

## SEPARATING EPILEPSY STIGMA FROM TRUTH: RESEARCH AND RESOURCES (WEBINAR TRANSCRIPT)

- Dr. Laura Lubbers: [00:03](#) Welcome, everyone today's webinar. I'm Dr. Laura Lubbers, and I'm the Chief Scientific Officer for Cure and I want to thank you all for joining us today. Cure is pleased to present the final installment of our 2018 Leaders in Epilepsy Research Webinar series which consists of webinars that highlights some of the key research that's being done on epilepsy.
- Dr. Laura Lubbers: [00:24](#) Today's webinar which is sponsored by our friends at Sunovion is a great way to help conclude epilepsy awareness month this November. This webinar will focus on the stigma of epilepsy. A topic that is a universal challenge among the epilepsy community and affects individuals of all ages and ethnicities. Epilepsy stigma and stereotyping is experienced by many individuals diagnosed with epilepsy. In fact, approximately 50% of people in the US and Europe report feeling stigmatized because of their epilepsy diagnosis.
- Dr. Laura Lubbers: [00:59](#) This stigma exists in part because of a lack of understanding of epilepsy and difficulties in discussing it for fear of repercussions which can be real. This webinar will be presented by Dr. Ann Jacoby who has authored numerous publications on the subject of stigma in epilepsy over the last 20 years. Cure's mission is to find a cure for epilepsy by promoting and funding patient-focused research. This year, we're celebrating 20 years of impact. Over the last 20 years Cure has been instrumental in advancing research in many areas including infantile spasms, post traumatic epilepsy, sudden unexpected death in epilepsy or SUDEP, and genetics just to name a few of the areas.
- Dr. Laura Lubbers: [01:43](#) Today's webinar is entitled "Separating Stigma From Truth: Epilepsy Research and Resources". You will learn about common types of discrimination which people with epilepsy may be subject to, research findings regarding public attitudes and beliefs about epilepsy. The likelihood of encountering stigma because of negative public attitudes and how it affects quality of life.
- Dr. Laura Lubbers: [02:09](#) Dr. Jacoby will also discuss what research evidence suggests about improving public attitudes and what more can be done to reduce epilepsy stigma. Dr. Jacoby is Professor Emerita at the Department of

Public Health and Policy at the University of Liverpool in the United Kingdom. She's a social scientist whose research career has focused on the lived experiences of individuals with ill-health in relation to its daily life impacts and healthcare outcomes. She's had particular interest in chronic neurological illness with a major focus on epilepsy. She's been the holder of grants from the Medical Research Council and The National and Regional Health Service in the UK, as well as from the National Institute of Health in the US. She's served on the Council of Management for the United Kingdom based organization called Epilepsy Action from 1995 to 2003, and she acted as chair from 2000 to 2003 for that organization.

Dr. Laura Lubbers: [03:12](#)

She's chaired the international bureau for epilepsy's second and third commissions on epilepsy risk and insurability and is currently a member of the International League Against Epilepsy's taskforce on epilepsy stigma. She was made an international ambassador for epilepsy by the international league against epilepsy in 1999 and again in 2010, and was recipient of the Epilepsy Action's Lord Hastings Award in recognition for her service to people with epilepsy.

Dr. Laura Lubbers: [03:43](#)

Before Dr. Jacoby begins I'd like to encourage everyone to ask questions. You may submit your questions anytime during the presentation by typing them into the questions tab of Go To Webinar control panel and clicking send. My colleague from Cure, Brandon Laughlin, will read them aloud during the Q&A portion of the webinar. We do want this webinar to be as interactive and informative as possible, however to respect everyone's privacy we ask that you make your questions general and not specific to a loved one's epilepsy. I also want to mention that today's webinar as well as all previous webinars will be recorded and are available on the CURE website. Now, I'd like to turn it over to Dr. Jacoby.

Dr. Ann Jacoby: [04:32](#)

Well, good afternoon, everybody. I'm very sorry that I can't see you but I'm also very honored to be here to present on this really important topic, the stigma of epilepsy. I should start perhaps by saying a belated Happy Thanksgiving to you all before we get going on the slides. So, thanks to Laura for that very nice introduction. I want to start today by thinking, well, telling you why I think it's important to combat the stigma that we associate with epilepsy, and I think sometimes we hear people comment that epilepsy stigma is a thing of the past but I think when you listen

to people epilepsy talk and when you look at the many studies worldwide that have now been conducted into this topic you have to realize that stigma is alive and well and living the UK, the US and many places around the world.

