah, and one more. Yeah, there you go. Oop, back up.

85
00:15:35.560 --> 00:15:36.270
Fair?

86
00:15:36.450 --> 00:15:37.300
Yes.

87
00:15:37.650 --> 00:15:56.210
There was a study by Ben and colleagues showed that over a 5-week mindfulness training for parents and teachers of children with special needs, there was a significant reduction in stress and anxiety when mindfulness practices were implemented. Next slide.

88
00:15:58.470 --> 00:16:10.989
So, before we listen to these two remarkable parents share their journeys of trauma resilience and growth, let me leave you with an informal, mindful practice called STOP.

89
00:16:10.990 --> 00:16:23.190
T-O-P-P. It's portable, it's free, and it's very, very easy to do, and I use it on the daily myself, so I highly recommend it.

90
00:16:23.590 --> 00:16:24.520

S,

91
00:16:24.630 --> 00:16:40.239
is stop. Stop, pause any activity or movement, even if for it's just a minute. Then T is take a deep breath. I personally recommend 3 big breaths in through the nose and out through the mouth.

92
00:16:40.580 --> 00:16:48.640
O is observe what your thoughts are going through your mind, and what sensations you are feeling.

93
00:16:49.020 --> 00:16:56.369
P stands for pullback and get perspective. Are you safe? What's happening around you?

94
00:16:56.580 --> 00:17:06.360
And the final P is practice what works and proceed. In other words, what's the best thing to do right now to help you self-regulate?

95
00:17:06.720 --> 00:17:08.010
Next slide.

96
00:17:09.869 --> 00:17:26.019
So, let me say this, your calm is your most powerful intervention, because if you're in tune with yourself, you can be in tune with your child. And if you're in tune with your child, you're supporting brain development in a really real way.

97
00:17:26.069 --> 00:17:32.280
You're teaching self-regulation and decreasing family anxiety and fear.

98
00:17:32.610 --> 00:17:33.950
Next slide.

99
00:17:35.280 --> 00:17:42.170
So, as you all listen to Sharon and Alexis share, I invite you to reflect on the following.

100

00:17:42.280 --> 00:17:55.420
What resonates with you, and what resonates with you and your experiences? Excuse me. Where could individuals have shown up differently for them across their journey?

101
00:17:55.680 --> 00:18:01.080
When do you notice turning points in processing, acceptance, and joy?

102
00:18:01.240 --> 00:18:19.530
And are there actions you plan to take as a result of hearing about the research and hearing about them share? So, now I'm going to pass it over to Alexis to share her journey with her son, Tian. Alexis, the floor is yours.

103
00:18:21.900 --> 00:18:27.560
Hello, my name is Alexis Ramirez. I have 3 kids, like Lourdes mentioned.

104
00:18:27.670 --> 00:18:29.330
My…

105
00:18:29.520 --> 00:18:37.610
I have 2 girls and one boy. My son, Taein, is going to be 6 in February, and he has CHARGE Syndrome.

106
00:18:37.880 --> 00:18:48.280
Bear with me if my voice gets a little shaky. We've had a pretty hard couple weeks, so sharing our story has been a little…

107
00:18:48.640 --> 00:18:52.820
more difficult as of late. But…

108
00:18:54.650 --> 00:19:02.709
In June of 2020, when my oldest daughter was 8 months old, I found out I was pregnant with my second baby.

109
00:19:04.510 --> 00:19:09.609
We had known we'd wanted our kids close in age, and this felt like a dream come true.

110
00:19:10.840 --> 00:19:20.450
A few months after finding out, my husband and I got married, and I found out that we were having a boy. That summer was the happiest I have ever felt in my life.

111
00:19:21.750 --> 00:19:26.750
We went into our anatomy scan, excited to see his tiny toes and fingers.

112
00:19:29.190 --> 00:19:32.930
But as the scan progressed, I knew something was wrong.

113
00:19:33.490 --> 00:19:41.360
There ended up being a few unusual findings that indicated that our son may have an esophageal fistula.

114
00:19:41.500 --> 00:19:44.490
And something might be wrong genetically.

115
00:19:45.280 --> 00:19:51.599
We were filled with fear of the unknown, so we did all the testing they offered, and everything came back fine.

116
00:19:52.520 --> 00:19:53.509
It was…

117
00:19:54.870 --> 00:20:03.099
It was a rollercoaster, but after discussing things with a pediatric surgeon, we had a plan for after he was born.

118
00:20:03.560 --> 00:20:07.030
We were scared, but we were all… we also had so much hope.

119
00:20:08.050 --> 00:20:11.760
In February of 2021, our son, Tan, was born.

120
00:20:13.030 --> 00:20:16.279
And within a few hours, we knew something was very wrong.

121
00:20:16.890 --> 00:20:25.839
He was taken to the NICU, where he would soon undergo multiple surgeries and receive so many diagnoses, it felt like our heads might spin.

122
00:20:25.960 --> 00:20:28.030
The main one being CHARGE Syndrome.

123
00:20:28.510 --> 00:20:36.079
After 6 weeks, he came home with a G-tube and a laundry list of medications and a whole lot of specialists I never knew existed.

124
00:20:37.150 --> 00:20:41.770
He wouldn't be home long before needing to go back inpatient and receive a trach.

125
00:20:42.070 --> 00:20:44.530
Something we thought would be temporary.

126
00:20:46.510 --> 00:20:56.600
Little did we know that we would come home at 6 months old on… with him on a ventilator 24-7, and needing round-the-clock care for the next several years.

127
00:20:56.970 --> 00:21:03.440
All while in the height of a global pandemic and a nursing shortage that would make it near impossible to get help.

128
00:21:05.440 --> 00:21:08.450
To say that I was overwhelmed is an understatement.

129
00:21:10.620 --> 00:21:18.479

Suddenly, I was thrust into a world of medical complexities with this tiny human who depended on me in a way…

130
00:21:19.400 --> 00:21:30.929
Sorry, he's yelling in the background. On a way… in a way my first baby never did. I experienced trauma alongside my child that no parent ever wants to imagine.

131
00:21:31.160 --> 00:21:39.090
I had to learn medical terminology and get a crash course to become a nurse, RT, PT, OT, and more for Tayin.

132
00:21:39.710 --> 00:21:48.250
Our reality was filled with appointments, therapies, testing, potential hospitalizations, and managing his day-to-day medical needs.

133
00:21:49.530 --> 00:22:09.500
When you're pregnant, you imagine all the things you'll get to do once you bring your baby home. Going on walks, taking them to playgroups, story times, music classes? Sure, you'll have to adjust and learn how to do things with a baby. How many diapers do you bring? Will they need a bottle while you're out? Motherhood, after all, is a huge learning curve. Next slide, please.

134
00:22:11.780 --> 00:22:26.159
When you're a medical mom and your son is on a ventilator 24-7, suddenly leaving the house for any reason becomes a logistics nightmare. Going on a walk? Sure. But it requires you to load a mini ICU into your stroller.

135
00:22:26.910 --> 00:22:28.380
That music class.

136
00:22:28.650 --> 00:22:32.380
Too risky with an immune-compromised infant.

137
00:22:32.750 --> 00:22:37.699
At some point, you have to, though, right? You have appointments to get to, but don't forget.

138
00:22:37.910 --> 00:22:46.920
You can't drive with them alone in the car because the doctors told you not to. So you always have to rely on a nurse who you just met and are learning to trust.

139
00:22:48.720 --> 00:22:52.409
The reality is… I was scared of everything.

140
00:22:52.560 --> 00:23:02.410
how to manage all the equipment, of having to trust someone else with his life, of strangers staring, of all the questions they would ask, how I'd respond.

141
00:23:02.780 --> 00:23:12.530
I would have a million thoughts running through my mind every time we left the house. Did I forget anything? What if I have to suction him in the waiting room and everyone is staring at us?

142
00:23:12.890 --> 00:23:15.979
What if… what if he has an emergency and I freeze?

143
00:23:16.550 --> 00:23:21.869
What if I forget to ask the doctor XYZ? What if, what if, what if?

144
00:23:22.760 --> 00:23:27.870
I was basically… basically walking around, having a panic attack on the inside.

145
00:23:28.030 --> 00:23:30.209
But outside, I kept it together.

146
00:23:30.590 --> 00:23:37.429
Not because I wanted to, but I had to. Who else was going to take care of this baby if not us?

147
00:23:37.770 --> 00:23:42.399
I didn't feel normal. I felt… Isolated and alone.

148

00:23:43.520 --> 00:23:46.089
Like, no one understood what I was going through.

149
00:23:46.830 --> 00:23:50.420
I could feel people's eyes on me every time we left the house.

150
00:23:50.900 --> 00:24:03.859
And I was so anxious about their reactions, or even the idea of having to interact with them. I was a brand new mom, and I didn't know a lot about disability at the time, or how to respond to people, even when they meant well.

151
00:24:04.860 --> 00:24:06.479
We got a lot of pity.

152
00:24:06.820 --> 00:24:08.930
Of, oh no, we're theme.

