00:01.64

michaelholtz

Welcome to Further Together: The ORAU Podcast. As ever. It's me your host Michael Holtz in the communications and marketing department at Ora you and as ever these days I'm joined by my co-host.

00:11.65

Matthew Underwood

Um, it's going good Michael you know.

00:18.27

michaelholtz

Matthew Underwood also from the communications and marketing department Matthew. How's it going.

00:25.64

Matthew Underwood

We've done a few of the podcasts surrounding you know cancer within the organization and what or you does for cancer and brought in some special guests surrounding in the cancer space I'm excited for another conversation.

00:36.80

michaelholtz

I'm really excited for today's conversation um she your names is completely left my head damn it? Um, um, um so I'm gonna start that over. I am really excited for today's conversation um because the national coalition for cancer survivorship. Um, which we are talking about today has become an organization very important to me as a long term survivor.

01:05.37

Matthew Underwood

01:08.19

michaelholtz

Um, of cancer and is someone who is seeing um, long term effects of cancer treatment. Um the the longer I live past treatment the more side effects I'm seeing as a result which um on the one hand is good and on the other hand has its challenges.

01:12.71

Matthew Underwood

Are.

01:25.70

Matthew Underwood

Is correct

01:28.30

michaelholtz

But here to talk to us about the NCCS is my friend, Shelley Fuld Nasso, who is the CEO of the National Coalition for Cancer Survivorship and someone I've gotten to know really well over the last couple of years Shelley I'm so excited. You're here. Thank you so much for spending some time with us today.

01:40.70

Matthew Underwood

So.

01:48.30

Shelley

Thank you so much for having me Michael and I'm just going to take a second to brag about you a little bit I mean I know that you didn't ask me to do this but in your you know in addition to your work your work life. You ah are an incredible advocate I mean truly. You know, volunteering your time with so many organizations and sharing the you know good bad and ugly of cancer survivorship and really trying to support men with cancer because you know we know that you know, ah ah most and unfortunately most advocates.

02:15.23

michaelholtz

Um, move.

02:20.35

Shelley

Are women and we don't have enough men advocating for each other and for saying like it's okay to recognize that This is really hard. It's okay to get support for mental health for your physical side effects. You don't have to justtough it out and.

02:21.68

michaelholtz

Um, absolutely.

02:36.33

Shelley

So important to have people like you sharing your experience and being an advocate and the fact that you share it so broadly with many organizations and try to really get get that message out there. It's just you are. An incredible advocate I am grateful for what you contribute to nccs but also to the whole cancer Community. So that was ah he did not pay me for that. He did not ask me to say that but I just want to say like you are truly incredible and I I Thank you for all that you do.

02:55.95

michaelholtz

I.

03:04.79

michaelholtz

Well thank you for that Shelley I you know I decided actually really early probably within 24 hours of my diagnosis that and you know I was diagnosed back in 2012 when there weren't a lot of online and social media resources available right. Um, to just be wide open about what I was going through um to demystify really what the cancer experience is all about and to show people that hey if I can do this, you can do it too. Um, so all of that to say. Thank you for that. It has been.

03:29.88

Shelley

In here.

03:43.97

michaelholtz

The joy of my life honestly to be a cancer advocate and honestly so glad that I found and nccs um I was you know I've been ah, an advocate for nccs for three or four years now and.

03:48.19

Matthew Underwood

Um.

03:58.78

Matthew Underwood

Are.

04:02.43

michaelholtz

Really was at a point where I was like you know survivorship survivorship is an important issue and and Nccs focuses very specifically on survivorship issues and you know the the broad spectrum from policy to you know day-to-day life as a survivor. So. Um, grateful that Nccs is there and thank you for your work and the work of your team many of whom I count among my friends So I'm so very glad that that you and ncccs are there. So Let's talk About. Um.

04:28.81

Shelley

Thank you.

04:36.13

Shelley

You.

04:39.90

michaelholtz

Out of the gate Shelley what is the national coalition for cancer survivorship.

04:43.20

Shelley

So we are an organization that was founded in 1986 a group of people got together. People were starting to live longer after a cancer diagnosis. It had you know it had been a death semons and people were starting to have successful treatments that saved their lives.

04:59.49

michaelholtz

Um, but.

05:03.00

Shelley

But they were left to fend for themselves when they were done with treatment. There was no such thing as post-treatment care. Nobody knew what to do with people. Nobody knew how all these treatments were going to affect people in the long term and ah and at that time even people were considered kids are victims.