Dr. Ann Jacoby: [05:42](#)

So I think it's very important to recognize the experiences of stigma that people with epilepsy can face. Another thing that we sometimes hear is that really stigma is only an issue where epilepsy is intractable and very serious, but actually my own research and that of others has shown that even people with benign epilepsy, very well controlled can still feel stigmatized and can still report experiencing stigma. Finally, in an ideal world, of course, I guess Cure particularly would argue the most important thing is to cure epilepsy. Without epilepsy, no stigma. But I think it's important to remember that cure won't come necessarily very quickly. In the meantime epilepsy isn't just a clinical label. It's a social label. It carries all sorts of issues with it and those issues can have very large impacts on quality of life. Although I don't think there's an instant cure for epilepsy stigma either I think we can do some things to combat that stigma.

Dr. Ann Jacoby: [07:08](#)

So let's move to the next one. These are just my thoughts about what we need to do when we are trying to combat the stigma of epilepsy. I think we need most importantly to formulate interventions that try to address this question of stigma and we can only really inform both interventions if we understand something about the three Cs, what I call the three Cs. The causes of stigma in epilepsy, the context in which it occurs, and its consequences for people with epilepsy.

Dr. Ann Jacoby: [07:49](#)

So thinking about the causes of stigma I think what we need to do is understand ideas that underlie epilepsy stigma and those ideas, as I'm going to come into in a minute, are often very, very long-lived. Going way back in time. So if we begin to recognize the roots of stigma, the underlying causes, then we begin to have some feeling about what we need to be doing to address it. I think it's also very important to understand the context in which stigma occurs. At its broadest level we need to realize that in different cultures epilepsy stigma will be differently manifested. That means that any intervention we try to make need to address a particular cultural issues concerned.

Dr. Ann Jacoby: [08:46](#)

So we need to recognize that both causes and consequences can only be understood within specific cultural contexts. So what applies, for example, in the UK or the US may not apply in a county in the far east. We can come back to that later. Finally, I think we need to understand the consequences of epilepsy stigma. If we understand how it manifests and with what consequences, we then know what we need to target when we're trying to change people's attitudes and change the experience of people with epilepsy. Added to that, I think we need to explore why some people, but not all people with epilepsy experience stigma. We know that not everyone reports feeling stigmatized. Some people report feeling very high levels of stigma. We need to explore why that's the case.

Dr. Ann Jacoby: [09:52](#)

Okay. I want to start with a definition of stigma. I think it's important for us to understand what I think we're talking about here and I want to take as my starting point a quote from a person who's been referred to as the founding father of stigma research. He's an American sociologist, Erving Goffman, and wrote a great deal about the nature of stigma, not just in relation to epilepsy. In relation to many different attributes and he defined stigma as an attribute that is deeply discrediting. And he goes on to say that that deeply discrediting attribute somehow breaks the kind of rules of engagement between the person with the attribute and others, and somehow allows to treat the person differently.

Dr. Ann Jacoby: [10:56](#)

I think it's also important going on from the research that Goffman did and the writings he has made, contributions he's made to the literature to recognize that it takes two to stigmatize. So stigma in epilepsy, as in other conditions, arises from the interactions between the affected person and others who don't have that particular condition or issue. Those we might call the stigmatized, in this case, the people with epilepsy and the stigmatizers, people without. But it's also been pointed out that the people without have to have power to stigmatize. So unless they are in a powerful position in society compared with the person with the issue, the problem, then they can't create a stigma.

Dr. Ann Jacoby: [11:58](#)

So that's also just an important theoretical issue that we need to keep in our minds when we're thinking about how to get rid of stigma. It has been argued by other theorists that stigma is a mean by which

powerful in-groups separate themselves from weaker outsiders outwards, and in that sense they define a community which excludes others. It's also possibly a way of governing the distribution of scarce resources if you stigmatize a group you don't need to provide them with resources the way that you do others, and we might think about that later in relation to, for example, provision of healthcare services which are often quite poor for people with epilepsy.

Dr. Ann Jacoby: [12:56](#)

Theorists have also thought about how we might breakdown stigma into different issues, different key features and some of those key features it's been suggested include how visible the stigmatizing issue is, how disruptive it is to interactions one person to another. Its aesthetic aspects and whether or not it seems to present some kind of danger to other people and I think it's important for us to think about epilepsy in relation to all of these different key features that have been identified and that begins to help us understand why epilepsy becomes a stigma and why others who have no experience of it could be afraid or anxious around someone with epilepsy.

