Fight Stigma: You’re Never Too Young To Be a Hero
Seizing Life, episode 021 – Transcript

Stacey Pigott:	00:00	Hello, I'm Stacey Pigott and this is Seizing Life. If you were 14 years old and have epilepsy, what can you do to stop it? That was the question Henry Iida asked his mom. Their answer was the start of Henry's Heroes, a nonprofit whose goal is to raise awareness and funds for epilepsy research and support. Since 2013, Henry's Heroes has raised over $50,000 to support several epilepsy organizations. Henry and his mom, Nancy, are here to remind us that not just parents can make a difference in the fight against the epilepsy monster. Thank you so much Henry and Nancy for being here today on Seizing Life.
Henry Iida:	00:46	No problem.
Nancy Iida:	00:47	Thanks for having us.
Stacey Pigott:	00:49	So Nancy, you and I met several years ago and bonded over our children's epilepsy and worked together extensively on some advocacy projects and fundraising. And then Henry started Henry's Heroes. And before we get to talking to you, Henry about Henry's Heroes, Nancy, could you describe what Henry's epilepsy is like and how that's impacted your family?
Nancy Iida:	01:18	It's been a long road and it's definitely shaped our family and how we operate and how we've evolved as a family and how all of my children have developed to be honest. Henry started having seizures when he was just before his fifth birthday. He had a seven minute grand mal seizure at his grandma's house and then he had another one three weeks later and then another one three weeks later. And then they progressed and got really bad and he ended up in the ICU downtown at children's for a month. And the only way they could stop his seizures was to put him into a coma. So he was in status epilepticus and they had to shut off his brain and restart it and help it reset, which it did, thankfully. But he was asleep for almost a month and I brought home a five year old who had to learn how to walk again and talk again. He spent six months in rehab and then two weeks after we got home, the seizures came back. So we had to add this really heavy hitting drug called Felbamate. And that did the trick and he did well. He was on just Felbamate for a long time and he remained a seizure-free for almost two years. And then at that point we decided to start weaning him and see how he reacts because as we know, many kids that get epilepsy as a young adult can potentially outgrow it as the brain changes. And so we slowly took the meds away over about six to eight months and

Henry did well. So we were seizure-free, drug-free for a year and a half.

Stacey Pigott: 02:57 And how did that feel?

Nancy Iida: 02:58 Awesome. But it felt like I was walking on eggshells, just never really knowing if it was going to come back. And I started feeling pretty comfortable after about a year and then we started having some episodes where we were staring and not being able to communicate with him and stopping in time and not being able to move. And so we brought him in and they said unfortunately the epilepsy was back. So that was a pretty devastating blow.

Stacey Pigott: 03:26 Yeah.

Nancy Iida: 03:27 I felt like someone just pulled that rug out from underneath me again and we were back on the floor and fighting our way up. So it was tough and then they started getting worse again. So they went from staring seizures to the grand mals and that's when we decided to do something about it.

Stacey Pigott: 03:42 Henry, is there anything that you want to add to your mom's description of your epilepsy?

Henry Iida: 03:49 Yeah, it affected my ability to do stuff on my own, like riding a bike and going to a friend's house on my own and so on and so on.

Stacey Pigott: 04:00 It has had an impact on your whole childhood?

Henry Iida: 04:02 Yeah.

Stacey Pigott: 04:02 All those activities we kind of take for granted and you know, you have to kind of be more mindful of the risks of riding a bike and things like that.

Henry Iida: 04:11 Yeah.

Stacey Pigott: 04:12 Where did the idea for Henry's Heroes come from?

Henry Iida: 04:15 Well, I had a big seizure. I told my mom I want to stop it, "Let's stop this." And that's how Heroes was created.