05:22.19

Shelley

And so these folks got together to say we need to do more to help people and at this meeting um that they convened over a weekend in Albuquerque New Mexico they created the national coalition for cancer survivorship and decided to define. Ah someone as a survivor. Use the term survivor and define someone as a survivor from the day of diagnosis. So it's not just about you know, completing treatment and going on your way after cancer treatment. It's really about living well with cancer and after treatment ends.

05:40.45

michaelholtz

Awesome.

05:53.82

Shelley

And um, so they started just bringing together. Anybody who was interested in this topic and I feel like we've made a lot on the one hand we've made a lot of progress in you know, almost forty years ah we know that most people identify with the term survivor even if they're still in treatment which is.

06:10.86

michaelholtz

Right.

06:13.98

Shelley

Ah, our view is anybody you should use whatever term makes you resonates with you as somebody living with cancer and some people don't like that term and that's okay, um, but the fact that it's very much common parlance has to do with the the work that they've done over the years and people understand that survivorship is sort of this distinct phase after treatment and that it's really important and that we need to help people transition. But I also feel like we still have so far to go because all so much of the focus is on treatment.

06:47.81

michaelholtz

Um, listen.

06:48.22

Shelley

Early detection treatment ah research saving lives cures and not enough on what happens to the people afterward and I feel like we're always sort of fighting for the attention really to and for people to understand that you know cancer is not over when treatment ends. And we always hear from survivors that the first year after treatment is the hardest is harder than the treatment itself. Even if they've gone through brutal treatments because you go from seeing your care team every week multiple times a week whatever it may be depending on what kind of treatment you had to.

07:06.11

michaelholtz

Um, why.

07:24.50

Shelley

Ringing a bell saying see yeah in three months or six months or whatever it is and you're just left to pick up the pieces of your life and try to find your new normal. Whatever that may be and then even you may have family and friends who are like okay you survive you should be happy.

07:31.30

michaelholtz

Um.

07:40.12

Shelley

What's Wrong. Why aren't you happy why? Why are you still dealing like isn't this behind you and and people don't really understand and I'm not a cancer survivor myself but just in talking with you and so many other cancer survivors I mean we just hear that. Challenges people face and and I think we do a lot better at addressing the physical side effects and not enough of the emotional side effects and you know all of the other ways cancer impacts. Someone's life So back to what is nccs we work on all of these issues we advocate for in congress in the federal government.

07:59.34

michaelholtz

Thanks me.

08:07.10

michaelholtz

Um, right? so.

08:12.97

Shelley

Um, we we do a lot of public policy work because we know that policy public policy drives. How care is delivered and what kind of care you get so so part of what we do is bring people to Washington D C to talk to their legislators which you've done with us before and to talk specifically about survivorship issues.

08:28.30

michaelholtz

Um, me.

08:31.64

Shelley

We also provide a lot of data about survivorship. We do a survey every year our state of cancer survivorship survey we provide resources for healthcare professionals who want to improve survivorship care and research on survivorship needs. We educate patients and survivors and caregivers themselves and we also try to educate advocates like you who want to be involved in this work and we try to. Ah. Support you in your efforts but also match people with opportunities. So when people come to us and say I need somebody with this experience to help advise us on this project. We can say oh I know Michael is is a cold cancer survivor and.

09:10.35

michaelholtz

Um, next.

09:11.83

Shelley

And you know and he might be able to help you with this. So that's that's one of the things that we do as well. So those are just some of the things that we do.

09:17.74

michaelholtz

You said Shelley you're not a cancer survivor. How did you get connected to nccs.

09:26.20

Shelley

Um, well I started my ah I studied public policy political science and public policy got a master's degree in public policy and then I went and worked in the internet industry for a while which had nothing to do with my degree and I wanted to get back to using. My public policy skills and my nonprofit skills that I'd studied in graduate school I started working for Susan she Coman in Dallas and worked for them for almost ten years on a number of different issues working on public policy and um at at.

09:49.20

michaelholtz

Um, you know

09:57.81

Shelley

Ah, that's how I really got into the cancer policy realm and then after I left Coman I ah was hired by nccs initially as a policy director and then they asked me to be a Ceo so my family and I moved from Texas to the washington d c area and I last fall celebrated 10 years at nccs.

10:01.70

michaelholtz

Um, man.

10:16.34

Shelley

Um, I think you know, but in that time period you know I've had a lot more family and friends who were affected by cancer and you know Nccs definition of cancer survivor extends to the family. So by that token I have family and friends who have that I have supported through their treatment and some who have survived some who have not.

10:22.96

michaelholtz

Um, sure.

10:35.83

Shelley

Ah, but I don't call myself that because I don't feel the same kind of experience that you've had um but I've had a lot of close family members and friends and I've seen kind of the good and the bad and the ugly of the cancer care system and even clinical trials. My best friend.