Dr. Ann Jacoby: [13:54](#)

Finally, I think it's really important for us to remember that there's a very long history of epilepsy as shameful, and that shame has been accompanied with stereotyping about what it means to be a person with epilepsy. That history does I think still inform public attitudes and social policies to this day. So let's just quickly have a look at some of the historical ideas about epilepsy, which I think feed into the stigma that we sometimes experience.

Dr. Ann Jacoby: [14:35](#)

If you go right back into ancient times you find that epilepsy was very commonly seen as possession by Gods or evil spirits, or some kind of punishment from the Gods for sin, okay? And I have quoted here a Greek doctor who wrote around about the first century BC and he wrote a very, very impressive account of what epilepsy is. Remarkably up to date with modern ideas about the clinical form of epilepsy, but he did describe it as a disgraceful form of disease and he goes on to comment about the fact that it's not curable and that people keep away because of the disgrace associated.

Dr. Ann Jacoby: [15:37](#)

If we jump right forward, oh, I didn't mean to jump then sorry. Let's go back. If we jump right forward to the 19th century we find the very negative ideas about epilepsy still persisting with people writing

about the link between epilepsy and crime, and the link between epilepsy and violent behavior. At that time, in the 19th century there was quite a lot of consideration of what was described as the epileptic personality, which was seen as comprising imperfect intellect, weakened capacity for doing things, defective moral control, duplicity, egotism.

Dr. Ann Jacoby: [16:27](#)

So a lot of very negative words describing the nature of this so-called epileptic personality. Another set of theories that were very, very common then were the idea that epilepsy was an inheritable disease and authors at that time talked about the degenerate epileptic and it was thought that epilepsy was the second generation of a degeneracy in a family. It was a second generation outcome. We should also remember that it was very common for people with epilepsy to be institutionalized at that time. In fact, some of the very famous institutions for epilepsy actually started in the 19th century as a means of housing people with epilepsy.

Dr. Ann Jacoby: [17:22](#)

Let's move on to now. So if we ... Holding that information about the history of epilepsy as stigma in our minds let's think about today and the current social reality, if you like, of epilepsy. I'm going to focus on the developed world rather than the developing because they are rather ... Countries in the developing world do have not surprisingly different ideas about epilepsy and different ways of treating. So I'm really focusing on developed world countries, in particular the UK and the US where I have done most of my research.

Dr. Ann Jacoby: [18:04](#)

So I think it's important to start by saying that things are a great deal better than they were in ancient times and in the last century, last but not one. Restrictive legislation against people with epilepsy has been repealed. Epilepsy's now what's called a prescribed disability. Both the terms of the of the US Americans with Disability Act and the UK Disability Discrimination Act and those acts provide protections for prescribed disabilities. There have been many anti-discrimination initiatives a lot around employment trying to make sure that people with epilepsy are not discriminated against in that particular environment, and of course, we've seen the rise of epilepsy charities as very powerful campaigning bodies. Cure obviously being one of them and I myself was involved in the major one on the UK, Epilepsy Action.

- Dr. Ann Jacoby: [19:09](#) So these are very, very important progresses that have been made in the last hundred years or so, but we do know from research that people with epilepsy do still experience stigma and discrimination in all sorts of areas of daily life. In education, employment, insurance, healthcare, and so on. So it really is the case that stigma is still alive and well I think. So let's just think about present-day public attitudes to epilepsy. What do we know about them? Because I think this is very critical to the experience of stigma for people with epilepsy. Well, at this point in time there have been a lot of surveys done all around the world and these have been done not just of the general public as a whole but also of particular subgroups within general public.
- Dr. Ann Jacoby: [20:08](#) So studies have looked at the attitudes of healthcare workers, the attitudes of employers and co-workers, teachers and police. All these studies document low levels of knowledge and negative attitudes are common. Now, I think it's important that we note there that these studies also suggest that there have been marked improvements with time in relation to public attitudes. Now, if you look at the little graph on the right of the slide, my right I just produced one question for you to think about which came from a series of studies done by Caviness and Gallop in the United States. They did the first study in 1949, repeated it in 79, 89, and 2001 and they asked a series of questions of people responding to the survey about epilepsy.
- Dr. Ann Jacoby: [21:10](#) So one of these questions was would you object to a child of yours playing with one with epilepsy and you can see what a massive improvement there has been in attitude from almost 30% of people in 1949 saying they would object right down to two, three percent, two percent of people in 2001 saying that. So marked improvements by time and if you look at the other questions., which we'll come on to you see the same kind of improvement over that time period.
- Dr. Ann Jacoby: [21:50](#) I think however we also need to remember that there are marked variations in the experience of stigma and in public attitudes by place. So if we look across different countries in Europe we find the percentages of publics expressing negative attitudes is quite variable and that has a very clear effect on felt stigma amongst people with epilepsy, and I suspect if we did it across different sections of the US we might find similar differences to those in Europe.