153
00:24:09.570 --> 00:24:11.290
Of, you're so strong.

154
00:24:11.530 --> 00:24:12.990
I don't know how you do it.

155
00:24:13.170 --> 00:24:15.580
I can't even imagine.

156
00:24:15.920 --> 00:24:17.990
It gets easier with time.

157
00:24:18.620 --> 00:24:25.120
Platitude after platitude that often left me speechless and feeling even more isolated than before.

158
00:24:25.770 --> 00:24:37.669

Sure, on the outside, I was composed. I asked all the right questions. I replied with a smile and a thank you. Coordinated every appointment and piece of equipment needed to keep my son alive.

159
00:24:39.380 --> 00:24:47.730
On the inside, I felt like a ticking time bomb. That perpetual feeling of anxiety and overwhelm taunting me at every corner.

160
00:24:47.840 --> 00:24:53.770
And I constantly second-guessed every decision I made for Tayin, and wondered if I was even doing enough.

161
00:24:55.940 --> 00:25:03.610
I remember the first time another medical mom said to me, it gets easier, just wait. And thinking, when?

162
00:25:04.880 --> 00:25:16.379
Because it felt like, at every single turn, we were hit with another curveball, another surgery, another setback, and it felt so hopeless, because there was always a new hard, and I hated it.

163
00:25:16.550 --> 00:25:22.689
I hated the platitudes. Eventually, they didn't just make me feel more alone, they made me angry.

164
00:25:22.880 --> 00:25:34.049
I knew people meant well, but it also felt like there was a lack of empathy, and I just wanted someone to notice and acknowledge how hard it was, and give me the space to not be okay.

165
00:25:34.470 --> 00:25:37.089
The weight of what I carried felt like too much.

166
00:25:39.120 --> 00:25:43.250
People often told us, The first year is the hardest.

167
00:25:43.580 --> 00:25:53.889

And that was true in so many ways, but in some ways, it gave me a false sense of hope that I use as a mantra throughout that first year.

168
00:25:54.100 --> 00:25:59.699
All I had to do was get to one year, and suddenly everything would be better.

169
00:26:00.360 --> 00:26:07.420
I remember getting… Titan's first birthday, and feeling a little bit of the weightlifting.

170
00:26:07.660 --> 00:26:10.050
A sense of, we made it.

171
00:26:11.320 --> 00:26:17.210
But I also remember feeling… having this moment of thinking, What just happened?

172
00:26:17.420 --> 00:26:27.750
it felt like… it felt like I spent so much time in fight or flight, and just putting one foot in front of the other, trying to deal with the trauma and the anxiety.

173
00:26:28.290 --> 00:26:35.630
on my own that I eventually just sort of blocked out so much of his first year and couldn't remember bits and pieces.

174
00:26:36.320 --> 00:26:37.660
Next slide, please.

175
00:26:39.700 --> 00:26:41.419
The hardest part…

176
00:26:41.530 --> 00:26:48.799
was that goal of, oh, just get to the first year, it gets better, kept moving. It became…

177
00:26:49.240 --> 00:26:58.540

oh, well, once we get to 3 and do his IEP, then it's easier. Or, if you just get to 5, the mortality rate drops.

178
00:26:58.850 --> 00:27:07.599
And you'll be able to breathe again. Or once he has this surgery, life will be normal. The heart just kept changing.

179
00:27:08.340 --> 00:27:09.810
It never goes away.

180
00:27:10.700 --> 00:27:14.350
It's just a new hard, even in those hard moments.

181
00:27:14.960 --> 00:27:20.250
I would ha- I would be still… I would still be filled with so much gratitude.

182
00:27:20.640 --> 00:27:24.759
Because he… he was here. And we had so many moments.

183
00:27:25.090 --> 00:27:27.710
Where we didn't think we would get that time.

184
00:27:30.780 --> 00:27:32.659
He brought so much joy.

185
00:27:40.250 --> 00:27:46.530
And even with everything, He experienced daily, he was still such a happy baby.

186
00:27:46.920 --> 00:27:49.469
He taught me what true resilience was.

187
00:27:54.840 --> 00:27:56.720
He's smart, and funny.

188
00:27:57.480 --> 00:27:58.680
Sassy.

189
00:28:08.900 --> 00:28:10.160
determined.

190
00:28:10.340 --> 00:28:11.850
I'd love to be.

191
00:28:12.540 --> 00:28:15.770
Sorry, loves to be at the center of attention.

192
00:28:17.800 --> 00:28:23.969
He wasn't suffering like so many people assumed he was. He didn't know anything but this life.

193
00:28:24.160 --> 00:28:26.220
And he lived it to his fullest.

194
00:28:28.030 --> 00:28:32.220
I think that's one of the reasons I hated pity from others so much.

195
00:28:33.040 --> 00:28:38.720
Not many people understand The dichotomy of grief and joy coexisting.

196
00:28:42.590 --> 00:28:52.569
And it's really hard for them to wrap their head around that disability does not automatically equate to suffering. Every time I had someone say to me.

197
00:28:52.700 --> 00:28:57.030
I'm so sorry, or… poor baby. I started asking why.

198
00:28:57.250 --> 00:28:58.460
Or saying.

199
00:28:58.860 --> 00:29:05.430
Oh, no. Don't feel bad. There really is no need. He's the happiest baby, and he's living his best life.

200
00:29:05.650 --> 00:29:15.779
I remember looking back at videos pre-Trach, and seeing how much he struggled to breathe, how off his color was, and how tired he constantly was.

201
00:29:16.700 --> 00:29:22.210
Post-trach, he had energy, and was hitting milestones faster than we thought possible.

202
00:29:23.020 --> 00:29:32.249
So when people hear about his trach and get sad for him, it would make me roll my eyes, because that tiny piece of plastic that seems so scary.

203
00:29:32.540 --> 00:29:36.969
Gave him quality of life, and showed everyone just how capable he is.

204
00:29:39.190 --> 00:29:51.300
So we just kept living our life, experiencing the grief of what we had imagined life to be, mixed with the reality of how hard things were, and loving every moment of joy in between.

205
00:29:51.650 --> 00:30:00.279
One day, I can't even tell you when, maybe sometime after Taein turned 3, I had a realization that I felt like I could really breathe again.

206
00:30:00.440 --> 00:30:08.690
And it wasn't because suddenly things were less hard. It was because through everything that had happened, I had become a different person.

207
00:30:09.290 --> 00:30:11.420
I learned so much about myself.

208

00:30:11.680 --> 00:30:25.459
About finding joy in the mundane moments of advocating, setting boundaries, about building relationships and communities, about asking for support, and about how to show up and support others along the way. I didn't do it alone.

209
00:30:26.170 --> 00:30:28.330
And that's what I want to focus on here.

210
00:30:28.490 --> 00:30:39.750
at some point, I had a realization that there hadn't be other parents with young kids in this community who felt the same as me, and I wanted to find a way to connect with them outside of social media.

211
00:30:39.860 --> 00:30:46.140
Two things happened around the same time that really changed me and had a profound impact on my life.

212
00:30:46.830 --> 00:30:53.339
Right after Tay In Turn 1, I decided to become a family liaison, as if life wasn't already chaotic enough.

213
00:30:53.560 --> 00:31:01.219
But I knew it would be a lifeline of sorts. I had briefly connected with a family liaison in my state when Tane was first diagnosed.

214
00:31:01.660 --> 00:31:16.370
And that conversation brought me so much peace and comfort. I knew I wanted to connect with other families, but I deeply wanted to support the ones who were newly diagnosed as they navigated the intensity of that and be the person I so desperately needed in that first year.

215
00:31:17.880 --> 00:31:32.040
Shortly after that, another new liaison and I helped Lourdes create a support group for new parents, a space where parents could share the good, the bad, the ugly, and not feel judged, to ask questions and be each other's sounding board.

216
00:31:32.400 --> 00:31:43.069

That they might not have otherwise. When I became a liaison, I didn't want to be… I didn't want to just be another person to give new families those same well-meaning platitudes.

217
00:31:43.220 --> 00:32:01.649
Instead, I wanted to show up and be authentic to say the hard thing out loud. I'll never say it gets easier, but I will say that you adapt. You get better at learning to carry it and cope in new ways, to not care about what those strangers think, to leave the house without all the what-ifs, to trust yourself.

218
00:32:02.010 --> 00:32:09.280
To gain new confidence, you'll grow and stretch as a person and as a family. I know that feels unfair, because it is.

219
00:32:09.630 --> 00:32:14.460
But we continue to show up and do hard things and feel it all because we have to.

220
00:32:15.010 --> 00:32:24.619
We weren't granted some unknown strength or ability to handle these things. We are just showing up for our child in the way they need us to, because if we don't.

221
00:32:24.970 --> 00:32:28.320
No one will, and our children deserve that from us.

222
00:32:29.440 --> 00:32:30.930
The second thing…

223
00:32:31.050 --> 00:32:40.829
was when another mom with a daughter close to Tayon's age posted in the CHARGE Facebook group about wanting to start a group chat of moms with kids around the same age.