10:40.65

michaelholtz

Um, move.

10:53.19

Shelley

Died in I believe it was 2012 of of kidney cancer and he was a doctor himself and he um you know, just seeing what he went through he he was diagnosed with stage 4 cancer knew that it was not curable at at the time he lived for nineteen months he was on a clinical trial. Um, he you know he didn't always report symptoms that he was experiencing during his clinical trial because he was afraid he was going to get kicked off the trial and he was so sure that this this drug was going to save his life and um so you know and and I saw some of the really.

11:21.10

michaelholtz

Right.

11:28.10

Shelley

Great care that he received and also saw some of the really terrible care that he received in terms of you know, not ah, not recognizing what his prognosis truly was and not getting him the palliative care and end of life care he needed until it was way too late. And he only had a hospice for about a week and he could have had a better quality of life in the last few months of his life but no one wanted to acknowledge and he was he knew because he was a physician he knew it was time for hospice care. But his doctor wasn't really helpful in that so it was it was frustrating. Yeah.

11:44.52

michaelholtz

E ryan.

11:58.11

michaelholtz

Wasn't There wasn't ready for that. Yeah I can totally see that.

12:01.34

Matthew Underwood

So you talked about you know how cancer does touch more than just the patient. Why was it so important to kind of expand that term of survivorship and the scope of that to include the friends and the family and the caregivers.

12:14.91

Shelley

Well, that was something that our our you know early on in nccs's tenure that they did that I think um, you know, but way before my time but I think they just recognizes how it it is a a disease of the family if you think about kids who watch their parents go through a cancer treatment and that how that may affect them or. Having to care for a loved one that you lose and there's not enough support for caregivers and you know we actually are ah mentioned our state of survivorship survey last year we added caregivers to that and it was the first time we'd surveyed caregivers and we had 500 caregivers in our our survey sample and just I mean it was.

12:41.67

michaelholtz

Are.

12:51.69

Shelley

Kind of like we already knew from you know, Anecdotally What some of what it meant but it was able we were able to kind of quantify some things and see where. You know, asking the same questions of survivors and caregivers and seeing where they differed and how they approach treatment decision making and the stress they feel and the support they feel and and caregivers have higher levels of stress in some instances lower levels of support because they're not the focus. Everybody's focusing on the patient and not the caregiver.

13:16.95

michaelholtz

Right.

13:21.57

Shelley

And even when we looked at time off from work. Um I think the average amount of time off of work per week. That's somebody who continued to work to their treatment for for patients for the cancer patients themselves. It was 18 hours for the caregivers 15 hours so that's almost half of your time away from work every week

13:34.92

michaelholtz

Wow.

13:40.60

Shelley

To care for somebody and there's no support for that. You know there's no and you know fmla is unpaid if you can get it and there's no paid leave for caregivers. Um, it's you know you can't take short term disability but for for caring for somebody else. That's paid. So It's just um I think it's I think it's an important recognition of how cancer is so affects the whole person and their family.

13:59.50

michaelholtz

Um, run.

14:08.70

michaelholtz

Absolutely and and you know I've often said that caregivers are definitely highly underappreciated and you know the unsung heroes of a patient's cancer journey because as a patient I had 1 job right? My job was to get well. Caregiver my wife had to you know, make sure that I'm taking my meds and getting to my appointments and sleeping and also paying the bills and making sure I was eating and and working you know so that she was working at the same time. So yeah, it's the stress is unbelievable for. Caregivers and you know in this couple of things. My cancer. My cancer scenario was fairly simple. They are far more complicated you know far more difficult. Um cancer scenarios as well. So you know and hats off to caregivers.

14:47.21

Shelley

Um.

15:00.63

Matthew Underwood

Oh.

15:04.30

Shelley

Yeah, truly the unsung Heroes and it was interesting too. We found that caregivers were ah almost a little bit more of truth tellers when it come to the experience so you know when you've survived. So we find that cancer survivors when we ask them? how um.

15:04.63

michaelholtz

Across the board. Truly.

15:16.39

michaelholtz

Um, and.

15:21.88

Shelley

How they rated their care. They usually rate it pretty highly. They're just so grateful to be alive you can interview somebody and have them talk about real you know lapses in care or you know things that are not ideal or challenges that they faced in getting the care. But then you ask them to rate their care team. They give them high high ratings because they're just.

15:41.56

michaelholtz

Um, sure.

15:41.71

Shelley

Grateful to the people that saved their lives when when we asked the caregivers the same question. Not so much they were they rated the quality of care across the board at like 10 to 15 points lower than the survivors did and these weren't like match pairs like you and your wife it would just be you know, but we could compare them to the 1300 survivors in our sample.