Dr. Ann Jacoby: [22:29](#)

So I think my conclusion there is that stigma is a global problem and public attitudes are key to it. I just wanted to show you a bit more about the Caveness and Gallop data and I think in particular you will be interested in these bars, the blue and the brown here, here, here which are showing you the percentages of people in the United States in 1949 and 1979 who answered yes to particular questions. So, I'm so sorry. That's jumped. Let's move it back. So here it was a question about whether epilepsy was a form of insanity, and you can see that that figure dropped right down. This is the question about whether you would want your child to play with a child with epilepsy. Massive decrease in the percentages of people who would object to that. This one was about whether people with epilepsy could work in employment or could not work in employment the way other people would, again, a massive drop. So really very marked improvements over time and if you look across all the blocks then you can see different countries and the reporting in different countries, and so you also see these differences by place that I talked about on the previous slide. Let's move one.

Dr. Ann Jacoby: [24:11](#)

We did a study in the UK in 2003 where we interviewed 1,600 people. A random sample across the UK and asked them some fixed questions about their attitudes towards epilepsy but also gave them an opportunity to just comment on what they thought about epilepsy as a condition and these are just some of the comments that came back to us. People with epilepsy can't do the things normal people do. They need more looking after. It's embarrassing, people having epilepsy. They're not in full control of themselves. So they're different. They're a health risk to the public.

Dr. Ann Jacoby: [24:51](#)

Now, this is not very long ago so it's quite sad to see these sorts of opinions being put forward in so large a study. Just moving on I think it's important as well that we realize that media has an important role in reinforcing or trying to counteract stigma of epilepsy and the way that media has represented epilepsy has not always been helpful to our cause. So if you look at media representations you find they're often inaccurate and misleading about epilepsy, and they often reinforce public misperceptions and stereotypes.

Dr. Ann Jacoby: [25:42](#)

A colleague and friend of mine in the UK, Sally Backsindale, analyzed representations of epilepsy in



movies, films made going right back to 1929 and in those films, in her analysis she found that epilepsy was still being conveyed as the outcome of demonic possession. It was often portrayed as representing vulnerability and weakness in the person so affected. So, very negative ideas often being presented or if not negative, misleading about the nature of epilepsy.

Dr. Ann Jacoby: [26:33](#)

The Scarlet E is an article that was printed that came from a group of researchers in the US. They looked at print stories in the US newspapers and found that 54% used the term epileptic, one which we've tried to steer away from as being quite a negative labeling. 31% of stories contained scientific inaccuracies and six percent even in 2000 used demonic imagery to describe seizures. So a lot of very difficult issues here that we need to be challenging very firmly, but I don't want to paint an entirely gloomy picture here so I want to highlight that there are also signs of improvement. Epilepsy Action has done an analysis of media coverage over a number of years and found that it is increasing and it is increasingly more positive, and it's interesting that it's also appearing as a storyline on programs on TV in the UK. There's what we call a soap opera called EastEnders, it's very, very popular. Many people watch it. Recently featured a person with epilepsy and it was a very sympathetic portrayal and some of you may know that ER, which came from the US but was extremely popular here too took epilepsy as a storyline on more than one occasion, and I think at least one of the doctors had experienced seizures. So there are some signs of improvement here.

Dr. Ann Jacoby: [28:31](#)

A study about knowledge, because I think people often think if we can address knowledge stigma will go away. So I just wanted to remind you, if you haven't come across it, of a study that was done in the US in 2003 about knowledge of epilepsy in the US population. This was a male survey coming out of the Center for Disease Control and Prevention. The nine questions were included on epilepsy. The sample was over 4,000. So a lot of people took part in this study and only half of them had ever witnessed a seizure. So that's something we need to think about too.

Dr. Ann Jacoby: [29:25](#)

Only a third knew what to do if somebody was having a seizure, quite worrying. And few, under 20% said that they had either read or heard anything about epilepsy in the previous year and the authors

concluded that based on all of the answer to these nine questions epilepsy remains very much a mystery in the United States. Now, around the same time another group of researchers was looking at attitudes to epilepsy in North American continent. I think this was actually done in Canada rather than the US, but they wanted to explore that old 19th century idea that epilepsy was associated with potential for violence. They were interested in whether that concept contributed to stigma as felt in the present day and they used a questionnaire which they sent out at two different time points. The first survey was done in 1982 and then they repeated it in 2006.