Nancy Iida: 04:27 He ended up having a couple of bad seizures in gym class in front of all his classmates and they were extremely supportive. After the second one, a few weeks after the first one, they all

		went home and told their parents, "We need to fix Henry." And Henry woke up after that seizure and said, "Mom, we need to make these stop." So I said, "Let's do something about it." I said, "All your friends want to help. Why don't we come up with something?" So we came up ... Henry didn't want to really call it Henry's Heroes. He just wanted to call it Heroes. So Heroes, what does Heroes stand for? Do you want to say it?
Henry Iida:	04:59	Henry's Education Research and Outreach to end Epilepsy Soon.
Nancy Iida:	05:02	So that's what Heroes stands for. And then Henry drew an awesome logo, which is on his shirt. And can you tell them what that is?
Henry Iida:	05:10	It's epilepsy monster that I drew when I was like ...
Nancy Iida:	05:13	Third grade.
Henry Iida:	05:14	Third Grade.
Nancy Iida:	05:16	Because epilepsy is kind of a monster, right?
Henry Iida:	05:20	Yeah.
Nancy Iida:	05:21	So we came up with a logo and got some t-shirts made and asked our friends if they would buy a t-shirt and consider joining us to maybe do some fundraising to raise awareness and money. Right?
Henry Iida:	05:33	Right.
Nancy Iida:	05:33	And make a difference because we couldn't control the seizures at that time, but we could control how we dealt with it and doing something positive made more sense than just sitting there.
Brandon:	05:44	Hi, this is Brandon from Citizens United for Research in Epilepsy or Cure. Did you know that 1 in 26 Americans will develop epilepsy in their lifetime? At Cure, our mission is to find a cure for epilepsy by promoting and funding patient focused research. Learn more at cureepilepsy.org. Now back to this episode of Seizing Life.
Stacey Pigott:	06:02	Who are your volunteers? Who helps you?
Henry Iida:	06:05	Seventy-Five kids and my mom, mostly my friends from my school.

Stacey Pigott: 06:08 What kind of activities do you like to do?

Henry Iida: 06:12 We do car washes, sidewalk sales, bowling events and so on and so on.

Stacey Pigott: 06:18 What's your favorite one so far?

Henry Iida: 06:20 Well, my favorite one is the one we did about the movie where me and my friends went in my dream and fought the epilepsy monster.

Nancy Iida: 06:38 So where's the movie?

Henry Iida: 06:39 It's on the website and YouTube.

Stacey Pigott: 06:42 What's the basic story of the movie?

Henry Iida: 06:46 The basic story is in the movie there was like a kid that says he can enter people's minds and we ended up going in my mind and fighting the epilepsy monster. It's one of those things where it all comes down to the main character.

Nancy Iida: 07:11 And who's the main character?

Henry Iida: 07:12 Me.

Nancy Iida: 07:14 All right.

Stacey Pigott: 07:15 As well it should be. So Nancy, what kind of an undertaking was that for the organization?

Nancy Iida: 07:21 It was actually really easy. And another way to get great support with a project that you want to do is to reach out to people who are knowledgeable in that field. And one of Henry's fourth grade teachers, Drew Peterson, happened to teach a photography camp and a movie making camp over the summer. And Henry really wanted to partake in that. So I approached him about doing a movie for Henry because he asked me. He said, "Mom, I really want to make a movie." And I said, "Well, let's ask Mr P."

So we reached out to him and during the movie making camp, we got consent from the parents and the kids if they would be okay with being in a movie that would be on the Internet and the kids wrote the story together and we made a four foot epilepsy monster that actually cruises down the hall and chases

		the kids and they battle him, just like in our logo with swords and weapons. Right?
Henry Iida:	08:13	Yeah.
Nancy Iida:	08:13	So it's a pretty cool movie.
Stacey Pigott:	08:15	I like how it's not just posted out there, but you're also able to use it before other events and showing it and using it as part of your messaging too of the organization, so it serves that kind of purpose as well.
Nancy Iida:	08:27	Yes, yes. It's pretty fun.
Stacey Pigott:	08:29	How much money have you raised?
Henry Iida:	08:32	50,000 ... well, yeah, 50,000 dollars since 2013. We give money to organizations that support epilepsy funding.
Stacey Pigott:	08:45	That's really, really an amazing sum of money. How do you decide who gets ... I know that you've been very generous with that money and dividing it up amongst different epilepsy groups. Who makes that decision?
Nancy Iida:	08:59	Sometimes we'll go to events and support things that way. Sometimes we'll get asked for a need. So we kind of farm it out to make sure we get foundations that are doing research. Not only research but support programs as well. So it's nice to kind of diversify and give our funds a little bit to everybody. And so we're all making an impact while we go through this together.
Stacey Pigott:	09:20	Right, right. What have some of your volunteers learned from doing something like this?
Henry Iida:	09:28	Well, they learn responsibility and ...
Nancy Iida:	09:36	Well, they learn how to go ask for donations. Right? That's pretty hard thing. Right? So it's pretty much me and 75 of your friends, right? So the kids do most of the work. I'm kind of the secretary, I kind of gather everybody for meetings and kind of lay out the plan of what we need to do. And the kids go do the asking. So if we're having an event and we need raffle items, the kids go to town, they ask the adults that they don't know if they can have a raffle item and it's hard work and it's kind of scary to walk up to a stranger that you don't know and ask for something. Especially, you know, in particular, there's this one boy who was just incredibly shy and we were out in a group in

