

COMMISSIONER ASTRUE: All right, I think we're going to get started for the homestretch now. For our final panel, we are very pleased to have three distinguished guests, our first guest is James Baranski, who is chief executive officer for the National Stroke Association, we also have Dr. Richard Zorowitz, who is chairman of Physical Medicine and Rehabilitation at Johns Hopkins Bayview Medical Center, we also have Jose Maldonado, who is co-founder of Centre TEK, who is a stroke survivor and advocate. And we'll start with Mr. Baranski.

JAMES BARANSKI, CPA: Hi, Good Afternoon, and thank you for the opportunity to be here this afternoon. On behalf of National Stroke Association, we're delighted and grateful to have this opportunity. Some of you know, many of you don't know, that stroke is the third leading cause of death in this country. Roughly 780,000 incidents a year. That's third behind heart attack and cancer. Perhaps even more disturbing is that stroke consumes roughly 6 million survivors in this country right now, and as every year edges forward, and us boomers get older, there are many researchers that are predicting really a true tsunami of stroke. Obviously, many of us are living longer these days, and the incidence of stroke in those 50 years and older is really at its greatest. That's not to say that infants can't have a stroke, and it's not to say that those younger than 50 have strokes, they certainly do. But it's important for all of us to recognize the enormity of this disease, and also, I'm sure most of you know that stroke has been around for a long, long time. Hippocrates writes of strokes, so that's like 400 – 400-something B.C. If we fast forward to today, it really wasn't until 1996 that the first approved, FDA-approved treatment came online with which to treat stroke. So think about that stroke in terms of treatment is truly in its infancy. Since that time, two other devices, actually devices have come online in the last three years that are also able to remove a clot, one of the forms, one of the two forms of the stroke. So, again, there aren't a whole lot of tools in the tool box, but meanwhile we have 780,000 people a year having a stroke. And it's always been curious to me, and I am speaking to you more as a layperson than as the CEO of the National Stroke Association, that considering how many survivors there are -- and by the way, National Stroke Association is big on calling those who have a stroke survivors, versus victims, but it has always surprised me that the recognition of those who survive a stroke, particularly considering some of the disabilities that they are faced with really go unrecognized. If you compare that to, say, breast cancer, you have champions who have survived breast cancer. It is not the same with stroke. And you'll hear a little later from a stroke survivor who can share some of his personal stories, but for us as a patient advocacy organization, we believe it is incredibly important to be able to provide those who have a stroke hope. Hope that there is recovery, hope that there is rehabilitation, hope that they can once have the freedom again that they once had before. Hope that they can go back to work. Changing gears for a moment and commenting on some of the barriers and struggles that survivors have in the world of social security and disability claims, it is quite challenging for them. Not unlike many of the stories that you've heard earlier regarding brain injury, you're talking about people who suddenly have lost in many cases significant cognitive function. I mean, it is not like doing your tax return. People kind of get used to doing their tax return every year. You can use turbo tax or you can even hand it off to a professional and have them do it. The process of applying for

these claims is totally new to all of these individuals, plus oftentimes they are working with a deficit in the process to try to fulfill those -- the information documents, so, and unfortunately there aren't really tried and true standards to determine what recovery, what disability truly is with respect to stroke. And, again, I think one of the reasons for that is, as I said, stroke truly is in its infancy in terms of treatment and the whole rehab and recovery side is also in its infancy. However, there is hope, once again, that as the availability and as the technology behind imaging improves that -- I have five minutes left -- [laughter]

I just noticed that. did I get like an eight minutes, too? [laughter]

UNIDENTIFIABLE VOICE: Don't tease her, she'll cut your minutes down. [laughter]

JAMES BARANSKI, CPA:As I was saying, as the technology behind imaging continues to advance, we're hopeful that we can truly be able to recognize the individual likelihood of recovery for the stroke survivors, because not every -- I once heard a physician say to me that strokes are like snowflakes, you know, each one is uniquely different. And attached to that unique difference is a very unique rehab and recovery process as well. I also hear many physicians speak to how these advancements in imaging technology, regardless of brain injury, can hopefully help us better understand what types of rehab, recovery systems are available, and those who truly can recover from a disability, and those who can't. And I'll dismount before my three-minute card. [laughter]

COMMISSIONER ASTRUE: Thank you. Dr. Zorowitz?

RICHARD ZOROWITZ, MD: Thank you very, very much for allowing me to come and talk at this forum. I will take Jim's statement of the 780,000 stroke survivors just a little step further. Approximately 28% of people who have strokes are under the age of 65. So this is not necessarily a disease of the elderly. There are many, many people, as Mr.Maldonado is going to talk about, who are younger, and the big decision really comes up whether or not we can get people back to work or whether or not we're going to end up having to apply for disability benefits. This becomes rather challenging for a number of reasons. Instead of the usual epidemiology of stroke, which is about 85% ischemic, 15% hemorrhagic, actually, the number of hemorrhagic strokes in younger patients is really a lot higher and the types of reasons that patients have strokes really are a lot different. You play into, you know, aneurysms, avm's, arteriovenous malformations, bleeds, drugs, just to name a few. And so really the way that we go about treating these patients actually can be somewhat different. But what makes everybody relatively similar is the challenges of trying to get them through the process. Part of the issue that we have in terms of getting patients rehab is that we have to deal with, you know, not only the patient, but then we have to deal with the psychosocial issues, we have to know what their support systems are at home, what are their living situations so that we know that maybe we can match what we expect their function to be with what we hope them to be down the road a little bit. Unfortunately the third thing that always comes up is the insurance issue, which is a very major issue. And that actually even includes medicare. And because of the fact that Medicare, with everything going on these days in government affairs and now with the economy especially, is ratcheting down and has