15:50.80

michaelholtz

Interesting sure.

16:00.84

Shelley

And and caregivers were much more likely to be engaged in decision making and really want to do all the research about the treatment options. A lot of the survivors are just you know you're like the empowered advocate who wants to know everything and does all the research but ah more than half the people in our survey say they just rely on the doctor to tell them what to do. And it does differ by age and demographic group and things like that but overall and we do make sure our sample is representative who has cancer in the country So half of the respondents are age 65 and over because that is who has you know that is representative who has cancer in this country.

16:20.73

michaelholtz

Um, you know.

16:36.83

Shelley

So it could you know sometimes it's age related but and but also it's you know you're overwhelmed by the decision or by the the diagnosis. So you're just tell me what to do Doc whereas the the caregivers are much more involved in the decision making and doing the research and so that's another burden on the caregivers too.

16:45.51

michaelholtz

Right.

16:54.90

michaelholtz

Um, absolutely absolutely.

16:59.27

Matthew Underwood

You you talked about that survey a little bit kind of talk about you know the latest survey in 2023 were there any things that came out of that that maybe surprised you or what was the focus of that survey, um, kind of the results from that.

17:10.50

Shelley

Yeah, so we do so it was our fifth year to do this survey and we're gearing up for our 2024 survey. Um, we some questions we ask every year just to kind of be able to have it as a baseline and see where there's comparison like the question about decision making about care and the first time we asked that question it was even. It was like more than 60% said they told their they do whatever the doctor tells me then we saw a big dip during in covid where people were not as willing to just do whatever their doctor said and then it's been sort of creeping back up and but we like to be able to compare year over year and then we also have different areas of focus ah each year so in 2023 the survey that the one component was the caregivers and I've already told you a little bit about that and then the other was about working through a cancer diagnosis based and some of the positives too I mean so we did see and some of it's not It's not always surprising as much as it is.

17:53.68

michaelholtz

Which means.

18:06.63

Shelley

Good information for us. It's good to quantify it like what we think we share it. We do share this survey widely with researchers and Clinicians and and but what we found on work. You know, not. Surprisingly the earlier somebody was diagnosed in terms of staging of their diagnosis the the more likely they were able to continue working with their and ah and and.

18:40.17

michaelholtz

Um, hey Shelley you're baiting in and out all of a sudden and I'm not sure what's happening. Um.

18:43.50

Shelley

Is that.

18:50.85

Shelley

Is that better. So okay, okay, where do you want me to go back to like the beginning of this question.

18:52.76

michaelholtz

That does yeah that sounds better. Sorry try that again. I'm so sorry.

19:03.75

michaelholtz

Um, you were talking about cancer survivors and cancer patients and work.

19:09.52

Shelley

Okay, okay, um so one of the areas that we focused on in our survey in 2023 was working through a cancer diagnosis and so some of the respondents were already retired of the of The. Responded to worked through their cancer Diagnosis. We asked some questions about you know how much time they had to take off how how they were able to.

19:35.53

Shelley

And and not surprisingly we found that the earlier.

19:43.52

michaelholtz

I Don't know what's happening. But.

19:44.15

Shelley

They be productive that their work didn't suffer and and and so you know that's not totally surprising because often if you have a early stage diagnosis. You may not have to have chemotherapy which might be more debilitating or.

19:58.38

michaelholtz

Um, move.

20:00.10

Shelley

You know some some cancers are even treated with just surgery alone and that's it and then you can you know recover and go right back to Work. So The later stage ah diagnosis the more intensive the treatment the more debilitating it might be the more challenging it was to keep working and the more likely people were to have to. Either stop working or take a leave of absence and we did say people did say they wanted to continue working through their cancer treatment. It gave them some sense of Normalcy. Ah, they felt a lot of support from their coworkers. Although we know some people don't even want to tell anybody at work. They just want to keep it completely private and and people want to let people know so that they can support them and some employers do a great job of really supporting people through it Others not so much so you kind of hear the ah the gamut of it. But.

20:32.33

michaelholtz

Right.

20:42.23

michaelholtz

9

20:45.51

Shelley

I think to me I wouldn't say it was as surprising as it was nice to have sort of data to back up what we were what we sort of thought we knew about what it was like to keep working through cancer and I think we're going to ask those questions again this year it helps to have a couple of ah years of data on it to kind of compare.

20:59.14

michaelholtz

Um.

21:02.39

Shelley

The other thing we do is when we do our survey we start with some in-depth interviews and we usually focus those we do about 10 to 15 interviews and we focus them on whatever kind of our topic area is so last year we did some of our interviews were with people who worked through their cancer diagnosis through their cancer treatment and then the other part was.