town trying to ask for donations and he did not want to ask and did not want to ask.

He was just kind of hanging back and it's hard, right Henry, to walk into a store and ask people for help. And finally near the end I said, "Okay, it's your turn." And he said, "Okay." And he did a great job and I could tell that that moment really made a difference for him. I think walking up to a stranger and asking for a donation really made him realize that, "Wow, that wasn't so hard." And I could see the difference in him after that. And then the next time we went out, he jumped right in and said, "I'll ask." And that was a big moment for me, make me realize that I've made a difference in this other child's life as well. So they were learning about all different aspects of fundraising.

Stacey Pigott: 11:06 There's so many worthy causes out there. It can be very crowded. How do you find that you're able to stand out? How do you think that you're able to attract attention to Heroes?

Henry Iida: 11:21 Well, I meet friends along the way in school. I mention Heroes sometimes. So it's sometimes a matter of what I do.

Nancy Iida: 11:37 Yeah. And they know you and they like you and so they kind of want to help and you tell them how much fun we have. So he'll come home from school and say, "Mom, I think I got a new hero."

Stacey Pigott: 11:46 Have you ever gotten new volunteers just from, I know that you've participated in some of the sidewalk sales and things like that. Have you ever had anyone up to you who knows someone with epilepsy or wanted to join Heroes because of their own experience with epilepsy?

Nancy Iida: 12:01 We've had a lot of people come up and offer support because they do know somebody with epilepsy. So they will make a donation even if they don't really know us. And they always stop and look at the booth and they're like, "My cousin has epilepsy," or "I know a friend who has epilepsy," which is nice. They stop, they donate, they gather information, especially if they're local and usually pass it out. But yeah, it's mainly, you know, some of just Henry's friends, it's really gained kind of ... we're kind of gaining momentum as we go along here. We started with, like I said, 30 of his friends and most of those friends are the ones who saw him have the grand mal seizure in gym class.

		And as you kind of know, there's life before epilepsy life before that first seizure and life after that first seizure. And I think even for his friends that saw that seizure. They were really profoundly affected by what they saw happen to their friend. And they really wanted to do something about it. So, and I think that memory is still with them. I mean, I've had kids come up to me and this was six years ago saying, "That really scared me and I really want to help Henry and I'll never forget that seizure."
Stacey Pigott:	13:04	Yeah, yeah. How would you, or what recommendation would you make to families with kids with epilepsy encouraging their own child to be an advocate? We're so used to seeing us parents as advocates for our kids or for our kids at epilepsy. But I think the unique thing about Heroes is that this is really coming from a kid. What recommendations or advice would you give to other families?
Nancy Iida:	13:29	Really just talk about it. For so long, epilepsy was kind of something you didn't talk about. You didn't talk about seizures, you didn't want to let people know that you had epilepsy because there was a huge stigma attached to it. And I think you really just have to start changing the conversation and obviously, the cat got out of the bag with Henry when he had those seizures in front of everybody, but people knew he had epilepsy before that. But once it was more visible, we really wanted to talk about it. So I talk about it probably almost every day to anybody I meet. I'm like, "Yes, I have a son with epilepsy and this is what we did and this is how we started it."
		And I think talking about it makes it almost easier to kind of deal with too. So, and it can be empowering just to start something to make a difference whether it's having, we started off with lemonade and hotdog stands, didn't we?
Henry Iida:	14:21	Yeah.
Nancy Iida:	14:22	In the beginning. We live pretty close to the high school. So setting up shop at the corner of New Trier and selling hot dogs to those hungry cross country runners after races was an easy target. So just doing something minor, but it's empowering to do something and then be able to give back. And I think the kids all feel that there's a lot of excitement that goes as the day goes on, as the sidewalk sale nears its end and we see how much money's in that can and all those dollar bills add up and the kids get pretty excited.