224
00:32:41.000 --> 00:32:45.679
On a whim, I joined… with the hope that I could connect.

225
00:32:45.940 --> 00:32:47.909
With other moms who just got it.

226
00:32:48.850 --> 00:33:04.050
I had no idea how life-changing that group would be, how those women would impact my life, become the family I needed, and the support system I was missing. The bond you share with people who have walked a similar path to you is unlike anything else.

227
00:33:04.640 --> 00:33:17.680
I didn't have to explain my son to these women. They already knew what it was like to go through the trauma of diagnosis, of living in the NICU, of being afraid of the future, of dealing with each and every curveball.

228
00:33:18.130 --> 00:33:24.210
We shared in each other's pain. We celebrated the wins, no matter how big or small they were.

229
00:33:24.730 --> 00:33:30.239
We've had in-person meetups, mostly at conference, but we try and meet up whenever we can.

230
00:33:31.300 --> 00:33:32.870
So many times.

231
00:33:33.030 --> 00:33:39.650
when I felt like I had no support from those in my daily life, I knew these women would be there without judgment.

232
00:33:40.020 --> 00:33:41.840
We've all heard the saying.

233
00:33:44.900 --> 00:34:03.889
It takes a village to raise a child. Your village doesn't have to be just filled with the people related to you, or even those who live near you. Not all of us have family we can lean on, and oftentimes, when you're going through the most traumatic moments of your life, is also the moment you look around and you realize who was there holding you up.

234
00:34:05.500 --> 00:34:07.930
My Village was created in a group chat.

235
00:34:08.670 --> 00:34:10.520
We worked hard to build it.

236
00:34:11.730 --> 00:34:13.690
And I'm grateful for each of them.

237
00:34:14.810 --> 00:34:16.999
I talk to them pretty much every day.

238
00:34:17.239 --> 00:34:20.650
They're who I've texted about TAN being in the PICU this month.

239
00:34:20.820 --> 00:34:23.700
Invented to… vented my frustrations.

240
00:34:24.000 --> 00:34:28.639
They're who I go to bounce ideas off for IEPs. They're who I mourn with.

241
00:34:29.130 --> 00:34:31.750
Who I will show up for time and time again.

242
00:34:32.550 --> 00:34:37.219
some of the most important things I have learned from this found family.

243
00:34:37.420 --> 00:34:39.949
is that I don't have to always be strong.

244
00:34:40.239 --> 00:34:46.259
Someone else has probably felt or is feeling the same thing as I am, and I don't have to carry it alone.

245
00:34:48.739 --> 00:35:03.909

Finding community, connecting and building those relationships with other moms hasn't just helped me process. It has made me a better person, a better mom, and taught me how to advocate, and how to show up for not only Tian, but for myself.

246
00:35:04.240 --> 00:35:08.830
We talk a lot about self-care, and I know sometimes that can feel impossible.

247
00:35:09.130 --> 00:35:11.510
When you have a medically complex child.

248
00:35:11.780 --> 00:35:14.690
There's so much value in carving out time.

249
00:35:14.800 --> 00:35:25.499
For self-care, however that looks for you. Maybe it's therapy, taking 20 minutes nightly to do your skincare, meditation, getting outside, moving your body, etc.

250
00:35:26.010 --> 00:35:42.079
I also encourage you to be a part of community care, and lean into those connections, and build your village. Because feeling less alone, supported, heard, and seen, that will have an… that will have a profound impact on your life.

251
00:35:42.230 --> 00:35:43.220
Thank you.

252
00:35:43.610 --> 00:35:46.690
Now I'm gonna pass it over to Sharon to share her story.

253
00:35:49.970 --> 00:35:56.639
Thank you, Alexis, and thank you for sharing your story, and the pictures of Tayum are adorable.

254
00:35:58.780 --> 00:36:00.070
Okay.

255

00:36:01.160 --> 00:36:14.289
So, when I was asked to do this, it was hard to decide where I would start my story. But I think it starts with the overwhelming feeling of being isolated and alone after receiving Molly's CHARGE diagnosis.

256
00:36:14.870 --> 00:36:20.470
It's a feeling I imagine many of you on this call can relate to.

257
00:36:21.210 --> 00:36:29.920
After years of struggling with infertility, my husband Bob and I were thrilled… excuse me, sorry, to learn that we were pregnant.

258
00:36:30.530 --> 00:36:34.489
And when we found out we were expecting twin girls, we were overjoyed.

259
00:36:34.740 --> 00:36:40.219
I immediately started shopping, planning their nurseries. One room would be pink, the other purple.

260
00:36:40.370 --> 00:36:47.150
And imagining what life with two little girls would look like. We were finally going to have the family we had dreamed of for so long.

261
00:36:48.130 --> 00:36:56.500
But our excitement quickly turned to fear during a re-chain ultrasound when we learned that Twin A, who we would later name Molly, had an emphalicil.

262
00:36:57.600 --> 00:37:06.429
Many of you on this call may know what that is, but for anyone who doesn't, it meant that some of her intestines had developed outside her abdomen.

263
00:37:07.380 --> 00:37:13.969
Of course, I did what so many of us do when faced with something we don't understand. I went straight to Google.

264

00:37:14.450 --> 00:37:21.539
And I quickly learned that Googling medical conditions, especially when you're pregnant and scared, is not a good idea.

265
00:37:22.360 --> 00:37:26.279
We were heartbroken and terrified of what this might mean for our daughter.

266
00:37:26.900 --> 00:37:34.309
Eventually, we met with a pediatric surgeon who assured us that Molly's omphalocele was small and could be repaired.

267
00:37:34.910 --> 00:37:41.180
He told us that before we knew it, she would be running around a soccer field like any other girl.

268
00:37:41.580 --> 00:37:44.700
And it turns out, he was right about her playing soccer.

269
00:37:45.520 --> 00:37:47.989
But not everyone offered that same hope.

270
00:37:48.910 --> 00:37:56.569
We met with a geneticist who told us that Molly likely had some type of genetic condition, although she couldn't tell us what it was.

271
00:37:57.170 --> 00:38:02.970
And despite not having a diagnosis, she presented us the option of terminating the pregnancy.

272
00:38:03.910 --> 00:38:06.970
I remember how painful that conversation was.

273
00:38:07.090 --> 00:38:16.900
We were already frightened about what the future might hold, and instead of reassurance or support, we were left with the feeling that our baby's life was somehow less worthy.

274

00:38:18.170 --> 00:38:25.240
We tried our best to enjoy the rest of the pregnancy, but fear and uncertainty were always there in the back of our minds.

275
00:38:25.680 --> 00:38:28.349
But we continued to prepare for our girls.

276
00:38:28.530 --> 00:38:38.950
We bought all the pink clothes, celebrated with family and friends at our baby shower, and planted two pink hydrangeas in our garden that summer, one for each of the girls.

277
00:38:39.450 --> 00:38:40.880
We were scared.

278
00:38:41.290 --> 00:38:43.149
But we were also hopeful.

279
00:38:43.470 --> 00:38:49.400
On September 28th, 2011, our beautiful girls, Caitlin and Molly, were born.

280
00:38:49.950 --> 00:38:54.330
And from that moment on, life became something we never could have imagined.

281
00:38:54.880 --> 00:39:02.699
Molly was immediately rushed to the NICU, while Caitlin was taken to the special care nursery because of her small size.

282
00:39:03.680 --> 00:39:06.980
Caitlin would spend several weeks there before coming home.

283
00:39:07.280 --> 00:39:15.660
And Molly would spend several months in the NICU, followed by another 12 months in a pediatric facility before she would finally come home to us.

284

00:39:16.670 --> 00:39:18.930
Those first few days were a blur.

285
00:39:19.470 --> 00:39:27.440
Bob spent his time running between 3 different floors of the hospital, trying to keep up with the medical needs of all 3 of us, and getting very little sleep.

286
00:39:28.610 --> 00:39:33.580
When Caitlin and I were discharged, we were grateful, but life didn't get any easier.

287
00:39:33.700 --> 00:39:41.210
I was recovering from a C-section with significant blood loss, while also trying to navigate how to be a first-time mom.

288
00:39:42.010 --> 00:39:45.859
Meanwhile, Bob spent most of his days at the hospital with Molly.

289
00:39:47.590 --> 00:39:51.850
Once I was strong enough, Caitlin and I would make the trip to the NICU together.

290
00:39:52.090 --> 00:39:59.929
Our day's result revolved around hospital visits, doctors, medical updates, and trying to make sense of everything happening around us.

291
00:40:00.710 --> 00:40:11.839
We were suddenly learning a whole new language. Columbomas, coanial atresia, TEF, tracheostomy, words I had never heard before were now part of our everyday conversations.

292
00:40:12.860 --> 00:40:16.350
And with each new medical finding came more questions.

293
00:40:16.570 --> 00:40:19.399
More uncertainty and more fear.

294

00:40:20.340 --> 00:40:24.960
Several weeks after the girls were born, we finally learned that Molly had CHARGE Syndrome.