Dr. Ann Jacoby: [30:39](#)

The samples for these two studies were students, physicians, care workers, the general public, and people with epilepsy themselves. Somewhat surprisingly high figure, 50% of respondents believed that violence was possible or likely during seizures and the authors note that that that figure didn't really change between these two time points. It was a pretty stable view taken by people who responded.

Dr. Ann Jacoby: [31:12](#)

So where do we go from here? Now, this is really hot off the press from the UK and I'm very privileged to be able to present it today. I've been given permission by its authors and by Epilepsy Action because they felt they would like CURE listeners to be able to share in this research. It is going to be published. This was a study looking at ideas that the UK and attitudes that the UK public had about epilepsy, and what it shows is that for every 100 adults in the UK that took part in this survey one will have a very negative attitude. That little red person there. 10 will have a negative attitude towards epilepsy. So these are our orange people, but very reassuringly 59 will have a positive attitude and 30, a very positive attitude. So actually it looks like public attitudes in the UK in the present day are pretty good but one thing that did emerge from this study was that the UK public does have concerns about risk and safety issues. So, for example, if they were working with a person with epilepsy or if a person with epilepsy was looking after someone, so forth.

Dr. Ann Jacoby: [32:47](#)

So the authors have concluded that there are some really important educational messages here for the UK public and for other public elsewhere because they need to understand much more about epilepsy and about what risks it does and doesn't present to others, and that would help perhaps to change Mr.

Negative at least to only negative but hopefully to positive. So there's a lot of work there for us to be doing.

Dr. Ann Jacoby: [33:18](#)

How does all of that translate into the way that people with epilepsy feel? Well, I think this is just a useful slide. This is just showing the results from different studies that have been done across the last few years showing the percentages of people feeling stigmatized. The first study was one I did and you'll see only 14% reported feeling stigmatized. Now, these were people with epilepsy in remission. So they hadn't had a seizure for at least two years. Then we look at people who had active epilepsy. Their seizures were ongoing. 51% of them felt stigmatized. So a very big difference there.

Dr. Ann Jacoby: [34:07](#)

A study that spanned the UK and the US found 35% of people with new-onset seizures felt stigmatized. In a study I did in the UK, only 26%, and again, new-onset epilepsy. People in New York City, 22% feeling stigmatized very early on. So being in remission helps you not to feel stigmatized, but the rates are variable and in all studies feeling stigmatized was associated with feeling that you had a poorer quality of life. If we look at what studies have shown collectively as the consequences of epilepsy we see that it can have a massive impact on a person's sense of well-being. If you feel stigmatized you are likely also to report, well, to be at greater risk of depression, anxiety, to have reduced sense of self-esteem and efficacy and to be more socially isolated.

Dr. Ann Jacoby: [35:17](#)

Negative attitudes and discrimination we see are linked to lower achievements in education, in employment. People with epilepsy earn less. They have fewer opportunity at work and that has been attributed in part to the impact of stigma. They report increased social isolation. They even are less likely to get married. So there are some major consequences for well-being.

Dr. Ann Jacoby: [35:49](#)

So let's move on then to think about what we can do to combat epilepsy stigma and reduce those negative consequences that we've seen, which don't affect everyone with epilepsy but for some people are very, very real. Well, I would argue that we need global, worldwide, we need national and we need local strategies to identify what we need to do, what we need to try and change and to think about how we can bring about change. We need culturally-

based interventions so that we know exactly what aspects of stigma play out in particular cultures, particular subgroups of populations and so on and we can target those specific populations to make change happen. We also need some formal assessment of what our interventions achieve. We need rigorous scientific studies showing how effective interventions are so that we can argue the case for getting funding for more. Okay?

Dr. Ann Jacoby: [37:03](#)

This is one international initiative, the global campaign about epilepsy. "Epilepsy Out of the Shadows". Some of you may have heard of it, some of you may be involved with it but it is trying to stop epilepsy being misunderstood, feared, hidden, and stigmatized. A very, very important initiative worldwide and one of the things that that campaign is currently doing is looking at epilepsy in relation to legislation. It's collecting information worldwide about legislation as it relates to epilepsy in all these different areas, and it's trying to identify key human rights issues that need to be addressed. Develop guides for policymakers, lawyers, advocacy groups. To provide instruments for advocacy and lobbying, and to increase awareness about how we can better integrate people with epilepsy where they may currently not feel that integration is good of them.