been ratcheting down. So it becomes much more difficult to try to get patients really the services that they need. Although rack audits which have been going on have been put on hold, there are other issues in Medicare and also with commercial insurance, things like cognitive rehab, so patient may be physically okay, but if their executive functioning, memory attention, and all those other things are not working properly, it is often very difficult to get them treated. And so often what we have to do, then, is depend upon the government possibly to give some of those -- get some of those benefits, if we can't get it through insurance, the only other alternative we have is through voc rehab services which every state in the country has. Unfortunately every state in the country may vary depending upon, you know, the amount of money that states are putting into their vocational services. In theory what should happen is that we should be able to get patients things that insurance don't pay for, whether it's neuropsych evaluations, work assessments, driving evaluations, you know, all these things are essential for people to make that decision whether they can or cannot work. And so we really have to go through this process of doing this to make those decisions. Other things that have been going on in stroke, really, that we have not seen a lot of is really the systems of care, which really this is a big part of. Starting in around 2004, the joint commission with the help of a group that -- some of the groups that I have been involved with came up with the accreditation for primary stroke centers to be able to start getting center -- hospitals that can meet the bar and provide services for stroke, at least to treat them in the acute phase. Actually, even as we speak, I've been seeing the e-mails, our comprehensive, which is the higher level, is going to be proposed and hopefully will be passed and we will hopefully get very good centers of stroke systems within the states. There are a number of states, such as North Carolina, Florida, New York, New Jersey, Maryland, that are really coming up with their own stroke systems, and so very, very good. The problem is is that down the road, we have those issues of how do we organize care so that patients can really get the services that they need to try to determine whether or not they are able to work or whether disability benefits have to be applied for. I think finally what I really just want to talk about, then, is just the process. As I mentioned before, getting people into, you know, levels of rehab, you know, can be somewhat challenging depending upon insurance. That can go into acute comprehensive rehab such as -- places like in town here, the National Rehab Hospital, which is very well known. Kessler institute in New Jersey, Rehab Institute of Chicago, just to name a couple. They can get them in sub-acute facilities which are not quite as intensive. They can get them in nursing homes. It's really been shown through the evidence that more intensive rehab, if we can get it for that patient and if they can tolerate that, is better for the patient. Again, some of the financial issues sometimes come to play. If you go to the west coast, it is sometimes hard to get patients into acute rehabs, and they end up getting this lesser intensive type of rehab, and that may affect their ability to be able to work and do these things. We can also worry about outpatient and home therapies as well. So we have to get patients through all of these different levels of care eventually to see how well we can maximize their function, both physically and cognitively. Probably I think the biggest issue is that it's often hard, as Jim has suggested, that getting patients to understand what benefits they might be, you know, they might qualify for is a challenge unto itself. Good follow-up, either with a neurologist or physiatrist such as myself, you know, is difficult. I've had patients who come, you know, who found me on the web and will say, Dr.Zorowitz, where have you

been all my life, you know, I need you. But we don't have, you know, the really good systems there to be able to take patients, you know, to follow them for the long-term and help make those decisions. Those decisions, by the way, are really, as we can talk about later, are clinical, not necessarily through a lot of the diagnostic things, although they may have a little bit of impact, but largely these are clinical diagnoses, as I think you've heard through the rest of the day. Some of these things do take time. Some of them are slam-dunks in terms of how, I think, that we can say that patients are not going to be able to be able to return to work, but some are, and can take a year or two. Again, there's not a lot of evidence out there, you know, to support this, and so we have to have that good follow-up. So ultimately, I think what I want to conclude by saying is that this is a really important issue in terms of, you know, getting patients. We would like to be able to lower the burden, as you may be aware, the Heart Association estimated that in 2008 the cost of stroke is about \$65.5 billion, of which about two-thirds are the direct costs, the other third of it happens to be due to loss of productivity. So it is a very, very significant challenge that we look at. If we can get these patients back to work, then absolutely wonderful. If not, then we need to steer them in the direction to allow them to get some of the benefits that they hopefully qualify for. Thank you.

COMMISSIONER ASTRUE: Thank you. Jose?

