Brandon Laughlin: Hello everyone. Thank you for joining us today on our third and final day of Unite to CURE Epilepsy.

Today, we actually are uniting to give, and I am joined by a proud member of the CURE Epilepsy community, Erin Monast, who is joining us today to share her daughter Reagan's story and how she actually used her desire and her passion to control Reagan's epilepsy to fuel the creation of one of CURE Epilepsy's most successful fundraising events, Reagan's Run. Reagan's Run, which actually takes place outside of Philadelphia, Pennsylvania, is an annual run-walk event that engages the entire community, that includes family, friends, neighbors, and businesses. In fact, our third actual Reagan's Run event will be next Saturday, September 17th.

But before I do turn it over to Erin, I do want to encourage everybody, all attendees, that we will be taking questions at the end of Erin's talk today. So feel free to go ahead and throw those into the chat panel of your WebEx platform and we'll do our best to kind of get through as many as possible.

So Erin, I'm going to go ahead and turn it over to you.

Erin Monast: Great. Thank you, Brandon.

So as Brandon mentioned, my daughter, Reagan, she's 11 years old. She was diagnosed with epilepsy actually 10 years ago this month, just shy of her second birthday, after three unprovoked seizures.

So it was quite a shock to my husband and I at that time, having a very small child and knowing little to nothing about epilepsy and really how this diagnosis would affect Reagan and our family as a whole.

She shortly started her first medication right around that time, it was Keppra. And we had hoped this would just be a blip on the radar. We quickly learned that would not be the case and that this would be a lifelong journey for Reagan and for our family.

Reagan has since tried and failed multiple medications, and some locked her in such a fog that I often say she was hiding in plain sight.

When she was seven years old, she started the medical ketogenic diet. While some first-graders would fight the strict diet, Reagan actually fully embraced it. She became an active part of the cooking, the meal planning, and quite the keto foodie. We saw the fog lift really about two to three months in. We were able to wean from her medication and we were just so hopeful. So we kept our fingers crossed and we prayed that keto was the answer.

And it was for a good 18 months, until Reagan lost a seizure freedom in April of 2020. And since that time, she has not been able to reach that level of seizure control and seizure freedom, unfortunately. We did push through for many years after, hoping the ketogenic diet would kind of kick back in and get her to that place. Unfortunately, it did not. And we weaned her from the diet of January of this year.

So we are now looking into surgical options, the RNS and the VNS. When Reagan was first diagnosed almost 10 years ago, I was really anxious and nervous to share about her diagnosis, as we didn't know many people whose children had epilepsy. I think at that time I maybe knew two people. One was a neighborhood friend when I was a child, and one was a family member babysat.

So I kind of felt like we were alone in this journey. But as the years have gone on, I have found that I have become quite the medical parent and an advocate and really Reagan's biggest cheerleader. And sharing her story and our family's story has helped me to meet others within our community. But it's also just opened up these conversations that need to be had surrounding epilepsy and really removing the stigma that there is.

So I guess, around five years old, when she was five years old, we really started looking into awareness and how can we let others know what we go through. So we did little events in our community at Reagan's elementary school, who was super supportive of our family, and the response was overwhelming. So many people supported us. They wanted to learn, they wanted to learn about seizure safety, they wanted to learn about how epilepsy affected her learning. And so many people came forward and said, "I know someone who has epilepsy too." And it was really then we knew we weren't alone in this fight, but we still knew that there was no cure for epilepsy, and the likelihood of a medication working for Reagan at that point in her life was slim to none, as she had failed so many medications.

So we knew our only hope really was research. So that's where we started to turn to CURE and focus really all of our awareness, our advocacy, and our fundraising efforts towards CURE. It started out really simply, there were some great initiatives through CURE that I participated in, our family participated in as a whole, and Reagan participated in. So it was the CURE's run for research, the virtual scavenger hunt, and then we hosted a virtual yoga class called Warriors for Warriors. Again, the response was so overwhelming that I knew I wanted to do more, and I knew I wanted to make this a community-wide event.

So as Reagan's 10th birthday was approaching, I thought, "Let's do something to celebrate her and let's do this in our community, for our community, not just for Reagan." So in the fall of 2021, we started Reagan's Run as a virtual event, and the concept really was 10 for 10 in 10. So 10 miles in 10 days for 10 years to raise $10,000 for CURE.

We did not meet our fundraising goal, but what we did do was bring our community together, including our local high school. They dedicated a run to Reagan, allowing her to come to one of their practices. They all ran in purple. It was really a wonderful day.

And seeing that the community wanted to be involved, the wheels kept turning and I kept thinking, "Well, we can do more. What else can we do here?" So I reached out to a friend who is also a part of the CURE Epilepsy community, whose child also has epilepsy. And fortunately, she lives locally. I said, "I've got a crazy idea, let's put on a 5K." And fortunately, she liked my crazy idea and said yes.