They all want to count the money, they want to see where are we going to put it? And I said, "Well we'll see who needs it and who we haven't given to in a while and we'll figure out where it goes." But it can be very empowering to just do something positive. But I think talking about it, accepting that this is what you have and finding a way to process it and deal with it, this for us, this has been a really a positive experience. And I know I've heard from many parents that they're very appreciative that we've given their kids a way to empower themselves to help their friend. So it can be a pretty powerful thing.

Stacey Pigott: 15:31 Nancy as a mom, do you see any changes in Henry since taking on this role and this responsibility?

Nancy Iida: 15:39 I do. I see a lot of confidence. He's, like I said, he has owned the fact that he has epilepsy, it's part of who he is. It's definitely shaped who he is as a young man and it's been a really powerful thing for him. So it's really helped him blossom I think as an individual. It's something that he's very proud of.

Stacey Pigott: 16:02 Henry, how has Heroes helped you as you think about your own epilepsy? Has doing this changed how you view it?

Henry Iida: 16:11 Yeah. It has changed how I view it immensely actually. At first I thought of it as a torture, but now I just use it as a way to help me make friends because of the organization.

Nancy Iida: 16:30 The thing about epilepsy is you can't necessarily see it all the time. Henry's been seizure-free now for eight months and in general he looks like a normal 14 year old boy, but he takes 16 pills a day. He has to make sure he has to get sleep. He can't ride a bike, he can't ride a skateboard unless he's kind of holding onto something. But when we started Heroes, selfishly as a mother, I wanted the world to know that my son had epilepsy because I knew this was going to impact who he was as a person and I really wanted to change the conversation. I didn't want him to be treated differently because he had epilepsy. I wanted people to know he had epilepsy. That might be why he's more shy or he's quiet or he has trouble finding his words or that's why he's staring into space when you're talking to him and he can't answer you.

I thought I felt it was really important to let all the kids and our family and community know that this is happening to my child and I kind of wanted to be a voice for him. I think it's important to be vocal about something that you have to deal with that is a struggle. So kind of selfishly I kind of wanted to make sure that there was no more stigma attached to epilepsy. It was kind of my mission. It became kind of the drive for me to get more kids involved and get it out there that this is happening to my child. Raising awareness was a big part of Heroes in my book.

Stacey Pigott: 18:12 Yeah. Well not only is Henry having the tools around advocacy at such a young age, but all of the 75 heroes that are along the whole journey and process with him, you're getting them at a young age and breaking down that stigma before it even develops.

Nancy Iida: 18:31 Right.

Stacey Pigott: 18:31 So that cycle gets broken right there.

Nancy Iida: 18:34 Right. I really do think we're changing the conversation from how it used to be even 10, 20 years ago.

Stacey Pigott: 18:40 It can't be understated to how brave you are, Henry, to put yourself and your story out there. Not every person struggling with all different issues is always comfortable doing that. And it's just really admirable and brave that you've put it out there and have put it out there into the universe to do something really great with it too. So you're really to be commended for that, Henry. That's awesome.

Thank you, Henry and Nancy for your awe inspiring story. You can learn more about Henry's Heroes at henryheroesfoundation.com and both parents and kids can use your talents and interest to raise vital funds for epilepsy research by becoming a cure champion. Visit cureepilepsy.org/curechampions or email events@cureepilepsy.org to get started.

Legal Disclaimer: 19:34 The opinions expressed in this podcast do not necessarily reflect the views of cure. The information contained here is provided for general information only and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs. Cure strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with the patient's physician or other qualified healthcare professionals who are familiar with the individual specific health situation.