JOSE MALDONADO: Well, my name is José Maldonado, I didn't know what I was going to say or talk about today. I am a stroke survivor. my stroke was about six years ago, and I am an example of what is possible, of what can work right. I like to say that my case, you know, my glass is half full. it is not half empty. I have had a lot of support throughout this journey, starting with the good doctors, you know, good therapists, but I realized early on, for reasons that I will tell you about later, that my entire answer to my predicament didn't lie with the doctors and the physical therapists and the nurses, I was very lucky in that I have a very extended family, my wife, my kids, my mother, and millions of cousins that I got, but also I have my own company, an I.T. company, and when you have a small company, they are like an extended family. and they wouldn't let me stay at home, feel sorry for myself, they were always visiting me, and the only way that I could get these people to go back to work was if I would agree to at least pretend to go to work. And so, you know, the same attitude that they displayed was the same attitude that my wife and my kids, in that they were always egging me on. I would love to sit here and say that I am doing well today because I have an iron will, because I had a plan, because I was strong. Nothing could be further from the truth. I was convinced early on that I couldn't get better. When I went home from the hospital, I went home in a wheelchair, I could barely talk, I couldn't read or write. And I certainly couldn't drive. but I knew that I was lucky to be alive. So I felt grateful, and I felt that I had plateaued early. But for some reason, my family, my friends, my company, whatever I was doing or not doing wasn't good enough for them, and so you know, I felt humbled and guilty by all the attention and love I was getting, and I tried, at least tried to get better, and the more that I tried, the better I got, better I got, the more I tried. Now, I was doing this because I felt that it was my way to show to people around me that I was trying and that I cared, but, you know, it was also a way for me to focus -- my focus was entirely on my family, my friends, and everybody else, and I didn't think about myself. And so, you know, if any

one message I can give, you know, the answer isn't only with your institutions, all of them, which are well-intended, but you have to have this other half of this support group, basically, that is out there, you know, pushing you. I like to tell everybody the story about my little girl. When I came home one day from the hospital, she was 10 years old, and I don't know what possessed her. To this day I don't. But she decided she was going to arm-wrestle with me. And I was feeling very dejected and I said I didn't want to do anything. So, and she was very insistent. And so I finally, you know, wheeled up to the table and I put my arm up and I said okay, come on, I'll arm-wrestle you. And she said, well, not that arm, silly. I know you can beat me with that arm. [laughter] And so I said, okay, you know, what the heck. And I put my other arm up, and then she said, now, I want you to try real hard. This is a 10-year-old girl. Now, up to that point, every adult in my life was telling me that I should try, but I wasn't believing them. Now, here was my little girl, you know, telling me, listen, Dad, I want you to try real hard. And so I was trying to concentrate, and I beat her, but I thought that, you know, sweet little girl, you know, she let me win. And she said, okay, Dad, two out of three. [laughter] And so then, you know, second time, I beat her again. Now, and then she was very excited about that. And so the more excited she got, the more I tried. And my mother, who was staying with us, you know, got interested in what was going on, and my daughter told her, listen, Grandma, watch, Daddy is really strong. Why don't you arm-wrestle with him. And so then I arm-wrestled with my mother, the same arm. And I beat my mother. and all of a sudden I started thinking, you know, could this really be happening? Because, again, up to that moment my arm hung limp at my side. Now, so I beat my mother a couple times. Now, my son was watching us, and he was 14 years old at the time. And my son was, when he was in high school, he was basically undefeated in Howard County, Columbia, and so he said, I want to get in on this, you know. so I was feeling very cocky because I had just beat my 10-year-old daughter and my mother. [laughter] And so then I said, okay, here goes. Now, I'm going against a wrestler who probably had 2% body fat, and he proceeded to slam me down to the table. And he said to me, that's to give you something to shoot for. You know. And it took that for me to realize what was possible. Up until then, you know, the best efforts of the doctors, best efforts of the therapists, you know, couldn't convince me that it is possible to keep improving, even when you've plateaued, you know. Good, I thought I had only one minute left. [laughter] But, you know, the doctors, in spite of their best intentions, you know, I truly believe that they are not the total answer. That try as they may, you know, you know, some people say, you know, it takes a village, you know. Well, that's really what happens in the case of having a stroke, you know. I'm still showing signs of improvement. I sign up for every clinical trial I can at DNH, at the VA up in Baltimore, Kennedy Krieger Institute, some folks are mentioned here as well, there's well -- you know, I work with -- tirelessly with stroke support groups, you know, I helped found Howard County stroke support group, I have been to all over Montgomery County, Anne Arundel County, you know, Baltimore county, because I feel that it is possible to get better. Everywhere I go, I tell everybody, there is life after stroke. It is not a dead-end, you know. You know, I wanted my talk to you today to be one of hope, you know, you have heard a lot of other people, experts and a lot of other people before me talk to you about the stories and, you know, and some of them are pretty gut-wrenching, you know. But I do want to also tell them that you can look at me, you know, and you can see what's possible when things are working right,