295
00:40:26.210 --> 00:40:37.370
You might think that having a diagnosis finally would have brought some relief, that we would have answers, a better understanding of what was happening, or at least some direction of what came next.

296
00:40:37.930 --> 00:40:39.969
But that wasn't our experience.

297
00:40:40.190 --> 00:40:47.799
Instead, we found ourselves sitting in a room with a team of doctors who seemed unable to come right out and tell us what Molly had been diagnosed with.

298
00:40:49.400 --> 00:40:54.810
I remember leaving that meeting feeling confused, overwhelmed, and upset.

299
00:40:55.130 --> 00:41:02.269
We had just been given life-changing information, yet somehow we walked away without really understanding what we had been told.

300
00:41:03.620 --> 00:41:11.599
As we approached the elevator while returning to Molly's room, a social worker we had never met before was standing there with her jacket on and purse in hand.

301
00:41:12.030 --> 00:41:14.579
Clearly ready to head home for the weekend.

302
00:41:15.480 --> 00:41:24.519
She asked if we were okay, but it felt more like a mandatory question than a genuine offer of support. And we never saw her again after this encounter.

303
00:41:25.800 --> 00:41:36.279

I remember feeling angry, angry about the diagnosis, how the diagnosis had been delivered, angry that no one seemed to recognize how frightened and overwhelmed we were.

304
00:41:36.480 --> 00:41:43.510
And angry that something so life-changing for our family seemed just like another Friday afternoon for everyone else.

305
00:41:44.760 --> 00:41:49.079
Looking back, I think that was one of the first times I felt how alone we were.

306
00:41:49.420 --> 00:41:57.099
We were new parents, trying to care for two premature babies, one of whom had incredibly complex medical needs.

307
00:41:57.670 --> 00:42:03.679
We were exhausted, frightened, and trying to process a diagnosis we didn't understand.

308
00:42:04.530 --> 00:42:10.239
Almost immediately following Molly's diagnosis, we were faced with a major medical decision.

309
00:42:10.830 --> 00:42:16.120
I remember feeling an enormous sense of urgency and pressure to make the decision right away.

310
00:42:16.480 --> 00:42:20.340
But we were still processing what we had just learned a few minutes earlier.

311
00:42:21.080 --> 00:42:29.190
In hindsight, I wish we had been given more time to ask questions, understand our options, and make decisions without feeling so overwhelmed.

312
00:42:30.240 --> 00:42:40.299
We later learned that the doctor asking us to make those decisions hadn't even known about the diagnosis meeting we had just attended minutes beforehand.

313
00:42:41.010 --> 00:42:44.160
And I think that says so much about those early days.

314
00:42:44.440 --> 00:42:49.530
We were surrounded by doctors, nurses, specialists, and social workers.

315
00:42:49.850 --> 00:42:53.630
There were people everywhere, all focused on Bali's medical needs.

316
00:42:53.980 --> 00:42:58.649
But somehow, in the middle of all those people, we still felt completely alone.

317
00:42:59.060 --> 00:43:01.180
No one focused on our deeds.

318
00:43:02.150 --> 00:43:08.600
During those early months, we turned to the geneticist who was working with Molly and had extensive experience with CHARGE Syndrome.

319
00:43:08.780 --> 00:43:15.759
We were looking for guidance, reassurance, and someone who could help us understand what the future might look like for our daughter.

320
00:43:17.040 --> 00:43:21.390
She encouraged us to attend a local presentation by another CHARGE expert.

321
00:43:22.250 --> 00:43:31.219
I remember feeling very reluctant to go. I wasn't ready to spend an entire day hearing about CHARGE Syndrome and all the challenges Molly might face.

322
00:43:32.010 --> 00:43:40.730
At that point, I was barely managing what was in front of me. I just wanted to focus on Molly, get her through each day, and eventually bring her home.

323
00:43:41.990 --> 00:43:55.799
But I felt pressure from the geneticist and some of Molly's nurses to attend. And as a new mom, already feeling so overwhelmed, I also felt guilty. Like, somehow, if I didn't go, I wasn't doing everything I could for Molly.

324
00:43:55.990 --> 00:43:57.800
That I was letting her down.

325
00:43:59.120 --> 00:44:02.939
So I agreed to go, and it was a decision I would later regret.

326
00:44:03.580 --> 00:44:13.070
I honestly can't tell you much about that presentation, because I only made it through about 15 minutes of what was supposed to be an all-day presentation.

327
00:44:13.260 --> 00:44:15.249
It was simply too much for me.

328
00:44:15.530 --> 00:44:18.660
I ended up sitting on the bathroom floor in tears.

329
00:44:19.180 --> 00:44:25.590
I remember feeling completely overwhelmed by everything I was hearing, and terrified about what our future would look like.

330
00:44:26.210 --> 00:44:31.479
At that moment, I decided to step away from the CHARGE community and focus solely on Molly.

331
00:44:32.750 --> 00:44:40.009
Back home, I kept wondering, what kind of life would Molly have? What would our life as a family look like, and how would it affect Caitlin?

332
00:44:40.760 --> 00:44:46.230

I was grieving the life I had imagined for our family, while also feeling guilty for having those thoughts.

333
00:44:47.260 --> 00:44:51.740
I remember repeatedly saying to Bob, we're never going to Disney World.

334
00:44:51.920 --> 00:45:00.389
It was, like, such a strange thing to focus on. I had only ever been there once before, and Bob and I had never talked about going.

335
00:45:01.380 --> 00:45:05.199
Looking back, I realized Disney wasn't really what I was talking about.

336
00:45:05.400 --> 00:45:09.599
It represented all those ordinary family experiences.

337
00:45:09.810 --> 00:45:12.179
I imagine we would share with our girls.

338
00:45:13.550 --> 00:45:19.390
Family vacations, holidays, adventures, and the simple joy of watching our daughters grow up together.

339
00:45:19.930 --> 00:45:23.820
I was afraid that those experiences were no longer possible for us.

340
00:45:25.230 --> 00:45:35.159
I debated whether to include this next part of my story because it's very personal, and even after all these years, it isn't easy to talk about. But I think it's important.

341
00:45:35.720 --> 00:45:41.340
I was struggling with depression and a sense of despair that I couldn't find my way out of on my own.

342

00:45:41.910 --> 00:45:46.100
Thankfully, Bob recognized that I wasn't in a good place, and that I needed help.

343
00:45:47.060 --> 00:45:52.620
With his support, I began seeing a therapist, and eventually found medication that helped me.

344
00:45:52.970 --> 00:45:56.120
Slowly, I started to feel like myself again.

345
00:45:57.640 --> 00:46:04.719
I began to find a way forward, to accept the life we were living, even though it looked very different from the one I had imagined.

346
00:46:05.240 --> 00:46:10.790
Acceptance isn't something that happens once and then stays with you forever. It comes and goes.

347
00:46:11.090 --> 00:46:15.850
There are times when I feel confident, hopeful, and grateful for the life we have.

348
00:46:16.180 --> 00:46:24.580
And there are other times, even 15 years later, when something happens that brings back those feelings of sadness, fear, or uncertainty.

349
00:46:25.700 --> 00:46:33.649
But I've learned that I don't have to navigate those feelings alone. I have people I can turn to, and I have tools that help me get through the harder days.

350
00:46:34.780 --> 00:46:39.970
I also learned something that I wish someone had told me when Molly was first diagnosed as… diagnosed.

351
00:46:40.830 --> 00:46:51.280

I didn't have to learn everything about CHARG Syndrome all at once, I didn't have to become an expert overnight, and I didn't have to be strong every minute of every day to be a good mom to Molly.

352
00:46:52.930 --> 00:47:01.670
After that difficult experience, I knew I needed to find a way to create some sense of normalcy for our girls, especially for Molly's sister, Caitlin.

353
00:47:02.690 --> 00:47:05.100
So I joined a local mom's playroom.

354
00:47:06.080 --> 00:47:14.530
I wanted Caitlin's days to be filled more with… more… filled with more than hospital visits and playing alongside her sister in a hospital bed.

355
00:47:15.180 --> 00:47:18.899
I wanted her to have the childhood I imagined for both of my girls.

356
00:47:19.620 --> 00:47:23.020
Throughout that playgroup, I met an incredible group of moms.

357
00:47:23.160 --> 00:47:27.460
And Caitlin made friends who, all these years later, are still some of her closest friends.

358
00:47:28.040 --> 00:47:36.339
We started having playdates, going to the park, celebrating birthdays, and doing all those ordinary things that families with young children do.

359
00:47:37.790 --> 00:47:46.289
And when Molly finally came home, we were do- we kept doing those things. Only now, Molly could be part of the fun, too. Something I had never imagined.

360
00:47:47.200 --> 00:47:54.879
What meant so much to me was that the friends welcomed Molly without hesitation. They accepted her as part of our group, just as they accepted the rest of us.