So last fall, Reagan's Run became an actual 5K and one mile walk. The event brought in over 300 people in the pouring rain and raised nearly $30,000 for CURE. It was truly one of the greatest days, not just for our family, but for the family who helped us with this event, for other families that came, who their children also have epilepsy, for our school district. So many people showed up and it was just really such a wonderful day to celebrate these people within our community, not just Reagan. Local businesses sponsored the run, donated items to the raffle table, and as I said, the runners braved the rain and just got out there.

So while Reagan's Run is named after Reagan, and I'm so honored to be her mom, this run to me is so much more. Over the past 10 years, I have met more people whose children have been diagnosed with epilepsy than I can count. And truly, the hardest part for me has been some of the people that have come back into my life who were maybe childhood friends, neighbors, Reagan's friend's sister at school, people that were there but they weren't part of our epilepsy community, then suddenly became part of our epilepsy community. And that, for me, was very hard. I didn't want another family to go through what we had gone through, but I also wanted those families to know that they weren't alone. So when we do Reagan's Run, it's not just for Reagan, it's for all of those people. It's for all of the people within our CURE Epilepsy community as well.

And one of the reasons that we really focus on our efforts on CURE is because for Reagan, that research is critical. We know that she's failed 7, 8, 9, 10 drugs, the ketogenic diet. Hope for her is having this research move forward to create a better quality of life for Reagan, possibly even a cure for Reagan, to create a better quality of life for our neighbor's child, to create a better quality of life for the next person that has been diagnosed with epilepsy.

So on September 17th, we're going to host our second annual Reagan's Run in Wayne, Pennsylvania, right outside of Philadelphia. And we're super excited because we're hoping to get even more people this year. We'll have some pharmaceutical companies showing up, setting up tables, a raffle table, and a table there that just supports CURE. So you can learn all about cure at our event, why we support them, all of the research that they're doing. Again, not just for Reagan, but for everyone living with epilepsy.

And for us, this is just really about community. Reagan has always been my driving force in all of this, but seeing these people show up for us and show up for everyone in our community who has epilepsy is truly amazing. I feel honored that I get to do this, that we get to then take all of those funds and pass them on to CURE and they can then move forward with more research.

It's been 10 years since Reagan was diagnosed, and in that time we've seen improvements in the types of treatments that can be offered. We were told for many years Reagan would not be a candidate for any type of epilepsy surgery, and now we're learning she probably might be. Things like that, I know are because of CURE and the research that they are doing. So we are just so thankful for CURE and all that they do every day for Reagan. So again, this is a community event, and really, CURE is our community and we are just so proud to be a part of it.

Brandon Laughlin: Well, thank you very much, Erin, for sharing all of this information and obviously sharing Reagan's story with us.

So, we're going to go ahead and get to some questions. So, luckily in advance, we got submitted a good many questions, so we have some nice starters. And those of you that are attending today, again, feel free to go ahead and put those questions in the chat and I'll add those to our list.

Now, I've been with the organization for a few years now, and I think probably the question that I've gotten asked the most when it comes to fundraising, and probably every fundraiser has dealt with in their life, is the nervousness around being able to ask people for money. How do you go and tell people... You know why you're fundraising, but how do you convey that message to others? So maybe tell us a little bit about any strategies or tips that you use when asking your community to donate to Reagan's Run or any fundraiser.

Erin Monast: Sure. I mean, we have a very active social media, and I do think that helps us in the sense, I try to share the good, the bad, and the ugly about what it's like to live with a child who has epilepsy. I often find the people then who have gone to our social media and say to me, "I had no idea. I know you told me, but I really didn't understand it until I read that." So there's so much power really in sharing your story.

Reagan's gotten older, so some of it has died off in a sense, to protect her and to let her steer the ship now, but she really wants to be involved in that as well. So she's very open to telling people, "Hey, I have epilepsy. This is what it's like for me." So I think that's what really what's helped me to approach anybody when asking for this, "These are the statistics. This is how many people have epilepsy. Here's my kid. Here's how many medications she's failed. Here's what she's up against. We'd love for you to help us and to be a part of this and to continue and to grow our community and for you to be a part of it." So I think you're putting it all out there, but sometimes you have to.

Brandon Laughlin: Absolutely. And actually something that came to me through the chat here real quick is, and you kind of addressed this, but maybe you can elaborate just a little bit on how you utilize your social media. Do you share pictures, videos? How do you just use your social media? I think that's a question that a lot of people would have.

Erin Monast: Sure. We do a lot of pictures, not so many videos. Do a lot of pictures. We have posts. I am very active during certain times of the year, especially during November and Epilepsy Awareness Month. So I use that month really to lay out all the facts. And then throughout the rest of the year, you'll kind of find day-to-day stuff with us. There are often posts about what it's like the day after Reagan has had a seizure, what it's like for a parent. Unfortunately, parents understand what it's like to watch your child have a seizure. Of course, I don't show that on our social media, but I do show how I feel after that and really how it affects our family. We like to share the happy stuff too. Reagan is a cheerleader, so we like to show that despite epilepsy, there are so many things that she is doing. She swims, she cheers, she loves the Philadelphia Eagles. So I like to share those things too, because while epilepsy is a part of her life, it is not her entire life.