you know. And that, you know, you need a partnership, you know, that you need the -- in this case the stroke survivor, to also realize that it is their job, too, to get better, you know. Like I did. Like my kids showed me. You know, I have been so lucky. You know, my company grew in spite of my stroke. You know, I like to say to everybody, you know, my company survived my stroke, you know. And to that, you know, I believe that when you have a stroke, you know, everybody that's around you, that loves you, you know, that's your best friend, you know, or a co-worker, they are right there having a stroke with you. You are not in it by yourself, even though it feels like that sometimes. You know, that my wife was right there having the stroke with me, and so I realized that early on, and that forced me to focus on them rather than focus on me. One of my favorite little stories that I tell everybody is that, you know, after I had my stroke, you know, that's when I knew that I loved my wife, you know. She stayed with me and she stuck beside me, and I told her one day, honey, you know, I love you. She said, well, I love you, too. I said, no, no, no. I really love you. I mean, I know, I mean, up until the stroke, you know, I didn't know Just how much you mean to me. And I actually have told some people here, I told her, well, I want to get married again. she said, excuse me? I said well, I want to get married again, you know, I want to have a small ceremony in a church here in Maryland one night. And she said, hold that thought. She went, made a couple phone calls. Next thing I know, we were going to Vegas -- [laughter] An Elvis impersonator. [laughter] You know, that they transmit on the web, you know, my son was best man, my daughter was a maid of honor. And, you know, and then when they filmed it, you see my wife, you know, she was Viva Las Vegas and dancing, and I was standing right next to her crying, you know, because, again, I was taking it a little bit more serious than she did, you know. [laughter] But I knew how lucky I was to be here, you know, to be able to not only be here, but actually, you know, I think that in some ways better than before, you know. now, I don't wish this on my worst enemy. I mean, strokes are, you know, they are not for the faint-hearted, you know. but I do feel gratitude, you know, I feel this commission, you know, and all you fun folks here listening to me, you know, on behalf of all the other stroke survivors, you know, I mean, thank you. You know, you don't have to be here. You don't have to be here, but you are, and so many times, you know, we forget to say that, you know, because we are focused on ourselves. So, you know, thank you, thank you, thank you. And if you are ever in Vegas, you know, I know where you can get married. [laughter] With a good Elvis impersonator. Thank you.

COMMISSIONER ASTRUE: Thank you. I wanted to, I think, start with Dr.Zorowitz. If we have, if I did my math correctly, a couple hundred thousand cases each year that potentially could be disability applicants, you know, part of the whole purpose of the compassionate allowance program is to at least try to find some segment of that population where there just is no doubt that they are going to be qualified and not put them through our usual five-step process, and just try to say, you know, you know, here's a check, and perhaps review it a few years down the road, but, you know, here's the check and let people get -- move on with their lives with the certainty that that's coming, the Medicare is coming after the 24-month waiting period. Is there any -- are there any suggestions you have for us as any way to segment this population, to take the cases where we know that people either will never be able to work, or it is going to be at least a

year of very difficult rehab before they can even start to face up to the question of work? Is there any lines we can into using the new imaging techniques or other bio markers or anything else we may be we ought be thinking about that we haven't thought about before?

RICHARD ZOROWITZ, MD: I think that it's going to be largely clinical, again, I mean, if you have a huge stroke, it may be more of the slam-dunk kind of diagnosis, but I think you really have to look at the patient and really look at, you know, what are the impairments that they have. as Jim said, basically, I mean, you know, it is like snowflakes, everybody is different, you really have to look at those things, how much weakness is involved, how much speech involvement is there, how much how much cognitive involvement is there. Then what you really have to do, you have to go back to the job description. You really have to see what that person was doing, and what are the component parts that are part of that job. and then really try to put the two of them together. We know, for example, physical recovery actually occurs within probably the first few months. Functional recovery that can take a lot longer than cognitive and speech recovery, so if you have, say, the assembly line worker or the construction worker, somebody who, you know, really requires, those kinds of physical things and it is clear that physical nature is not going to return for that person, you can probably do something like that. It is a lot harder when you're dealing with speech and cognition, because I like to say for some of the patients of mine who are, you know, the graduate degrees, you know, the doctors, lawyers, engineers, whatever, who need 110% of their brains to do their job, that takes a lot longer for us to get there, and sometimes they can do it, and sometimes they can't. If, again, if those cognitive aspects or the speech aspects, somebody is aphasic, it is very clear that you are not going to get a person to a point where you can, you know, where they can at least communicate reasonably with somebody, then we may be able to make those determinations a lot sooner. Unfortunately, it is often very difficult, you know, you sort of have to look at the timeframe of maybe six months and see where things are rather than waiting for a full two years. As I said before, in some patients, it can take a year or two, but some, you know, potentially that much sooner.

COMMISSIONER ASTRUE: One more question. then I'll turn it over to my colleagues. Are there unique considerations to juveniles that have strokes that we need to be thinking about and evaluating differently, or is it still pretty much in your view a case by case analysis looking at the functional limitations?

RICHARD ZOROWITZ, MD: I think largely it is going to be case by case, because really, again, I think you have to match the impairment with, you know, with whatever they were doing out in the community, and that's really the only way that you are going to, you know, make that match.

COMMISSIONER ASTRUE: Okay. Anybody else?

UNIDENTIFIABLE VOICE: José, did you have a feel you were unemployable during your recovery?

JOSE MALDONADO: Yes, at the beginning, simply because, I mean, my faculties weren't there, and I thought -- and I was convinced that I would never work again. My partner, Jay Miller, he was convinced I would come back, but at the beginning I felt that I wasn't able. Again, I was very negative. I would love to tell you guys I was geez I was gung ho, but I was really lucky that those around me knew better than I did, you know. they were actually gung ho, helping the doctors and stuff like that. But I felt that I was unemployable. and I also know tons of other stroke survivors who are having trouble finding work, because not everybody has a Center Tek, and, you know, they are out there trying to find work, you know. But you know, for reasons that are, you know, obvious reasons that they are having trouble, either the jobs they find require them to talk, and obviously suffering from aphasia, they can't. Or, you know, the job requires them to carry things, you know, having one arm basically won't allow them to do that. so not everybody has the same things I had.