361
00:47:55.310 --> 00:48:08.619
And our adventures grew along with our girls. We took weekend trips to Storyland and Santa's Village, went hiking in the mountains, spent evenings around campfires, and enjoyed countless summer pool days by the pool.

362
00:48:10.240 --> 00:48:14.840
These were the very kinds of experience I had once been so afraid we would never have.

363
00:48:15.280 --> 00:48:20.640
I honestly don't know how I would have made it through those early days without this amazing group of friends.

364
00:48:21.510 --> 00:48:27.349
They gave us friendship, laughter, support, and a sense of normalcy when we needed it most.

365
00:48:27.680 --> 00:48:31.630
They were our lifeline, and I will always be grateful to them.

366
00:48:32.650 --> 00:48:36.980
But even with those wonderful friendships, there was still a part of me that felt alone.

367
00:48:37.300 --> 00:48:53.830
As much as my friends loved and accepted Molly, I couldn't fully understand what it was like to be her mom. The constant medical concerns, the appointments and surgeries, the uncertainty, and the emotional weight of raising a child with such complex needs.

368
00:48:54.270 --> 00:48:59.619
When the girls were about 11, I decided to contact the CHARGE Syndrome Foundation.

369
00:48:59.930 --> 00:49:06.650
I was hoping to connect with the Massachusetts Family Liaison, but unfortunately that position was vacant at the time.

370

00:49:07.970 --> 00:49:12.630
The woman I spoke with suggested I reach out to another CHARGE mom who lived nearby.

371
00:49:12.850 --> 00:49:17.549
She told me that she saw many similarities in our stories and thought we might connect.

372
00:49:18.370 --> 00:49:23.109
I was nervous about making that call, but a few days later, I finally picked up the phone.

373
00:49:23.270 --> 00:49:25.070
And I'm so glad I did.

374
00:49:25.200 --> 00:49:30.750
I don't remember exactly how long we talked, but I think it was probably close to 2 hours that day.

375
00:49:30.880 --> 00:49:37.369
Our stories were so similar. She understood things I had never really been able to explain to anyone else.

376
00:49:37.840 --> 00:49:42.329
It felt like talking to a long-lost friend, someone I had known for years.

377
00:49:42.870 --> 00:49:48.479
For the first time, I felt a connection with another mom who truly understood our family's journey.

378
00:49:49.420 --> 00:49:56.370
That decision to reach out to the CHARGE Syndrome Foundation turned out to be one of the best decisions I had ever made.

379
00:49:57.230 --> 00:50:11.079
Over the years, it has brought some incredible women into my life, women who have become dear friends. Through dinners, trips to Florida, heartfelt conversations, and plenty of laughter, we've built friendships that I know will last a lifetime.

380
00:50:12.240 --> 00:50:22.550
Eventually, I became the Massachusetts Family Liaison for the CHARGE Syndrome Foundation, which gave me the opportunity to connect with even more wonderful families, right here in my state.

381
00:50:24.130 --> 00:50:33.690
We've gotten together for pizza and bowling, organized drumming events, participated in walk and rolls, and connected through regular Zooms calls.

382
00:50:35.090 --> 00:50:42.970
And through all these experiences, I found something I hadn't even realized how desperately I needed in those early days. I found a community.

383
00:50:43.220 --> 00:50:46.059
A community where I didn't have to explain everything.

384
00:50:46.200 --> 00:50:53.630
Where other moms understood the worries, the challenges, and the complicated emotions that come with raising a child with CHARGE Syndrome.

385
00:50:54.550 --> 00:51:04.000
A community where we could celebrate the smallest victories, laugh about things that only another CHARGEM would understand, and support one another through the difficult days.

386
00:51:05.610 --> 00:51:09.480
And perhaps most importantly, a community where I no longer felt alone.

387
00:51:10.340 --> 00:51:16.699
When I was first asked to share my story and talk about resilience, my immediate thought was, I have no idea what to say.

388
00:51:16.980 --> 00:51:20.310
So, to start, I looked up the definition of resilience.

389
00:51:20.720 --> 00:51:25.069
I found several definitions, but they all shared a similar message.

390
00:51:25.660 --> 00:51:32.319
Resilience is the ability to adapt, recover, and keep moving forward when life becomes difficult.

391
00:51:34.050 --> 00:51:43.309
Our family's journaling certainly didn't begin the way I had imagined. Those early years were filled with fear, uncertainty, and sadness.

392
00:51:43.610 --> 00:51:48.889
And a tremendous sense… tremendous sense of isolation. But we kept moving forward.

393
00:51:49.390 --> 00:51:59.360
And while I will never pretend that the past 15 years have been easy, I am incredibly grateful for the life we've built, the experiences we've shared, and the community we've found along the way.

394
00:52:00.540 --> 00:52:10.089
And I'm happy to report that in 2023, after attending our family's first CHARGE Syndrome Conference in Orlando, Florida, we finally made that trip to Disney World.

395
00:52:10.470 --> 00:52:14.099
And it truly was the most magical vacation we've ever had.

396
00:52:15.140 --> 00:52:30.400
All those years earlier, I'd been so afraid of what our family would never be able to do. I couldn't imagine what our future would look like, and I was grieving experiences I thought we'd lost. And there we were, 12 years later, enjoying that very experience together.

397
00:52:31.740 --> 00:52:44.930
Our life hasn't been easy, and it certainly hasn't been what I imagined when I was decorating those pink and purple nurseries. But it has been filled with love, friendship, laughter, adventure, and so many moments of joy.

398
00:52:45.600 --> 00:52:53.940
If I could go back and say something to the frightened new mom sitting on the bathroom floor, I think I would tell her this. Your life is going to be different from what you had imagined.

399
00:52:54.540 --> 00:52:57.439
There will be challenges you never anticipated.

400
00:52:57.620 --> 00:53:07.459
But also, unexpected joy, love, laughter, and people who will change your life for the better. And most importantly, you won't have to face this journey alone.

401
00:53:08.560 --> 00:53:21.619
To the professionals on this call tonight, families receiving a diagnosis like CHARGE Syndrome need more than medical information. They need hope, compassion, patience, and clear communication.

402
00:53:21.880 --> 00:53:26.260
They need understanding as they process their grief, fear, and uncertainty.

403
00:53:26.680 --> 00:53:35.750
And they need you to meet them where they are. Connect them with resources and other families. Sometimes, one compassionate conversation can make all the difference.

404
00:53:36.650 --> 00:53:49.309
And to the many families on this call, give yourselves grace. You don't have to have all the answers or become an expert overnight. It's okay to feel overwhelmed, to grieve the life you imagined, and to have difficult days.

405
00:53:50.010 --> 00:53:55.379
And don't forget to celebrate your children's accomplishments, no matter how small they may seem to others.

406
00:53:56.090 --> 00:54:04.739
Don't be afraid to reach out for support, whether from family, friends, a therapist, another CHARGE parent, or your state liaison.

407
00:54:05.420 --> 00:54:14.280
Our journey began with fear and isolation, but along the way, we found friendship, community, and a life filled with experiences I thought were impossible.

408
00:54:14.630 --> 00:54:18.930
Resilience isn't about facing everything alone.

409
00:54:19.130 --> 00:54:24.859
Sometimes, true strength means reaching out, letting others in, and accepting their support.

410
00:54:25.370 --> 00:54:26.400
Thank you.

411
00:54:30.680 --> 00:54:47.659
Thank you so much, ladies. I think it was… it was such a pleasure to see, to hear your stories. Thank you so much for being so brave and, sharing… sharing today with us.

412
00:54:48.190 --> 00:55:05.509
I wanted to, just share some things that really, got me from your presentations. Alexis, you know, it's… it was so impactful for me to hear that the heart just adapts, just changes, because you hear that a lot.

413
00:55:05.510 --> 00:55:09.110
In our community, that, you know, it does get better, and

414
00:55:09.110 --> 00:55:13.620
And you want those expectations to be realistic. And…

415
00:55:13.800 --> 00:55:38.190
And sharing that, I think that was just amazing. And that grief and joy can coexist. I think that is an amazing, message to share today with our families. And, and Sharon, definitely your story was also, very touching, and realizing that you didn't need help, and how that.

416

00:55:38.360 --> 00:55:44.369
Making that decision helped you, because, like you said very clearly, you don't have to be strong all the time.

417
00:55:44.450 --> 00:56:00.610
And that is something that we want our families to hear today. You know, you need to take time for yourself, and you don't have to be this incredible, perfect, and strong person all the time, because we all have our moments.

418
00:56:00.890 --> 00:56:12.260
I thank you for sharing your story, for sharing what your experience has been also as a liaison, and for everyone joining us, I wanted to just

419
00:56:12.260 --> 00:56:37.189
Very briefly, before we move to questions and answers or the interaction, I just wanted to share very briefly, the term that you have heard several times today about a family liaison. If you don't know what a family liaison is, I'm just gonna tell you real quick, they are volunteers. They are parents like, Sharon and Alexis. They are siblings. They are grandparents.