21:21.75

michaelholtz

Okay.

21:22.65

Shelley

Caregivers and what it does is give us that qualitative information and also helps us to shape the questions that we ask in in the quantitative survey that we send out to people.

21:33.36

michaelholtz

Shell it do you envision a new topic area may be being added to the 2024 surveyt

21:40.00

Shelley

There are several things we're talking about right now that we want to include 1 thing that we've been really interested in thinking more about is um medicare advantage and what that means for cancer survivors. Because we know that medicare advantage is now more more than half of benefits of Medicare benefitsfici issues are in medicare advantage plans and there are you know benefits and tradeoffs of being in a medicare advantage plan. You can have some insulation ah from. You know out of pocket costs but also a lot more prior authorization. A lot of ah limited networks and so we ask people what their insurance is right now but we don't we ask if they have Medicare. We don't necessarily break it down into Medicare Medicare advantage so we're thinking about. Additional questions. We get asked to give us some more data on that because I think it's something that we haven't focused on enough in the cancer community that challenges that medicare advantage poses to cancer survivors and it's only going to keep increasing that percentage of Medicare beneficiaries who are in medicare advantage plans.

22:42.19

michaelholtz

Um.

22:46.35

Shelley

And the the fact is you could choose a plan that's really great has a lot of benefits. You know there's all that advertising that goes on while during the open enrollment period I don't really watch much tv so I didn't see them. But I think if you do watch Tv you probably saw a lot of it back during that open enrollment time and um.

22:51.76

michaelholtz

Right.

23:02.10

Shelley

They offer you know gym memberships and all these benefits and um and it seems like a great deal. But then maybe you get a cancer diagnosis and then you find out that your cancer center is not in Network or that it's harder to get into a clinical trial because of your medicare advantage or something like that. So I think.

23:13.10

michaelholtz

Right.

23:20.64

Shelley

We're we're really thinking about it in terms of how we engage on it from from that more data from our survey would actually help us strengthen our policy efforts as well. So that's one of the areas that we're thinking about ah adding to the survey this year the other thing we want to do is. We want to over sampleple for lgbtq ah respondence because we didn't have enough in our survey last year to have statistical significance when looking at you know, comparing them. We asked the same questions of everybody but then we can kind of look at different all different demographic groups and whether.

23:41.68

michaelholtz

Um.

23:56.58

Shelley

The stage of your cancer The you know age all different kinds of demographics to see where there are differences in the responses and we just didn't have enough ah among those ah lgbtq respondents to be able to meet.

24:11.60

michaelholtz

Drunk Chuck that sounds great and really important audience to get data on because there's not a you know there isn't a lot. So yeah, um, one of the.

24:12.31

Shelley

Conclusion So that's one of the things we're going to do this year. Okay.

24:19.87

Shelley

Yeah, there's not enough. Yeah.

24:27.85

michaelholtz

As an advocate for ncccs. 1 of the bills that we have advocated for for a bit is the comprehensive cancer survivorship act. Um, which as again as someone who I'm a long-term survivor. It's been twelve years um cancer survivorship planning you know wasn't really even on that table. Um, at the time I finished treatment in 2013. Um, but is such a critical you know looking backward is such a critical need and I wish.

24:49.18

Matthew Underwood

Um.

24:49.88

Shelley

Right.

25:03.76

michaelholtz

A that it existed then but you know looking even today I'm like well let's let's start one because I'm going to be here for a while you know, um, because as you know as you said at the start cancer survivors are living longer. Um, because. You know treatments and all of that have improved so we have more you know 18 plus Million cancer survivors alive today. Um more than ever and their needs healthcare needs are still going to be great.

25:30.96

Matthew Underwood

Are. Are.

25:38.51

michaelholtz

And are impacted by the treatment that they have so the the comprehensive cancer survivorship Act is a really important piece of legislation for those of us who are still here after you know after our our cancer treatments. Um, what.

25:39.75

Shelley

Great.

25:44.19

Matthew Underwood

Are.

25:52.28

Matthew Underwood

Are.

25:55.55

michaelholtz

What is it about this and I know there are a lot of components. But what's important about the the comprehensive cancer survivorship act.

26:02.93

Shelley

Well, you did a great job teing it up because I think the care planning is really one of the important pieces. Let me just say that it was introduced back in um June of last year by Debbie Waserman Shultz Brian Fitzpatrick and Mark Dessonia in the house and then senators Amy Klobuchar and Ben Cardin and the.

26:14.70

michaelholtz

E.