ELIZABETH RASCH PT, PhD: So José, what was the length of time between when you had the stroke and when you returned to work?

JOSE MALDONADO: Oh good question about a year. it was a year and that was, you know, I remember they were constantly asking me to go back, and so, you know, I thought I was back too soon. now I had started going back before, but about a year, and also, I mean, the arrangement that we have now is that I only work part-time, you know, about 20, 25 hours a week, and so I do get part-time disability, because I feel that I really can't put in a full day's worth of work. I do get tired, in spite of the fact that I workout quite regularly, initially I was working four, five, six hours a day. Now I cut back, and but, you know, that tires me. so I only work half a day.

ELIZABETH MD: so to me it raises two issues that I will raise for the panel. One is that in supported work environments and work environments where people's functional abilities are well accommodated they are able to work, but we know that most individuals don't have access to supportive work environments and the SSA at this point doesn't even go about evaluating those kinds of issues which would, you know, get at this issue of functioning in environments which really is our current conceptual definition of disability, how people with functional limitations or conditions function in various environments. So that's one issue that I would like to hear the panel discuss a bit, because it came up quite a bit this morning as well, that in a supportive environment certain individuals are able to work, but many people don't have the kinds of supports available and then they are unable to work, in fact. And it is not a matter of their functional abilities.

RICHARD ZOROWITZ, MD: So I think you have to be -- sometimes you have to be relatively lucky, either you have to ultimately have a great employer, or, you know, in this case your own business where you can do it yourself, or, you know, you have to know enough, you know, to get yourself into the system, into the voc rehab agencies, you know, to start looking at some of those things, and that's really one of their jobs is to help, you know, look at your abilities and what needs, you know, augmentation in the

workplace and what can you be doing yourself. Again, you get to the point where ultimately it is the employer that has to say yea or nay whether they will be able to do that or not, and that's often a big challenge.

JAMES ZOROWITZ, MD: The other comment that I would make is, again, remember in many ways stroke is still in it's infancy, including the rehab and recovery side. so, for example, 4500, roughly, hospitals in this country, yet only around 700-ish are designated stroke centers by either the joint commissioner by their own state self certification processes. So the point is speaking out to educating the healthcare professionals, except for this one here, but educating those professionals to recognize that part of that supportive -- that support system runs far beyond the walls of the rehab center, much to what José is mentioning. And the evolution of those types of support systems really just haven't happened yet. it just isn't quite there yet.

JOSE MALDONADO: There is one thing I wanted to mention. strokes occur at different stages of life, so whatever solution, for example, or solutions an agency like yours has to offer has to also be tailored. If a person is married with kids, he's got certain needs, he or she have has certain needs. A person is much later in life, maybe almost nearing retirement, kids are grown and gone, you know, his needs and financial needs and everything are going to be also a little bit different. So you'll have to, hopefully have certain options to take that into account as well.

ELIZABETH RASCH PT, PhD: May I ask another question?

COMMISSIONER ASTRUE: Yes.

ELIZABETH RASCH PT, PhD: So then the next point that you started to allude to is that both, we were hearing this morning amongst people with traumatic brain injury and among people with stroke, we know that recovery's can be quite prolonged, and there's a fair amount of information now indicating that in fact people with stroke don't plateau at six months and they can recover, continue to recover years after their stroke. at the very same time they might not be able to yet work, they need support, financial support because of inability to work, but at some point in time they may be able to. so, you know, how do you balance out those issues?

JAMES BARANSKI, CPA: If you think about what you have just asked, it truly is a catch 22 scenario. imaging technologies demonstrating the plasticity of the brain, its ability to recover or rewire itself certainly is something that we didn't know existed not that many years ago. But at the same time, the ability for the survivors to have access to the continuing rehab and recovery, it is almost like kind of pay me now or pay me later, but the pay me later part, if I don't get the recovery and rehab, could be significantly more, so it truly is somewhat of a catch-22 right now. And I think it is important for all of us to recognize that how critical that recovery and rehab reimbursement, extending that and making it more available ultimately is ultimately save money down the road. again, I would remind us all of the tsunami, you know, the people are talking about in terms of the greater incidence of stroke affecting our boomer, our ever-aging population.

RICHARD ZOROWITZ, MD: What I think I would like to add into that, and I think José really demonstrated it very, very well, is that the recovery is really half the battle. The other half the battle is the motivation of the stroke survivor themselves. I see enough people who, you know, despite every type of cheerleading we can do, whether it's us or the family, you know, they sort of give up on themselves and, you know, they are condemned, they are not going to get better, and if there is any potential for returning to work, it is probably not going to happen. It is going to be the patient who really is, you know, who has the push, whether it's guilt or cheerleading or however it's done, you know, to get that patient, or if it's coming from within themselves. Those are the patients that are really going to make the difference and hopefully, you know, if they can't make the grade in the long-term, at least you can say they've given it their all, and let the cards fall where they may.