420
00:56:37.190 --> 00:56:51.470
They even are individuals with CHARGE that would like to volunteer their time to support families in their state, to help families meet other families in their state that are closer

421
00:56:51.780 --> 00:57:11.140
And you could share information about resources, what works for you, what doesn't work for you, and just build that sense of community. So, we wanted you to know that that's one of our programs here in the foundation. You could go to our website and see who's available in your state.

422
00:57:11.170 --> 00:57:16.740
If we don't have a state, we could still connect you with local resources as well.

423
00:57:16.900 --> 00:57:27.309
And also, if your state is vacant and you would like to help us out, we could definitely do that. Let me…

424

00:57:27.920 --> 00:57:43.560
stop the sharing so you could see all of our faces, and see, take it over to Sharon, I mean, Megan, to see if you had any, any other thoughts that you wanted to share with the group.

425
00:57:44.270 --> 00:58:09.209
Hi everybody, it's Megan speaking, and I just want to thank and echo what Lourdes says to Alexis and to Sharon for being brave to spend time to think about your life and your trajectory and the resiliency that you've developed over time. It takes a lot of guts to do this, and I'm confident that what you've said has resonated with other

426
00:58:09.210 --> 00:58:12.380
Families that really needed to hear your words tonight.

427
00:58:12.380 --> 00:58:15.709
So, I'm incredibly grateful to you.

428
00:58:15.710 --> 00:58:25.630
I was wondering, Lourdes, are there any questions in the chat that folks have? We have a lot of wonderful comments,

429
00:58:25.820 --> 00:58:50.270
for all of our, both of our presenters, thanking them for their bravery and for sharing their story. We have Aubrey, a 28-year-old, person with CHARGE, said that Alexis is a wonderful mom, and thank her for sharing her story. We have Simone also sharing and thanking you for sharing your story.

430
00:58:50.450 --> 00:59:05.439
Julie said that Alexis has met and supported many families, and made such an impact in those families in these early years. What a generous gift she is. Thank you for your leadership, Alexis. And…

431
00:59:05.910 --> 00:59:24.170
Sharon, thank you for being so vulnerable and sharing your story. Acceptance isn't something that happens and stays with you forever, and it comes and goes. That… that was, impactful. So, a lot of great, messages here.

432

00:59:24.980 --> 00:59:34.700
Now, one comment that, Julie had, and maybe we could start, just talking about it and discussing it, she said, I'm sure it was difficult to look back

433
00:59:35.070 --> 00:59:40.620
And write, and then bravely share your story, raising your two beautiful daughters.

434
00:59:41.050 --> 00:59:53.960
I'm sharing. This was incredibly impactful to learn from your experience. The friendships and support you found with other CHARGE Moms doesn't surprise me. You're all such an force of nature.

435
00:59:53.960 --> 01:00:12.470
I'm so happy to hear, how strong the community you found. So, my question to both of our presenters was when… tonight, when you shared your story, what was the part that… that was the most difficult for you to… to… to relive or to process?

436
01:00:16.790 --> 01:00:23.559
I can say for me, it's… the hardest part for me is the time in the hospital during those first early days.

437
01:00:23.910 --> 01:00:26.589
I felt like we just had a…

438
01:00:27.620 --> 01:00:39.410
didn't get the support that we needed from the medical professionals, and I feel like it just made our, our… we started our journey in such a hard way that I wish if we had gone back and just started it with the right supports.

439
01:00:40.020 --> 01:00:50.130
I feel like it wouldn't have taken me 10 years to reach out to the CHARGE Foundation, and I would have found my community a little bit sooner.

440
01:00:50.790 --> 01:00:53.210
Yeah, yeah, true.

441
01:00:53.890 --> 01:00:57.819
I agree with Sharon. I think it was, for me.

442
01:00:59.480 --> 01:01:15.710
I chose not to really go into detail about, the early hospital days, with Taein specifically, because, I knew how triggering it would be, so I apologize if that felt very glossed over, but,

443
01:01:16.010 --> 01:01:28.630
And then, I actually wasn't expecting this to trigger me as much as it has the last couple of weeks. I talk about our story a lot, and our experience.

444
01:01:28.790 --> 01:01:46.279
In the birth, Birth to Five group. I've shared my experiences lots of times, so I really didn't expect this to hit me quite as hard as it hit me this time, but I… I don't think I've ever sat down and written anything, like, out like this.

445
01:01:46.460 --> 01:01:54.430
in a script kind of format, so that I stayed on point, instead of veering off into very… various topics.

446
01:01:54.760 --> 01:02:04.709
So I think in combination of that, and being able to see… talking about those moments, for me, of especially the…

447
01:02:05.380 --> 01:02:09.690
The well-meaning platitudes that people would say to us.

448
01:02:09.870 --> 01:02:17.289
And the extreme pity that we received when people would see Taein, and they would see his trach, and they would just…

449
01:02:17.550 --> 01:02:18.710
B…

450

01:02:19.180 --> 01:02:29.280
Oh my gosh, it's so… and I mean, I'm sure a lot of parents who have experienced something of this scale of people just

451
01:02:29.360 --> 01:02:45.580
having this overt reaction, and you're just standing there, like, it's just my child! So I think putting myself back in that early headspace of not knowing what to say, what to do, how to respond,

452
01:02:45.580 --> 01:02:55.929
or how to even process, because I hadn't processed at that point, was really challenging for me, because now I feel, even though he's only 5,

453
01:02:55.960 --> 01:02:57.630
I feel a lot…

454
01:02:58.400 --> 01:03:16.609
I don't know if it's because I have a lot more confidence in my advocacy for him. I feel a lot more equipped. Of course, there's still moments that take me off guard, but I feel more equipped now to handle those, but that headspace that I was in in those early days with things like that was hard, too.

455
01:03:18.370 --> 01:03:32.259
So, speaking of which to, about the early days, for those families that are joining us today, that they're at the beginning of their journeys, what kind of advice do you have for them?

456
01:03:37.490 --> 01:03:45.890
I would say listen to your gut a lot of the time, and don't be afraid to ask questions, and…

457
01:03:46.600 --> 01:03:59.200
In the Facebook group is a wealth of knowledge. Even if you don't want to post a question, because you don't want to put your business out there, or whatever, you're scared, I totally get that, because that was me.

458
01:03:59.300 --> 01:04:00.470
For a while.

459
01:04:00.790 --> 01:04:13.959
go into the search bar and search things. You will most likely, 100% of the time, find a topic that you're looking for, that a question, a similar question has been asked.

460
01:04:14.090 --> 01:04:20.729
And then just, you know, talk to people, talk to other families. Even if you don't want to…

461
01:04:21.460 --> 01:04:33.599
connect with the foundation right away. If you don't want to join a support group, or you don't want to be active on the Facebook group, I encourage you to find one other family, one other parent that gets it.

462
01:04:33.690 --> 01:04:50.579
and connect with them, and build that relationship. Your village doesn't have to be big, it can be small, and it is just as impactful. But having somebody like Sharon and I both talked about, having another parent that just gets it, and that you can talk to.

463
01:04:50.660 --> 01:04:57.319
is really, really important, so I would highly encourage you, even if it's just one other family, to connect with someone.

464
01:04:57.990 --> 01:05:11.470
Yeah, thank you. Yeah, and I would echo exactly what Alexa said. I mean, for me personally, I wasn't ready to, you know, immerse myself in the CHARGE community just yet, at the time to…

465
01:05:11.740 --> 01:05:19.619
Coda conferences, to reach out to liaisons, or things like that, but I feel like if I had just had that one person just to talk to.

466
01:05:19.650 --> 01:05:35.270
Maybe even if it's a therapist who's familiar with, you know, genetic syndromes to help you understand that piece of it, or just a one family member, one liaison, just one person that really just understands it, I think is, great advice.

467

01:05:35.820 --> 01:05:41.730
Yes, and that answers Sabrina's question, so that… that was perfect.

468
01:05:41.880 --> 01:05:44.760
Now, both…

469
01:05:44.860 --> 01:06:00.639
Alexis and, and Sharon live in states that are pretty active in terms of we have a higher number of families with CHARGE. And that question is going to be for Megan.

470
01:06:00.640 --> 01:06:16.380
What would be your, your advice would be for those families that, might not be easier for them to find other families, to connect with? What other resources or options they have?

471
01:06:17.290 --> 01:06:35.380
Sure, this is Megan speaking, and I would say for all the families on the call tonight, it's a really great idea to connect with your state Deafblind project, so every state has a state Deafblind project, just to connect to them, because they'll have access

472
01:06:35.380 --> 01:06:42.870
To other families, and resources and support to help you navigate those systems that we talked about earlier.

473
01:06:42.870 --> 01:06:45.180
Particularly education.

474
01:06:45.190 --> 01:07:05.830
But they can also connect you to other families, so I would say connect to the State Deafblind Project. And then I know Lord ACE, too, even if there's not a CHARGET Family Liaison in a state, Lord Ace could help connect you to a family that lives geographically nearby. So maybe if you're in Kansas.

475
01:07:05.830 --> 01:07:10.839
She may have a liaison in Colorado, or someplace nearby that you could connect with.