Brandon Laughlin: And that's fantastic. We actually did, some of you on the call may know, we did a panel last night with a few young professionals, and how they used sports and athletics and different things as an outlet to kind of combat some of the struggles of seizures and their epilepsy. So, that's great to hear.

You mentioned before that at Reagan's Run you'll have pharmaceutical companies and things like that. How do you tap into the business world. And specifically, how do you solicit sponsors for Reagan's Run and other fundraising events?

Erin Monast: Sure. So I really try to find a connection. A lot of the local sponsors may be someone I have known my entire life. I actually was going through our sponsors this week and thinking, "Oh my goodness, I've known the owner of this business for over 25 years." So I really try to find that connection. So I think, "Hey, we went to high school together. This is what's going on in my life. We're doing this run and we're local. Would you like to join us?"

When it comes to the pharmaceutical companies, I think that connection is pretty obvious. I'm really tapping into pharmaceutical companies that really focus on medications for people with epilepsy, but it's just really getting the word out there. And even our local boutique across the street, she had started following me on social media and she said, "I had no clue when you came in here. Hey, let me tell you about my connection to seizures." And so, it can be uncomfortable, absolutely. But again, I go back to that, it's okay to share your story. You're going to find a connection, use that connection to then move forward.

Brandon Laughlin: Absolutely. And you kind of touched on this already. In fact, a lot of the questions that had come in before, you'd actually touched on in your talk. But maybe you can talk a little bit more about how Reagan... We specifically had a question from a mother who was a little concerned about involving her daughter in some of these fundraising efforts and how much her daughter would get involved. How has Reagan been involved and how does she feel about being involved? I know you mentioned she loves it and she wants to be involved, but maybe elaborate a little bit more on that.

Erin Monast: Well, for her, you'll constantly hear her say, "I do this because there needs to be a cure for epilepsy." Unfortunately, for Reagan, she has very, very long auras, so she's well aware when a seizure is going to happen. It's fortunate for us as parents because we can get her to safety, but she knows what it feels like. She remembers taking certain medications and how those made her feel. So she's active in this because she wants that better quality of life too. So she's constantly, "This is for CURE, but this is for me too, because I need the cure."

But we've also just been very open with her about disability over the years and that it's okay to talk about. She also lives with cerebral palsy, and we just kind of move forward with both of those things. They're a normal part of our life. They're really a normal part of a lot of people's lives, and we normalize it by talking about it. And I think that's how she really got involved at such a young age, because we were so open with her, "This is why you take medication. This is why you wear braces. This is a disability. This isn't going to limit you, but you need to understand it, because at some point you need to become an advocate." And really, over the past, I want to say two, three years, she has become that. And we watch her as she's so comfortable going into her school and talking about living with epilepsy.

And I often say now she's like a salesperson when it comes to Reagan's Run because she is out there like, "Hey, you coming to my run? You better come." Things like that. So she wants that too. And I asked her one time and she said, "I want people to understand what it's like for me." So I think that's really how she got involved.

Brandon Laughlin: And that's fantastic, she's her own self-advocate, which is great. And actually, we did get another question that came in. So, this is the final question in our thread, and this is actually a great question as well, because I think this is something else that people that have fundraisers, especially have done multiple fundraisers have struggled with, is how do you balance your asks? Like when you're doing multiple fundraisers over maybe sometimes twice a year or anything like that, how do you balance ensuring that you're not... Or do you ever worry about over asking your community?

Erin Monast: Sure, absolutely. Before we did Reagan's Run, we did a lot of smaller events throughout the year, and I felt like that was a lot harder for the asks, because we were doing so many. And really, once we started Reagan's Run, I kind of took a step back and said, "This is our big fundraising event. This is what we want to do." I think that helps streamline the ask and I think it helps people understand that this is what they're doing. There's not going to be another time that they're asking for things like this. We continue our advocacy in other ways without asking for fundraising or for sponsorship or for donations for our raffle table, but really streamlining our efforts to one event has helped with that.

Brandon Laughlin: No, that's some great advice as well. So yes, that actually is the end of today's questions. So I do want to thank everybody, all the attendees for joining us today.

And just a reminder that this actually is a recording. So this will be made available on the CURE Epilepsy website as well in the upcoming days. So please keep an eye out for that.

Also, if you have any questions about becoming a CURE Epilepsy champion yourself, you can visit our website. There's tons of information on there, as well as some contact information that you can reach out to us as well.

Also, I do want to encourage everybody, today being our Unite to Give event, we are actually celebrating, September 8th is our true 25th anniversary. So this is our founding day, and this is why today we unite to finding a cure for epilepsy. So, we are challenging the community, many of you may have seen some emails or social posts about this, to unite 500 donors from all 50 states with a gift of $25 or more. You actually can see an updated map on the giving page that will be on our website.

Also, you can triple your impact because dedicated families from around the CURE Epilepsy community have pledged to match your donations to really maximize the impact of critical epilepsy research funds.

So I do want to thank you again, Erin, for joining us today, for sharing Reagan's story, for everything that you do for the community. It's truly, truly an inspiration to all. And yes, thank you all for joining again, and I hope you have a great rest of your day, and enjoy your weekend.