COMMISSIONER ASTRUE: That's a perfect set up for actually a question I was warming up to ask anyway. Could you talk a little bit more about the mental health implications here? As I mentioned this morning, one of the things that changed in our system is a much higher percentage of the claimants file for disability, both on physical and mental health grounds. And I would imagine that depression is extremely common in this group of people. I guess toward the end, should we think about it any differently for this population for another population, I mean, anyone facing a serious medical problem is going to have a higher risk of depression. Is there anything different about depression in this group, anything about how they respond to medications for depression, anything else that we ought to be thinking about in terms of the mental health implications of stroke survivors?

RICHARD ZOROWITZ, MD: Well, stroke -- post-stroke depression basically is probably one of the most under diagnosed and under treated complications after stroke. It is a major issue not just because of, you know, mourning the loss of function, but because you're also changing the chemistry of the brain and sometimes those organic changes themselves can end up causing, you know, a person to become depressed. So it is important that whoever it is, and I always say everybody can be a back seat psychologist or psychiatrist, needs to kind of recognize the whole idea of what is, you know, whether that patient is depressed or not, bring it to the attention of the, you know, medical professionals, so that we can really do the two-pronged approach, one of which of course is medication, if need be, and the other one, psycho therapy is going to work, then, you know, then we go that route, too. Some of the other issues that come up really that can cause depression, too, are just the seclusion, you know, not being able to be mobile and being out in the community is enough, so I think, you know, being able to get patients back out into the community and active again, sort of the whole cheerleader kind of thing to get the patient going, you know, can make a difference. So, yeah, I think those are things we have to look at.

COMMISSIONER ASTRUE: Is clinical anxiety higher, significantly high in this population?

RICHARD ZOROWITZ, MD: Anxiety is another issue that does come up as well and needs to be identified.

JAMES BARANSKI, CPA: And if I can just comment quickly, the -- we conducted a survey among stroke survivors, both here in the U.S., Europe, and Pacific Rim, and depression affected over two-thirds of those respondents.

UNIDENTIFIABLE VOICE: What I'm hearing is that maybe there should be more of an emphasis on compassionate therapy rather than compassionate allowance.

RICHARD ZOROWITZ, MD: Yeah. I think part of it, part of it, and this is a continuous battle with Medicare and with the commercial insurances of trying to get patients therapy when we truly feel they could benefit from it. Treating depression, all those things are easy, we just go to the doctor's office, we can do it, we can make referrals as needed. When you're a few months out and you've run your course of physical and occupational therapy and we've identified issues sometimes it's just virtually impossible to get people the services that they need to see if you can get them to that next level.

JAMES BARANSKI, CPA: You know, I like that, though, compassionate allowance versus compassionate therapy. I guess I would ask which comes first, because I think they are both connected, certainly from the one individual story that you've heard here.

RICHARD ZOROWITZ, MD: I would agree. I actually, if I heard correctly, I think they are connected and you can kind of go both of those routes, that at some point you can do the compassionate allowance, you know, maybe on the condition that several months or a year or two down the road, you relook at the issue and see where things are, and if, you know, so at least patients get their benefits, hopefully you can allow them to continue to work through journey of recovery, and, you know, then re-look and see if there's enough improvement that they might be able to go out, you know, the key and the problem with that is just that, you know, you sort of get hung up once you sort of say, okay, I've got my disability, I've got my disability benefits, maybe I'm just going to stay that way. Again, that's the motivation of the patient.

COMMISSIONER ASTRUE: This is one of those diseases and conditions where, there is a pretty good argument that the one-size-fits-all statutory construct doesn't make as much sense as it did. And it wasn't really, you know, we have been living with it for half a century now, and it really was conceptualized as early retirement, back pain cases, you know, things like that, and here, particularly when you combine it with the 24-month waiting period for Medicare, for a group of patients where prompt and intensive therapy can really bring them back in many cases to be productive citizens, it is just insane that we have a 24-month waiting period for Medicare. It is not just for this group of people, there are other degenerative diseases where you if you can get them medical care and sometimes the high-priced pharmaceuticals early in the course of the disease, you can break, you know, deflect the course of the disease significantly and prevent someone from becoming disabled at all, or at least delay it for a very significant period of time. So, you know, the system for some groups of people just doesn't make as much sense as it

does for others. it is a very tough one to open up with the congress and that type of thing. But at some point, you know, we've got to get away, I think, from one-size-fits-all. same with work incentives. You know, we can have ticket to work, which is basically tries to treat everyone the same. That's very democratic, and that feels good in lots of ways. But ultimately at the end of the day, you know, what a stroke patient needs is going to be different from what a person with rheumatoid arthritis or a person with schizophrenia needs. At some point we have to start recognizing some of those differences and building some systems that are at least somewhat individualized or we are not really doing the best service for the public.

JOSE MALDONADO: The one thing I want to make sure we don't forget, and the same is true, you know, in other traumatic illnesses, is that, you know, as much as the attention of this discussion is focused on the stroke survivor, you know, those caregivers, you know, the relatives they are affected as much. You figure a spouse, you know, or brother or sister that's going to have to give up time at work, you know, to help take care of this person, you know. I'm not suggesting that, or maybe I am, that they be given benefits as well, but that, you know, the more that you're trying to solve this problem, indirectly; you're also benefiting these caregivers and stuff like that. So it is important to provide some form of long-term care for those survivors for the benefit also of these caregivers and the like.