476

01:07:10.840 --> 01:07:27.609
Because in today's world, geography doesn't seem to be as important as just the ability to connect through text, phone calls, FaceTime, email, all those kinds of things. So there's ways to connect, even if there isn't a support person in your state at the current time.

477
01:07:29.750 --> 01:07:37.469
All right, great. And, for those of you in the… in the call, don't forget that, you can reach out also to me.

478
01:07:37.470 --> 01:07:57.190
My information is on the website, and my email is very easy, lourdes at CHARGE Syndrome.org, and I could help you connect with our liaisons, or with anyone that you would like, and give you also some options of other ways that you could connect with our community. But,

479
01:07:57.250 --> 01:08:16.100
But that was definitely, a message that we heard in both of the stories that we heard today, that is so important to… to build your community, even if that community, like we just said right now, is just one person, at least you have one person that would understand.

480
01:08:17.609 --> 01:08:29.399
So now I have a question for, for both of our ladies, especially now that the holidays are coming, you know, one thing that,

481
01:08:29.399 --> 01:08:46.550
we heard from your stories, it was that, sometimes, you know, those that are closest to you, your family members, don't really understand or get what you're going through. How do you survive the holidays, or special occasions like that, that

482
01:08:46.550 --> 01:08:56.210
maybe their idea of participation isn't necessarily what your reality is. How do you… how do you deal with, with that?

483
01:08:56.750 --> 01:09:00.280
Dichotomy of those different worlds.

484
01:09:02.109 --> 01:09:06.400

Yeah, that's a good question. And I think for us.

485
01:09:06.479 --> 01:09:17.159
for some of the years, we've really tried to participate and do everything that everyone else is doing. Like, we just wanted to fit in with everybody and do it all.

486
01:09:17.160 --> 01:09:27.469
But I think, going back to what Megan talked about earlier, is setting up… setting the boundaries, we just learned that there were some things that were just not a good situation to take Wally to.

487
01:09:27.470 --> 01:09:42.709
And learned to say that that was okay, and even if it had to mean that, you know, Bob went with Caitlin, and I stayed home with Molly, or vice versa, we just learned to pick and choose the events that we knew that Molly would be successful at, because,

488
01:09:42.960 --> 01:10:05.730
it just made it easier for everybody, and if… so, for us, it was really learning to say no when we couldn't go to… when we knew it wasn't the best event, or we had to leave early, or, we, you know, maybe only go for part of it, or something like that. So, it was just learning… it was learning the boundaries for us, like Megan talked about earlier.

489
01:10:08.500 --> 01:10:11.360
This is Alexis. I…

490
01:10:11.370 --> 01:10:21.549
100% agree, and I don't know if it's because Tan was born during the pandemic, and I had a lot more boundaries in place because of

491
01:10:21.550 --> 01:10:34.180
sickness and stuff like that, and I was very firm on those boundaries, because, like, having such a medically fragile kid, during that was extremely scary.

492
01:10:34.400 --> 01:10:53.450
But we said no a lot. We built our own traditions and our own things that mean a lot to us. We don't go anywhere on Christmas morning. We… I don't… usually don't go anywhere on

Christmas Day, either. We stay home, and we just enjoy our kids, and we are… we move really slowly.

493
01:10:53.480 --> 01:11:10.890
We don't go to holiday parties and things like that, if we can avoid it. But we do do things with family. Most of my family has now been… is really, really amazing. We've had a few instances over the years, and

494
01:11:11.620 --> 01:11:14.969
And I don't mean this to be harsh.

495
01:11:15.260 --> 01:11:21.450
or anything of that nature, but I have learned that there are some people that…

496
01:11:21.940 --> 01:11:29.560
are not meant to be a part of our story or our journey anymore, and those… those boundaries were really, really hard.

497
01:11:29.800 --> 01:11:36.210
To put in place, and… It was its own grief and its own process, but…

498
01:11:36.690 --> 01:11:46.430
My child's well-being, his emotional well-being, and people who are going to support our family on all levels.

499
01:11:46.510 --> 01:12:01.520
Those are the people who I want to put my energy into, and people who put energy and time into learning ASL for my son, or anything of that nature, or ask questions to understand things, and…

500
01:12:02.160 --> 01:12:14.010
and adapt with us, those are the people I'm gonna put energy into, and so it… I… if I can say one thing, it's that it's okay to set those boundaries with people, and maybe not have them

501
01:12:14.150 --> 01:12:27.040

be a part of your journey if it's not serving you and your family. You don't have to bend yourself over backwards to make other people happy when you're dealing with so, so, so much in your everyday life.

502
01:12:27.040 --> 01:12:34.690
And that was something that I really had to learn, early on to protect my peace and to protect my kids' peace, too.

503
01:12:36.160 --> 01:12:52.349
Lourdes, this is Megan speaking, and I see that Julie Meyer from the California Deafblind Project put in a shout out to you, Alexis, and says, we do love when the Ramirez family shows up at our CDVS, family picnics, so…

504
01:12:52.510 --> 01:12:57.590
Show up to those. We love those.

505
01:12:57.700 --> 01:13:09.960
That would actually be another really great natural reason, to mention why it's important for families to try to connect with their state Deafblind project, because all the state projects offer various

506
01:13:09.960 --> 01:13:18.450
activities for the families to come to, and then that would open your community immediately to other families of kids that have Deafblindness, and

507
01:13:19.090 --> 01:13:23.520
It would… it would be great, so… Yeah.

508
01:13:24.520 --> 01:13:41.029
Now, going back to, part of your presentation, Megan, and I would love to hear from, Sharon and Alexis as well, self-care. A lot of times we hear that word, and we're like.

509
01:13:41.130 --> 01:13:57.609
Yeah, right. You know, who's got time for that? Or… or like you said, you know, self-care is not, you know, going to… a week to Hawaii and being, you know, drinking margaritas and pina coladas, you know, it's… it could be such a small.

510
01:13:57.860 --> 01:14:16.700
meaningful, moment for you. So you could… can you just re, address that and just share how little and how simple those moments could be, and maybe, our other ladies could share, like, some things that have worked for you that have bring… brought you joy and, and help with that.

511
01:14:17.070 --> 01:14:31.719
Sure. So this is Megan, and I would say that, again, it doesn't have to be a long, extended trip, but just finding things that bring you pleasure, just a quick walk around the block if you can.

512
01:14:32.110 --> 01:14:50.940
you know, sitting with your bare feet, if it's not too cold outside in the… in the grass to ground yourself to the earth. Taking some mindful, deep breaths, it's a pretty powerful technique to use that, I mentioned, and it's… the thing I like about it is it's portable, because oftentimes.

513
01:14:51.130 --> 01:14:54.300
You know, I don't have a true percentage, but it…

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01:14:54.300 --> 01:15:13.109
Well, well into the 90% time. When things happen with our kids, it's unexpected, and it comes to you quickly and by surprise. We don't often know that it's coming, and so things that can be portable to ground you are great. I've heard over the years, some families keep

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01:15:13.110 --> 01:15:37.979
a hospital bag ready in their house somewhere that's pre-loaded with some things that they know that not only their child might need if they have to go to the hospital in a hurry, but that would help the parents and caregivers as well. So whether that be mints, or some scented lotion, or some face masks that you could just peel off and stick on your face if you're stuck in the hospital for a long period of time when

516
01:15:37.980 --> 01:15:39.060
your child.

517
01:15:39.060 --> 01:15:51.369
bottled water, you know, things like that that would be little, simple helps are also good tricks, that I know that families have done in the past and I've heard of that were really creative.

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01:15:51.370 --> 01:16:15.710
And then I know Alexis mentioned that she, when we were preparing for this webinar, she was talking about, you know, all the things that she has that she carries with her, and puts on the stroller, and all kinds of things when they go places. And so, even too, thinking about, you know, could you keep things in your car that would help you practice self-care? You know, a nice fuzzy blanket, those types of things.

519
01:16:16.090 --> 01:16:29.800
Think about how… when… when and how urgent things happen, what you grab, and then make sure you've got things in those containers that will allow you to have some self-care opportunities there as well.

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01:16:33.740 --> 01:16:38.509
I don't know, Sharon and Alexis, if you have other thoughts about it?

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01:16:39.910 --> 01:16:41.330
Well, I…

522
01:16:42.050 --> 01:17:01.120
I'm still working on making sure I do enough of the self-care. I think it's a work in progress when you're in these situations. One of the things that has helped me a little bit, and this is a little bit different, is just that I realized after the end of this summer that I hadn't connected with a lot of my friends here.

523
01:17:01.140 --> 01:17:18.469
And so it was really just a quick, like, hey, do you want to grab lunch? And just kind of, like, removing myself from the situation a little bit, taking a break, and just connecting with some friends that, when life gets busy, makes it hard to see on a regular basis.

524
01:17:18.530 --> 01:17:32.470
And I think sometimes, maybe just even just a phone call to them, or a text message, or trying to grab lunch and trying to reconnect with some relationships that are often hard to maintain when our lives are busy the way they are.