Dr. Ann Jacoby: [38:16](#)

This is a UK initiative from Epilepsy Action. They have an E-learning project now and people who want to know more about epilepsy can do online courses and there are 30 short videos that they can watch about different aspects of epilepsy. Epilepsy Action's produced a number of short films which people can view via social media and they have a seizure app which can be downloaded onto people's smartphones helping them to know more about Epilepsy and what it means.

Dr. Ann Jacoby: [38:57](#)

Laura mentioned earlier than I'm on a task force currently. An International League Against Epilepsy task force which has been reviewing stigma reduction interventions and there's certainly evidence that such interventions work. 11 out of the 12 we identified improve knowledge, six out of 10 improved attitudes and perceptions but it's clear I think to see that so far we could only identify 12 interventions aimed at reducing stigma that were epilepsy specific and had some kind of assessment of outcome. We need a lot more of this kind of work to be done.

Dr. Ann Jacoby: [39:40](#) I said earlier that education is important and many intervention studies in other health conditions that are stigmatizing have shown that it is, but they've also shown it's just not enough. One of the key things that really does change public attitude is contact with people with the stigmatizing condition. So there are important lessons for epilepsy interventions from other health conditions and it has been argued that the consequences of stigma are remarkably similar in different health conditions. I would support that from my own work.

Dr. Ann Jacoby: [40:23](#) I think I want to also just say here that it's really important that people with epilepsy themselves are involved as experts in developing research and even doing the research and a really interesting study in the US recently was looking at how to project a participatory approach into developing a survey of public attitudes. So they asked people with epilepsy to suggest what they thought were the most common misunderstandings in the general public. What they thought was the best way to educate the public, and what kind of information they thought needed to be promoted. They came up with some very useful data from talking to people with epilepsy that then provided the focus for their intervention activities.

Dr. Ann Jacoby: [41:21](#) So some people talk about that as a bottom-up research approach. I think it's an involving experts approach to doing research and really key to taking things forward. Very quickly just to say we do need to challenge negative labels about epilepsy and terms that people use. A study that was done in the US in 2007, published in 2007 looked at how employers responded, potential employers responded to different labels about epilepsy. So they were asked to say how likely they were to employ a person who had epilepsy compared to a person who had a seizure disorder or a seizure condition, and epilepsy was more positively received in that study than seizure disorder or seizure condition. Similarly a study in South America, in Brazil actually, looked at student respondents and asked them about social difficulties of persons with epilepsy or epileptics and that study also found that there were more difficult perceptions for people labeled as epileptic, when we used the label epileptic.

Dr. Ann Jacoby: [42:46](#) So labels do really matter and that's another thing we need to challenge and think about, and we can do that using the new social media. There are three

different studies here, one using an educational video for children nine to 11. One using TV public service announcements again done in school pupils, and one using YouTube and all of these studies found that knowledge could be improved and telling real-life stories about people's epilepsy really could change the way that people think. These are things that are targeted at young people who are the ones who are going to come through and interact through their lives with people with epilepsy. So we really want to be targeting early on.

Dr. Ann Jacoby: [43:36](#)

So to finish then my key messages for combating epilepsy stigma. I would say it's really important to recognize what the public understand about epilepsy is changeable. That's really important for us. We can challenge about epilepsy as stigma and shame and we can get the public to think differently. We have to continue to challenge treatment gaps. We need to change the clinical reality for the better, but we do also need to change the social reality. We need to campaign for better resource research so that we can really take things forward and we need to demand well-formulated legislative support to help fight stigma and strengthen the position of people with epilepsy.

Dr. Ann Jacoby: [44:33](#)

So going right back the beginning of my talk. We may not be able to cure epilepsy stigma straight away but I'm sure we can do a lot to combat it. Thank you all very much for listening and for your patience today.

Dr. Laura Lubbers: [44:52](#)

Thank you, Dr. Jacoby. We'll now begin the Q&A session. Again, if you have any questions please submit them in the questions tab of the Go To Webinar control panel and click send, and Brandon will go ahead and read them. I believe there's already some questions in the queue. Is that right, Brandon?

Brandon Laughlin: [45:08](#)

That is correct. As you can imagine, Dr. Jacoby. We did receive quite a number of questions dealing with combating and helping change people's attitudes about epilepsy and I know you addressed some of these already. So I'm going to just highlight a couple in specific areas. One of the questions was how to help combat the stigma in regards to employment and when it comes to employers and actually co-workers. Are there strategies that people can use? And are people with epilepsy who need to take time off for doctor's appointments covered under the

Americans with Disabilities Act? A double question there.