RICHARD ZOROWITZ , MD: What also makes this incredibly complicated is that -- I mean, on one hand we talk about the pharmacy donut hole of Medicare. But, you know, between cobra and getting on to Medicare, I mean, there really is that donut hole of losing insurance for those few months. So that's one thing that could help. The problem -- and this is probably the \$64 million question in stroke rehab -- is that in terms of therapies, if you go through all the evidence there is really, aside from the one NIH sponsored study in constraint-induced movement therapy, there is absolutely very little if no evidence to suggest what the best therapies are, the timings, the intensities. And so that's what makes this even that much more complicated.

COMMISSIONER ASTRUE: Right. Absolutely. Anyone else?

DAVID RUST: One of the things we're trying to do with compassion allowances is to identify those conditions where the mere existence of that condition, the confirming diagnosis of that condition, would meet our standards for allowing the case. And then of course for maybe the less severe strokes, we have a normal process to evaluate those. Is there a way to identify those severe strokes that we could create a definition for where the medical evidence would be so compelling that we could process that case quickly and then grant allowance?

UNIDENTIFIABLE VOICE: At least in the in-patient rehab arena, you know, we do have the uniform data systems database which was adopted by Medicare for prospective payment and in-patient rehab, you know, that actually can take a look at that. And actually, if you look at the work of my former colleague at the University of Pennsylvania, Margaret Steinman, Margaret probably is like the mother of all this kind of

stuff who could potentially, you know, help out in terms of -- the bottom line is that usually on admission to rehab, we say the worse they are the worse they are. The more severe they're coming in, the likely they're going to be that much more severe when they leave. And there are going to be lower levels. People are coming in more mild. So, you know, there are going to be some, you know, points that we might be able to set. The issue that I always am careful about is that, you know, we're talking a probability game. There is nothing here that is going to necessarily talk something that is absolute because there's also that little possibility that the severe stroke survivor at the beginning may actually do well given enough time. So, again, if we're looking at this thing in serial fashion then, you know, I think that may help those people.

DAVID RUST: Well, as you suggested, we have the ability to diary a case, to indicate that we'll allow the case. but we'll look at that person. If we think medical improvement may be expected or medical improvement may be possible, we'll look in one year or two years and bring that case back up and look at it further. So we have that ability. But the question is defining what would make this stroke, this person's stroke a compassion allowance whereas this perhaps less severe stroke where you may have a question about whether the person is unable to work for at least twelve months or other factors, if we can define that, carve that out and identify it, then I think we have something we can work with from a policy point of view. Do you think that may be possible?

UNIDENTIFIABLE VOICE: Yeah. I think in terms of dysfunctional severity, that's where the bottom line is going to be. As I said, you know, the functional independence measure, which really has its pros and cons, you know, for the last few years, has been used in in-patient rehab to kind of look at that kind of thing. So it's a starting point. But, you know, I think there will probably be other measures that will be coming down the pike that hopefully will be a little bit better than what we have now.

DAVID RUST: I hate to be Johnny one note on this, but of course the audience has heard me say it before. The commissioner this morning -- and I don't know if you were here this morning -- mentioned the meld score and liver function where we have found over time that a score of 22 or higher on two consecutive tests -- I think two months or three months apart -- is conclusive evidence that the person simply doesn't have the stamina to work. So that gives us an objective base. We're always looking for that because we have a large number of cases where it's a very difficult call, a gray area in the middle. And there's a lot of litigation and so forth that falls from that. So we're always looking for ways to make less subjective and more quantifiable sort of decisions. You mentioned a couple of tests; best speech, cognition, and so forth. a combination like that, even if we're not talking now about compassion allowances, we're talking about evaluating stroke victims for our regular listings -- you mentioned a series of tests. Does some combination of those possibly give us an ability to assess our disabling the condition is and over what period of time?

UNIDENTIFIABLE VOICE: Yes. as a matter of fact, I think one of the tables that I supplied for you, which is actually based upon them and based upon really the pps for Medicare, demonstrates actually fourteen different case mix groups that, again, Margaret

Steinman who did a lot of this work demonstrated that these were really distinction groups. And they're based largely upon motor scores, cognitive scores, you know. And some of its age, although most of the ages are over the age of 80. So that's probably not going to be appropriate here. But I mean very clearly, I mean, a combination of those things would be quite helpful.

DAVID RUST: The commissioner mentioned strokes in children. Dr. Berger earlier said that injury to a developing brain is far worse than injury to a developed brain. Is that true with strokes also in children? Is their long-term prognosis worse?

UNIDENTIFIABLE VOICE: Well, it may or may not. I think it's going to depend on the amount. If it's a relatively small stroke, there are kids who actually do incredibly well. You have to remember that while stroke and brain injury really is a continuum of acquired brain injury, the big difference is that really a lot of traumatic brain injury is a much more diffuse injury where stroke is tending to be much more of a discreet injury. And so you have the potential of better recovery. The question is how big is the stroke. I mean, very small strokes, you probably should get a very good recovery. And there are kids who can do very well, and you don't know that really anything happened. But larger strokes, you know, obviously, they're not going to do quite as well.

DAVID RUST: Thank you.

NANCY GRISWOLD: Of course we are always trying to come up with ways of measure function at different at points in the process. And it has been my understanding of strokes that basically with strokes you have an immediate loss of function and then some recovery thereafter?