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01:17:35.520 --> 01:17:41.189

I agree with Sharon. It… especially in the early days, like, first two…

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01:17:41.560 --> 01:17:57.609
3 years. I didn't know what self-care was. That didn't exist. Getting a solid 5 hours of sleep was my self-care. But I think now, there are a few things that I have found over the years. I'm a,

527
01:17:58.990 --> 01:18:12.159
I hyperfixate on, like, activities or little hobbies, and I jump from hobby to hobby, so I learned how to crochet, I learned how to needlepoint, and finding new things that, like, piqued my interest, and…

528
01:18:12.160 --> 01:18:27.720
And things like that, was really helpful. Little things that I could take with me. I'm a huge reader now. I stopped reading for enjoyment when I was in college. I didn't have time. Then I became a mom. I really didn't have time.

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01:18:27.720 --> 01:18:45.250
Now I keep a Kindle in my purse, and it goes everywhere for me, with me, or you will always see me with an AirPod in, even in my driver's license photo, which is so funny, because I'm always listening to an audiobook, or a podcast.

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01:18:45.620 --> 01:18:59.340
That is my self-care. I love reading. And then recently, you know, it was really, really hard in the early days, but I knew that, like, movement would be really important to me.

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01:18:59.340 --> 01:19:12.869
So, as you saw in one of the photos, our very first family walk after Tam came home was quite the ordeal. I had him in a front pack, and he was on a ventilator, and the ventilator was on a stroller, and it was just a whole thing.

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01:19:12.870 --> 01:19:20.889
So I didn't go on a lot of walks with… with all of that in the beginning, but as it got easier and easier,

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01:19:21.050 --> 01:19:38.959

it… it's… it was something that we did as a family. We would go on walks. Now he gets out of the stroller, and he runs down the road a little bit, and then runs back to me. So it's continued to be something that's important to us, is, like, movement of any kind. So…

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01:19:39.000 --> 01:19:58.440
And I do… I value that a lot, and it's taken me a long time to set a boundary for myself around, I need this time to move my body, whether it's by myself or going on a walk with my family, going to the gym, whatever it is. I personally needed that a lot, and I didn't realize that until this last year.

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01:19:58.810 --> 01:20:13.489
And so I carve out time for that, and my husband helps me, and I lean on my husband. That's one of my biggest self-care tips, is leaning on people, to help you get that time, too. So…

536
01:20:14.150 --> 01:20:18.180
however you can. Like, skincare.

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01:20:18.800 --> 01:20:34.510
Taking an extra long shower, if you… if that helps. Those little shower steamers, I don't know if anybody's ever used those, but those are wonderful. Treat yourself to a little at-home spa. I always… we do that, like, once a month with our daughter, so…

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01:20:34.510 --> 01:20:40.890
Yeah, just whatever you can, whenever you can. I really love Megan's suggestion of, like, keeping a little

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01:20:40.890 --> 01:20:51.150
self-care box for yourself. I have a, like, travel box of activities for my kids in the car, but I'm totally adding a self-care box for myself, because I love that.

540
01:20:51.810 --> 01:21:16.370
Well, and Alexis, this is Megan. I was just thinking with the… your online community of friends that you've created, that you mentioned in your presentation, it would be kind of fun to email each other affirmations of things that you love about one another, and then you could print them off, cut them up, stick them in your little box, and then periodically, if you're having a really cruddy day.

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01:21:16.370 --> 01:21:20.459
You could open it up and read a note from one of the people that really loves you.

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01:21:22.760 --> 01:21:24.340
Yep. I love that.

543
01:21:24.910 --> 01:21:25.790
Yeah.

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01:21:26.100 --> 01:21:41.980
And we have, Victoria shared, one of her self-care, secrets, which is having music around, having your little playlist that you could, listen to and escape, from time to time.

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01:21:42.540 --> 01:21:58.240
And, today… oh, and we have David Brown has, one comment that says, one big part of self-care is occasionally reminding yourself that nobody else can do everything that you do better than you.

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01:21:58.970 --> 01:22:14.550
So, it's, giving yourself some props that, you know, it feels terrible right now, and it feels like, you know, you might not have control over a lot of things, but nobody could do it as great as you're doing, and

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01:22:14.800 --> 01:22:24.100
And you always need to give yourself a little bit of a pat in the back, because it's… it's not easy. And, and it's… it's an ongoing thing.

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01:22:24.870 --> 01:22:25.670
Yeah.

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01:22:25.840 --> 01:22:30.810
Lord Ace, I would also add to that, that I think that,

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01:22:30.940 --> 01:22:34.390

Families get really good at defaulting to

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01:22:34.410 --> 01:22:54.939
hoping for the best, but planning for the worst, right? And so you're always thinking about what's coming next, because you have so much to manage in terms of all those systems of support that we mentioned at the beginning of the webinar. And so, I even just think sitting still in space.

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01:22:54.940 --> 01:23:04.839
Literally sitting down, you know, in a chair and just taking a breath for a minute or two could be a helpful strategy for folks.

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01:23:05.890 --> 01:23:13.789
And yeah, I see that Lydia says, allowing yourself to have a big cry when needed is also great self-care. It absolutely is.

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01:23:15.530 --> 01:23:16.300
Yep.

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01:23:17.350 --> 01:23:28.660
Yeah, don't be afraid to ask for help, don't be afraid to cry and scream to your, pillow and, and vent, because, you know, we can only…

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01:23:28.930 --> 01:23:40.760
absorb so much, and, there has to be always an outlet. Is there anything, before we… before we finish? Do you have.

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01:23:40.760 --> 01:23:59.009
Any last, word of advice to everybody that's here that wanted to join today to, to get to learn something from you, and, and their experience might be very different, and you could just, give them one last,

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01:23:59.600 --> 01:24:03.339
One last glimmer of hope, or one last, tip.

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01:24:08.120 --> 01:24:10.440
Yeah, I would say… Oh, go ahead.

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01:24:10.460 --> 01:24:29.670
I was just gonna say that, remember, it's not… it's a marathon, not a sprint, and that you can't give 100% of yourself 100% of the time to every single thing in your life, and it's okay to prioritize things, and… and…

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01:24:29.780 --> 01:24:47.160
let some things fall behind, and then it can change. So give yourself grace, and give yourself that permission to run at 85% capacity, and not 100% capacity 24-7, 7 days a week, because you can't, you'll burn out.

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01:24:47.220 --> 01:24:52.750
And that's where the self-care comes in, but also acknowledging that

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01:24:53.430 --> 01:25:01.160
you can't do everything for everybody all of the time and… and still be okay. So, just give yourself the grace.

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01:25:03.450 --> 01:25:22.950
And I would just add into that is that… that nobody's alone, even though it feels so alone sometimes when you're in the midst of it, or especially in crisis mode or something like that, that there's… I mean, there was over 45 people on the call today that, you know, would… are here to help anybody, so just remember that you're not alone.

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01:25:23.700 --> 01:25:25.170
Absolutely.

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01:25:25.170 --> 01:25:44.380
And one thing that I want to remind everybody that I know that, you both, mentioned in your presentations is that, we have an opportunity to have our biannual, family reunion at conference. It's coming soon, and I know that for a lot of our families,

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01:25:44.570 --> 01:26:09.059

this is a moment to just refresh and, and get to see, you know, other families. So, if there's anyone that would be interested in joining us next year in Texas, I know it sounds like a big, tall, you know, ask, or, or challenge to, to do, but again, you have this community, we're here to help you, we're always going to be sharing information about

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01:26:09.200 --> 01:26:22.410
How you could get there, how you could connect with us, so just stay in touch with us, stay in touch with our, social media, our newsletters, and we'll walk you through anything.

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01:26:23.110 --> 01:26:27.509
So, Megan, any last word of advice?

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01:26:27.630 --> 01:26:37.959
I would just say, being here tonight was an act of self-care, so pat yourself on the back for coming and listening to Sharon and Alexis, really. And I hope that

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01:26:37.980 --> 01:26:53.069
Tonight, before you go to bed, you do something to practice self-care. Lay down in your bed and try the stop technique, or just say some affirming thoughts, which could be something like, I woke up today and I gave it my best shot, because that's enough.

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01:26:53.210 --> 01:26:54.170
Really.

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01:26:54.310 --> 01:27:06.010
So, thank you for allowing us to be here tonight, really, and for these two amazing human beings for sharing their truths with everyone. We grow resiliency when we share our truth.

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01:27:06.320 --> 01:27:30.970
Absolutely. You have a lot of love from our community. Thank you so much for being with us, for sharing, and we hope to see you at our next Asset Expert, which is going to be in December, and we're going to have Dr. Kim Blake and Claudia again to share information about their updates in their research regarding, medical issues with adults with CHARGE

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01:27:30.970 --> 01:27:39.010

So, I hope to see you guys back in December, and, thank you for joining us, and have a wonderful night.

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01:27:39.670 --> 01:27:41.809
Thank you. Thank you.