Dr. Ann Jacoby: [45:57](#)

Yeah, a double question. Okay, I think that, first of all, can I say that I don't know the answer to that last question because I'm not familiar enough with the Americans with Disabilities Act to know whether they are protected to go to hospital appointments or doctor's appointments, but I what I would say is that anyone who has an illness of any sort may need to see a doctor from time to time for a regular checkup or for treatment adjustments and so on. I think that employers would recognize that sometimes people have to take time off and that applies to anybody. To me, to you, to anyone. So I think we need to just be firm about our rights as employees to understanding if we are not well, but we also obviously can if we are really put into a difficult positive turn to acts like the UK and the US Act and look at how those acts protect us in difficult situations where employers are being unreasonable.

Dr. Ann Jacoby: [47:17](#)

So I think that's very important. I think a question that Epilepsy Action quite often has been asked about the position in relation to employment is if I'm going to be interviewed for a job do I tell the potential employer that I have epilepsy? And I think the positive that they have tended to take is that you don't need to disclose that you have epilepsy immediately. Sometimes you will be asked a question on an application form and you may have to then say something, but the epilepsy should not be the foremost thing. The question is, do you have the qualities and qualifications you need to do the job?

Dr. Ann Jacoby: [48:11](#)

So I think we perhaps need to be robust about going to employers and presenting ourselves to them in a robust way as a person who has the skills that are needed. Now, in the UK, and I suspect it's the same in the US under the disabilities act employers do have to make certain provisions for people who have long-term health conditions and when we did the survey where we asked members of the general public about their attitudes and knowledge of epilepsy we also did one with employers, UK employers and we found that employers were a strange mixture of willingness to adapt and still holding negative attitudes. But they were willing to consider things like letting people do shorter days, letting them have later mornings ... coming in later in the morning if they needed to or leaving earlier and so on.

- Dr. Ann Jacoby: [49:21](#) So they were willing to consider adapting the work environment to fit the needs of people with epilepsy. I think that's a really helpful thing to know and perhaps we need to just have that conversation with employers much more than we have so far to move their thinking along. Does help to answer the question?
- Brandon Laughlin: [49:50](#) Good point and actually to follow-up with that question, the ... On a similar note, we had a question about how do we really change people's attitudes in regards to cognitive ability?
- Dr. Ann Jacoby: [50:05](#) Yeah, I mean, again I think there is this problem that it seems that people always link having epilepsy with having conditions of being that may occur in epilepsy just as they may occur in other groups of people. We do know that in people with very severe epilepsy there may be cognitive problems. We also know that drugs that people take to control their seizures may create some cognitive difficulties. Quite often people talk about having memory problems. They feel that they're not as alert and so on. So these are difficulties that can occur but the important message is they are not necessarily happening for every person with epilepsy, and I think it's that conflation of the idea that if you have epilepsy you must also have cognitive difficulties that we need to really do something to change thinking about. That requires a lot of educational efforts in general populations but also in particular subgroups like lawyers.
- Brandon Laughlin: [51:29](#) Right, and as actually a follow-up to your answer there. It's a nice segue into the next question. Do you know if countries are combating stigma by actually helping educate people about epilepsy during adolescence and during school-age children?
- Dr. Ann Jacoby: [51:49](#) I think that there are projects to do that but I think our problem, our difficulty is they're often very small scale. It's actually really quite difficult to get funds to do those sorts of projects, which is where I think charities' campaigning have a big role to play because it can be quite difficult to convince teachers and school boards and so forth that this would be an important part of educating of young and teenage children. Buy, yes, there are small scale initiatives doing that kind of work and perhaps we can use the outcomes from those initiatives to convince funders that this is a really worthwhile piece of educational activity.



Brandon Laughlin: [52:49](#)

Great, thank you. I'm going to try to get through two more questions here in the time that we have. The next question, obviously, without getting into too much detail but you mentioned earlier the difference between the developed and the developing world in regards to stigma. Out of curiosity, what are some of the principal differences?

Dr. Ann Jacoby: [53:14](#)

I think this all goes back to understanding how different cultures think about epilepsy, and I and colleagues had funding from your national institutes of health a few years ago to look at the nature of stigma in China and Vietnam, and it was very interesting to us to first of all, explore ideas about what caused epilepsy and how it could be treated, and then also look at how people thought that you had to treat a person with epilepsy. Because actually the ideas in those two countries about the cause of epilepsy are not hostile ideas, the sort that I was talking about where people think about possession by evil spirits. They were much more aligned with traditional Chinese medicine ideas about imbalance in the body systems.