UNIDENTIFIABLE VOICE: Yes.

NANCY GRISWOLD: I am curious, is there any group of cases where there is deterioration post-stroke and if so, can you explain that a little bit?

RICHARD ZOROWITZ, MD: Deterioration after stroke usually will be as a result of either evolution of the stroke, more brain tissue is being infarcted, or often sometimes what we'll see, which is a little more common, sort of a rebound is if there are medical complications afterwards the patient becomes sicker, so they really don't function as well. But for those patients typically you would expect that once whatever that, if it's infection or whatever, once that's cleared up, they should start picking up. I mean, we see patients like that where, you know, they have a very rocky course, they can be in the hospital a month or two, but then things can start picking up afterwards.

NANCY GRISWOLD: That kind of leads to the follow-up question. at what point in the process is it really meaningful to try and measure stroke severity?

RICHARD ZOROWITZ, MD: You know, the neurology literature, I mean, does it right off the bat, for TPA, you know, they have to do that, that's part of the criteria. I mean,

typically a lot of the data, at least in rehab that we have, you know, actually a lot of it ends up being really on admission to the rehab facility. But I don't think there's anything I can really say that is, you know, really inscribed in stone. If you go back, probably another good colleague that has done some work is Pam Duncan, who wrote an article back in the '90s, you can explain amounts of variance, if you look five days afterwards, it gets better after 30 days, so there are some areas, but, again, it is a probability game, it is not an absolute game.

ELIZABETH RASCH PT, PhD: So I would just like to add on about Pam Duncan's work that she's actually looked at trajectory of recovery of stroke patients over the long term, and has found that oftentimes functioning is highest right after discharge from rehabilitation, and that certainly for at least a sub set of people, once they are back in the community, their functioning actually declines for reasons we don't completely understand. It could be environmental influences, they are not being challenged in the same way they were in rehab, that it's not clear exactly why it happens, but in fact it is well documented with large groups of people.

RICHARD ZOROWITZ, MD: One could make a good argument, although not proven, that you are going from a structured environment of three hours of therapy a day, back to where you're kind of left on your own, and that's what happens.

JOSE MALDONADO: I do know that when I am not working out, I do lose some functionality, you know. so it is like I'm addicted to it now.

DAVID RUST: Do you have an indication of who is more motivated, I mean, is there an assessment, a way to get an idea who is more motivated to come back and who is more willing to accept their condition?

RICHARD ZOROWITZ, MD: That really would be the \$64 million question. If I could get a pill for it, I would be the first to prescribe it. [laughter]

DAVID RUST: If you could figure it out, we'll write it into policy.

RICHARD ZOROWITZ, MD: Exactly.

COMMISSIONER ASTRUE: okay. I think we are going to start wrapping up. I'm going to give each of the panelists, if they choose, they don't have to feel -- obliged to make some closing remarks. We'll start with Judge Griswold and move down the table.

NANCY GRISWOLD: Certainly I would like to thank all the panelists today for the contribution. I found this extremely helpful and very very informative. As I said at the outset, I think from an administrative law judge's standpoint, this is one of the most difficult areas to assess, and so this has been very helpful. Also appreciate the opportunity to participate here. Thank you.

DAVID RUST: I would like to also like to thank all the witnesses, and the audience for their participation and support throughout the day. We're always looking for ways to do our job better we constantly have to update our medical listings, we are developing compassionate allowances we have other incentives to make the program work better. I think it is open discussions like this and input from the experts themselves and from, I think, I thank Mr. Maldonado and Mrs. Lang and Mr. Sharpe today for some very powerful testimony about their own situations and the way they responded to it and the way they've come back on it so. this has been very helpful to us.

ELIZABETH RASCH PT, PhD: I echo the thanks to everybody who has been here today. it has been really interesting. I would just like to challenge the SSA to hear between the lines of some of what was being said today. You know a lot of the basis on which decisions are made are diagnostic, but people with the same diagnoses can function very differently. And so to have functional criteria, to really understand how people can operate in a workplace environment and to understand workplace demands and how those things match up I think are really a critical aspect of what needs to be considered, in addition to diagnosis.

LYNDA DAVID, PhD: I would like to thank the speakers. I thought they were all very well. I would also like to thank the commissioner. I think this is an excellent presentation. glad I'm part of the process.

Thank you.

COMMISSIONER ASTRUE: Well, I also want to thank all my colleagues to my right. It's been great benefit having them help out on this. We've had a wonderful succession of witnesses, they've given a lot of time and work, and often sacrificed other things that they wanted to do. I know that there is another conference we're competing with today that a lot of people wanted to be at. So thank you all. I also wanted to thank one other person. We're actually all here today. I first started thinking about this 23 years ago, my dad had a cerebral hemorrhage and I did the paperwork for him. And that's when I first started thinking, geeze, we've got to make this easier for people. And the person who actually helped me was Diane Bronstein, Who is in the front row, so I was blessed to have her on my staff at the time, and subsequently we both wandered away from HHS, but it has been a great joy to be reunited with her. She's done a great job over the past almost two years putting this together, and this is in fact her last year, and she's earned the big promotion. so she's going to be moving on further up into our executive ranks, but let's give her a big hand. [applause] And with that we're done. thank you all very much for coming here today.