26:22.17

Shelley

And it really looks at the entire continuum of care from you know diagnosis through treatment through post-treatment to improve survivorship for all survivors. So One of the components is care planning that you talked so eloquently about and it would create a medicare service for cancer care Planning. We did find in our survey that. Patients who said they had a plan a care plan were more satisfied with their care and more satisfied or had better outcomes really and so it we and and that we think patients should have a care plan at diagnosis at any changes in the course of treatment during treatment.

26:44.83

michaelholtz

Um.

27:01.89

Shelley

And then as that transition to survivorship to really help primary care providers know what your treatment has been what are some of the potential late term effects that might come up What is the surveillance that needs to be done for any um you know recurrence of cancer or any other types of cancer. A lot of that coordination falls to you the patient, the survivor and so having a care plan to really be able to share that with other providers would be really important and helpful. Ah, and you know most people don't get a survivorship care plan that was there was a big push to do them and then a lot of providers found that it was too hard. It's not.

27:25.41

michaelholtz

Um, money.

27:35.41

michaelholtz

Um, and.

27:40.31

Shelley

Automatic to come out of the a good quality one for patients is not easy to get out of the ah electronic Health records. It takes some time and it's meant to be more than a piece of paper too. It's not just handing you a piece of paper and saying here's your plan. It's um. Talking you through what does this mean? what are the things you need to do um to take care of yourself after your treatment ends and then it really should be a living document that changes because was things come up, you know and you have different side effects that you're treated for that should also be incorporated into the plan.

28:06.85

michaelholtz

Um, when.

28:14.36

Shelley

So The fact that it would cover that this bill would cover care planning is a really huge a huge component. There's other pieces of it. It does have a lot of provisions and we don't have time to talk about all of them but a couple others that we think are really important and helpful is one ah an employment. Assistance program that would provide some assistance to cancer survivors or families and their caregivers that have barriers to employment due to a cancer diagnosis. We do see you know when we ask about financial sacrifices and financial difficulties Definitely higher among young adults among people living with Metastatic cancer.

28:32.51

michaelholtz

Um, lose.

28:50.68

Shelley

Ah, Hispanic and latino ah cancer survivors and black cancer survivors have more are more likely to have financial sacrifices and this would help give some targeted assistance like helping them to maintain their job to maintain their and their financial support while they're going through treatment. And then another component that we think would be really great. Is there an adult cancer survivorship study. There's ah, a childhood cancer survivor study that really and is an incredible source of data for researchers on the effects of ah cancer treatment on childhood survivors and part of that is because. Ah, the majority of pediatric cancer patients go through a clinical trial and go to a research at a cancer center that does research so we follow them for their lives and know a lot about how their treatments have affected them later.

29:34.83

michaelholtz

Um.

29:45.83

Shelley

We don't do that systematically for adult cancer survivors. You know. So if we had better data. It would really help us to see a lot of times you know survivors are talking amongst themselves about common side effects that they're dealing with and there's nothing in the literature about it because no one's following them. You know systematically so this would have a.

30:01.32

michaelholtz

Um, right.

30:05.14

Shelley

Like would would ask the and nci to create an adult version of the chacho cancer study that would really do a better job of collecting that information about the late and long-term effects of of cancer treatment. So those are just a few of the of the provisions and we have more information on our website about it. But. And those are 3 that we think are really important and could be useful to patients and survivors.

30:28.95

michaelholtz

I Love that I Love the adult cancer survivorship survey um for a number of reasons but you know primarily you know to be tracking, um among adults.

30:40.84

Shelley

Yeah I mean 1 example is even just like 1 of our founders and Susie lay. She's a 50 year cancer survivor now she was diagnosed as a young adult and after she came home from Vietnam where she was a nurse ah and she had non-hodgkin lymphoma. Well.

30:45.44

michaelholtz

Means.

30:56.38

Shelley

All the people treated for Hodgkin's lymphoma back in the early days that the treatment was so severe and it was all this radiation to the chest that has led to heart problems breast cancers lung cancers all kinds of issues that they have had to deal with over the years and so.

31:05.30

Matthew Underwood

I.

31:06.70

michaelholtz

Sure.

31:15.16

Shelley

When they when people were diagnosed as teens and in their early 20 s and live 405060 years after they go through all of these complications and there's not and they know they have to network with each other to talk about what they're going through because we don't have the systematic data following them up on ah or ob these years.

31:26.27

michaelholtz

But yeah, there's no one tracking right? What's going on with them I was just as an example I was diagnosed with hearing loss last year and it's.

31:34.92

Shelley

Yeah.

31:44.29

michaelholtz

Turns out, it's because of nerve damage from Oceoplatin that I was treated with um and there's I found one study that was done of patients treated with platinum based meds that experience hearing loss after treatment because again you know, nobody's.