Dr. Ann Jacoby: [54:17](#)

So epilepsy and seizures were seen as caused by bodily imbalance and treatments were focused at trying redress those imbalances. Get the body back in balance. So in China, for example, people do take modern western drugs but we found that very often they thought that those drugs were there just to stop seizures but you also needed traditional medicine to realign the body and that that would rid you of epilepsy.

Dr. Ann Jacoby: [54:53](#)

So these are very benign ideas and there was a great sense of care towards people with epilepsy but there was also a recognition that they presented danger to themselves if not to others. So, for example, they couldn't go and work in rice paddy fields because they might have a seizure and drown. People were worried about them having seizures outside in the community and being treated badly and so they tended to keep family members with epilepsy at home. Keeping them isolated from others. People with epilepsy in China and Vietnam were not considered particularly good marriage partners because they couldn't really do the tasks of childcare, and marriage, employment that were expected of them.

- Dr. Ann Jacoby: [55:50](#) So the ideas were very different from ancient ideas but the impact tended to be the same and the same as in our culture, even though the ideas are very different. If you look at some of the countries in Africa you see very different ideas again about causes of epilepsy, and there sin and possession by evil spirits still are held to be important causes of epilepsy and ideas about it are very hostile. So people with epilepsy are treated quite poorly in quite a lot of African countries, and in some countries there epilepsy is referred to as the burning disease because people are ... If they're having a seizure they can't be touched in case they pass epilepsy on. So they fall into open fires and get burned and so on.
- Dr. Ann Jacoby: [56:47](#) So I think those cultural ideas are really important and they do emphasize that you need to understand the ideas underlying epilepsy in order to develop educational programs.
- Brandon Laughlin: [57:02](#) Great. Thank you very much. Just to end on a good question here if you have maybe a 30 second answer to... Maybe just some of the resources that may be available to really help people talk more openly about stigma.
- Dr. Ann Jacoby: [57:20](#) Some of the resources did you say? Sorry.
- Brandon Laughlin: [57:24](#) Yeah.
- Dr. Ann Jacoby: [57:25](#) I couldn't hear your word. I mean, I think there is a lot of information available from the charities which is a really useful ... I mean, one of the points I made or one of the slides was that it's all very well to educate people in an abstract sense but actually what people really, really need to know is that I've got epilepsy and I'm just like you. Apart from the fact that I have that condition I am just like everyone else, and studies in different conditions worldwide have shown that contact with a person with a stigmatizing condition is so important because then people realize that, "This is a person just like me." And those stereotypes, hostile, negative, crazy stereotypes can't be held in your head if you've met and befriended and got to like someone who then turns out to have epilepsy.
- Dr. Ann Jacoby: [58:23](#) So I think that's my, not 10 words only or whatever, but as short as I can make it answer to your question, Brandon. Or to who the question is ... The question. I hope that helps.

Brandon Laughlin: [58:37](#) Thank you. Yes, thank you so much, Dr. Jacoby. I'm going to go ahead and turn it back over to Laura.

Dr. Ann Jacoby: [58:44](#) Okay.

Dr. Laura Lubbers: [58:46](#) My thanks you as well, Dr. Jacoby. We really appreciate your presentation on this very challenging topic and some ideas on how we can go about changing the stigma that just isn't justified. I'd also like to thank our partner, Sunovion, for sponsoring today's webinar and webinars throughout the year, and of course, always want to thank our audience for your engagement and your great questions, and also the topics that you suggested some topics that we want to ... that we should be sharing with you. So if you have any other questions about this topic or Cure's research programs or have suggestions on topics you want to hear about, please do visit our website at [cureepilepsy.org](http://cureepilepsy.org) and feel free to email us at [info@cureepilepsy.org](mailto:info@cureepilepsy.org).

Dr. Laura Lubbers: [59:33](#) Thank you all again. Please stay tuned for our announcements for our 2019 webinar series that will be coming soon. Thank you again, Dr. Jacoby. Good day to all.

Dr. Ann Jacoby: [59:45](#) Thank you, and thank you for inviting me to do it. And thanks to everybody. I'm really sorry I can't see your faces, but thank you so much for listening.

Dr. Laura Lubbers: [59:57](#) Good day.

Dr. Ann Jacoby: [59:57](#) Bye.