31:44.52

Shelley

Are.

31:46.99

Matthew Underwood

Are.

31:55.92

Matthew Underwood

Are.

32:03.80

michaelholtz

Nobody's putting all the pieces together like as a patient I've had to go okay is this related is there something else is it. You know and odds are because it's nerve damage. It's because my nervous system was kicked hard by.

32:12.39

Shelley

Here.

32:19.49

Matthew Underwood

When that goes back? Yeah, that goes back to the point that we talked about earlier you know it's you know your survivorship doesn't end the day that you are cancer free. You know there are those other side effects and you know it would be good to have a survey to track those and even.

32:19.69

michaelholtz

Climate based meds during chemo. So so yeah, it's.

32:21.95

Shelley

Well I.

32:35.93

Matthew Underwood

You know, not only for the patient to know if that's connected to their cancer treatment. But just you know for doctors and scientists so learn about all the other side effects that may be out there to be able to treat future patients.

32:44.73

Shelley

Right? And tell people about it beforehand so they know what to expect I mean and you know I think people I think if you are prepared for it. You can deal with it more effectively and interestingly Michael we add it so we we work really closely with it. Um.

32:50.55

michaelholtz

Um, it's right.

33:02.22

Shelley

Dr. Emily Tonorasos who's the director of the office of cancer survivorship at the National Cancer Institute and she has done a lot of work on hearing loss for cancer survivors and as a result of our conversations with her. We added hearing loss to our survey last year as a.

33:11.71

michaelholtz

Um, ah, interesting.

33:19.16

Shelley

You know we ask about the different side effects. You may have experienced I'm going to get back to you after this and see because I just looked at the data while we you were talking and it didn't show up among the top you know 15 or so that we show on the page and in the report and.

33:29.12

michaelholtz

Sure.

33:33.24

Shelley

So it was probably less than 10 percent of patients experience it. But I'll get back to you with exactly how many but we did ask that question because we were hearing more about hearing loss because it's not talk about very much that that's even a potential side effect.

33:42.62

michaelholtz

Right? right? and I think you know they're on some level doctors are still learning. Researchers are still learning what all of the side effects are for you know some of these drugs. We know they're effective against cancer. But what do they do.

33:53.51

Shelley

Yeah. Yeah, yeah.

34:00.75

michaelholtz

To the rest of the body and I think we're still learning a lot about um so we've talked a little bit. We've talked about legislative advocacy. We've talked about this survey um, but nccs has stuff going on. All of the time in terms of Webinars and programs and so Shelley just touched on so you know from a sort of high level perspective some of the other activities that nccs provides for survivors for caregivers their families.

34:35.45

Shelley

Well you mentioned Webinars we do a lot of webinars. Um, we have sort of 2 series of webinars. But really, they're available to anybody one is for our Cpat which is our cancer policy and advocacy team. That's our program to engage advocates which you are a part of and we have a.

34:52.15

michaelholtz

Um, um.

34:53.20

Shelley

Over 1000 people in that program and and we do different different topics on all kinds of issues. We have 1 coming up. Ah in February on um, head and neck cancer and we've done. It's on. On some of the functional mobility issues related to head and neck cancer and things that you can do about that. We've done webinars on kind of emotional emotional topics on and like heart health on some of them are kind of practical things about managing your own survivorship and some of them are. About being an advocate so it might be about policy issues that we're working on or effective advocacy techniques actually last year I think it was last year you did a great webinar for us on media advocacy and really teaching people how to tell their story in the media. How to get media attention for their.

35:37.36

michaelholtz

Um, yeah.

35:44.87

Shelley

Local events and their local advocacy. So so it's kind of a mix of you know, personal self-management advocacy skills and then policy issues and those are the the webinars we do for advocates and then we also do webinars for our? um.

35:54.32

michaelholtz

Um, right.

36:02.14

Shelley

Survivorship champions which is our program for clinicians and researchers who are interested in improving survivorship care. So they're a little bit more targeted to healthcare professionals but we also have a lot of advocates who attend and listen and we did one in January on oral health. Ah, during cancer treatment and how some of the oral side effects of some of the medications and what you can do about it. It was fascinating I learned so much about it. It was a woman who's a dental hygienist who saw in her practice and then through her family connections some of the challenges and again it goes back to There's no if we had but better care planning and we could tell people that these are some of the things that that might happen and here's how you can address them but the problem is like dentists don't know about every treatment and all the potential side effects. It could be um.

36:45.39

michaelholtz

Of you.

36:55.39

michaelholtz

Um, just bright.

36:57.49

Shelley

Oncologists don't know how to address all the oral issues and so you're left to sort of I was frustrated because I felt like well this is great information again. The patient gets caught in the middle and has got the burden of doing this for themselves and I want the system to work better for patients so they don't have to figure all these things out for themselves.

37:11.32

michaelholtz

Um, why.

37:16.72

Shelley

There was so much information there that I didn't know and so that was great so we do and we have other webinars throughout the year all kinds of different topics and we also do you know we did a webinar in January on um, some we do. Ah.

37:29.45

michaelholtz

Miss me.

37:30.60

Shelley

Policy roundtable twice a year in Dc and and so our fall policy roundtable. We talked about a number of issues and they were really great discussions that we wanted to bring to all of our stakeholders who couldn't come to Dc for the for the roundtable so we had we talked about the inflation reduction act and the. Medicare price negotiation. That's currently in process the first set of 10 drugs that Medicare is able to negotiate is they're currently going back and forth with the manufacturers right now and will release their their price for that later this year and includes 1 cancer drug. And then we also talked about medicare advantage which I'd already mentioned to you so I feel like we do a lot of webinars because I get to moderate a lot of them and it's fun I I channel my inner ah Oprah and do my interviewing of people and um and so that's it's a big part of what we do. It's a way we can. Also you know.

38:14.91

michaelholtz

Um, let's right.

38:24.72

Shelley

Be in touch with our advocates around the country. You know, besides just when they come to DC in June.

38:31.60

michaelholtz

Right? Um, shall we anything we haven't covered that you want to make sure that we talk about about nccs.

38:38.38

Shelley

I don't think so I just invite anybody if you're interested in learning more you can go to our website which is canceraddvocacy dot org and you can sign up to be on our mailing list. We do ah an email called Health Care Roundup once a month that kind of gives ah an overview of some of the health. Ah, cancer policy related activities. What's going on in Dc and some of the news that's coming out and about survivorship about disparities and health equity. And and also has updates on some of the webinars that we're doing and you know activities and Ccs is doing that you could be part of so it's a great way to learn more about what we're doing is just to sign up for that ah to be on our email list and get our health care roundup emails.

39:22.50

michaelholtz

It's a great email I Love I Love getting my email because it helps me stay a brass steppe.

39:26.60

Shelley

That's great and also if you're if you're an advocate a cancer survivor caregiver advocate and you want to sign up for the Cpat program that Michael is a part of you can also do that on our website and and it's free to join and then you get our our emails and learn about the different opportunities to engage and. And we have our our Cpa symposium coming up in June in Washington d c ah where we will have couple days of education and a hill day where we'll go to Capitol Hill Talk to members of congress about the cancer survivorship act and and it's a very fun time.

39:44.75

michaelholtz

Um, yeah.

40:00.31

michaelholtz

It is a very fun time. Great couple of days every June so I love I love doing it and I expect I'll be there again this year um Shelley last question for you? What brings you joy.

40:05.22

Shelley

Good. We hope you will. Well from a work perspective I always say one of my favorite parts of the job is taking somebody to Capitol Hill for the first time who's never been and sitting in their meetings where their members of congress when they realize like you can. The light bulb. Go off that like I have something to say and these people have to listen to me because I'm their constituent and you know they may not do what you ask them to do but they do have to listen to you and for the most part they listen respectfully ask questions engage with you. Sometimes you have people who are not as interested. But.

40:40.55

michaelholtz

Um, and me.

40:48.70

Shelley

You know for people to see that their story matters and they can make a difference for other people and that they can engage in the as broken as dc is and as much as you know members of congress have to deal with. All kinds of stuff they love to have somebody like you come in and talk to them like that's much better than most of the stuff that they deal with and so when somebody people often are very nervous that going up there for the first time and then when they do it and they realize I have something to say and they're listening to me and I can make an impact I just I love that that's.

41:08.00

michaelholtz

But right.

41:22.79

Shelley

That's my favorite part of my job I think just in general my job brings me joy because I love getting to know people like you and working with advocates and and just ah, well sometimes I feel like a broken record because we have to say the same thing over and over. We just have to keep doing it until people listen until we get. You know we have to get the message across that.

41:38.34

michaelholtz

Um.

41:42.35

Shelley

Cancer doesn't end when treatment ends that survivors quality of life throughout from diagnosis through the end of their life is really important and we need to focus on that and I just like being kind of an evangelist for that.

41:52.72

michaelholtz

I love it. Shelley pulled Naso. Thank you so much for spending this time with me and Matthew today I really really appreciate it. Awesome! Thank you so much I'm gonna hit stop.

42:00.62

Shelley

Thank you for having me it was It was a pleasure and an honor.

42:05.13

Matthew Underwood

Thank you.