>> Chase: All right. Thank you, Laura. And today, as Laura said, we're going to be discussing a little bit about health equity and how that affects Texans with disabilities, and just all Texans. And one of the exciting things that we're going to kick it off with that I've gotten to work on a little bit, as y'all all know, we do work a lot with kind of in the pharmaceutical area and medical side of policy.

And one of the more exciting things is where we're going with some of this new technology, and how it's getting out there, and how it can really affect and change the way our lives are. And that goes with precision medicine. So there are some really remarkable research being done, a lot of amazing treatments coming out. And with that is a cost that comes with that. A lot of these medications are very expensive, but they're very effective and very useful.

But there's also some tools out there that help, especially in the fight against cancer. And I think Texas took a big lead in cancer research over the years with MD Anderson and some of the other research being done in Texas.

And one of the areas that makes a really big difference in precision medicine is testing and making sure those medicines will work specifically for that person in those circumstances. And that can be done with biomarker testing.

And we wanted to bring on today James Gray, The Government Affairs Director, with the Cancer Society, and have him kind of explain where things are at with biomarker testing, and some of the things we need to do, because we are starting to see some health equity issues in some of these new issues and wanting to make sure everyone has access to them.

So we thought this would be a great way to kick off this discussion around health equity. And we know that cancer affects everyone. It affects families, it affects pretty much everyone at some point in their life will know someone, will go through it themselves. I know I've had a lot of close friends that have had to deal with cancer. So the steps and the progress we're making are really exciting.

And we kind of wanted to bring James on to talk about biomarker testing, how that can help with precision medicines and the next steps of what we need to do going into this session, and any possible legislation that's been filed that all of y'all can help on as the session goes.

So, James, I'm going to turn it over to you, give you control, and let you kind of talk about this issue, and we'll go from there.

You're on mute still.

>> James: Thank you. So, James Gray, director of government relations for the American Cancer Society. I'm working in my home office today, so behind me I have some pottery from two pueblos in Mexico, and then I have a photo of my wife, but at the time, she was my date in front of the Portland headlight house in Portland, Maine. I'm in one of those neighborhoods in Austin where they're tearing things down, and the one next to me is being torn down, and they're cleaning it up today, so I ap

First, let me just say I'm so appreciative of the work that the coalition of Texans with disabilities does. I get to work with Chase and Dennis and have worked with them for years, and more importantly, kind of seen the impact that they have in the capitol. And what they do, it's so well-respected, but more importantly so effective.

I work in an organization that is led by volunteers. So, patients, physicians, survivors, use their experience like all of you to shape public policy. And when I talk about what we do and how we do it and how effective it is, I use the coalition of how effective you can be in a fight against public policy.

So, your work is being seen and your work is having an impact as a coalition, but also as advocates.

So I want to talk a little bit about biomarker testing. I think it really is interchangeable. It's precision medicine, it's biomarker testing. And it does affect a range of diseases. So I'm going to talk about this through the obvious lens, which is the cancer lens. But if you had someone here talking through the rare disease lens, they would talk about the potential that we're seeing a rare disease, neurologic disease as we're starting to see a significant -- from the ability to use biomarkers

and deciding the treatment for these individuals.

So a really good -- and I want to show a video in a minute, but kind of a basic overview, a simple overview is, it wasn't that long ago, and even in some cases now if you were diagnosed with cancer, you had a certain type of let's say prostate cancer, they would treat it, and they would find out how that cancer is responding to your treatment.

And so it was kind of a fail first. Let's try that, and then try something else.

Now on the front end with biomarker testing, we get to look at your genomic makeup of that particular cancer tumor and determine what treatment will respond -- what treatment will respond -- will have the greatest response to that particular tumor that you have, right?

So, you know, some researchers and doctors will sit here and tell you that, you know, they won't treat breast cancer in 20 years. They'll treat a specific genomic mutation that will be in the breast, and that's kind of where we're going with the fight against cancer, which is so exciting, because we all know catching cancer early is one of the ways to survive it, but more importantly, getting the right treatment is another way to make sure you're surviving cancer.

So I'm going to share my screen, and try to share this short little video that I think does a much better job giving the kind of technical overview of what a biomarker is. And let me see if I can do that. I'm not used to Zoom. But that's no excuse. Is that showing up on your screen?

>> Laura: I'm not seeing it, James. Let me try to mess with some settings. Okay, see if you can hit that share screen button now.

>> James: All right. Hold on one second. And if it doesn't -- oh, there we go. How's that look?

>> Laura: We don't have sound. And here's what you'll do. End the screen share.

>> James: Okay.

>> Laura: We're just going to start from the beginning.

>> James: So do new share or end share?

>> Laura: End.

>> James: Okay. You know, Laura, it's not critical to the presentation, if this is too cumbersome.

>> Laura: It's up to you. It's just a matter of checking a box that allows you to hear your sound when you first hit that share screen button.

>> James: Let me start share screen again.

>> Laura: And there's a little check box that should be at the bottom.

>> James: Oh, there it is. Thank you.

>> Laura: That's it.

>> James: Thank you. I'm going to just go back to the beginning

>> A new way to use information from your own genes or proteins, to help doctors diagnose or treat disease, and to prove survival and quality of life with conditions like cancer. Well, biomarker testing is here, and it's full of promise. Now imagine this, thousands of Americans who could benefit from this scientific advancement, missing out because of lack of insurance coverage and other barriers.

Americans who have been marginalized, including in communities of color and those who are insured through Medicaid and people in rural communities far from academic medical centers are less likely to benefit from these life-saving advances. A biomarker is a unique signal that is specific to a patient's disease and can be measured in blood or tissue. In cancer, biomarkers can include molecules like proteins and gene mutations found in cancerous cells.

Cancer biomarkers are often notated by an abbreviation, which can include numbers and letters. A positive test means the patient's cancer cells have that biomarker and this information can be used to select the most appropriate treatment. Scientists are working to advance new treatments for cancer and other diseases by determining what biomarkers can convey about the effectiveness of different therapies.

Currently, there are rapidly increasing numbers of biomarker informed therapies doctors are using, and these therapies are leading to improved survival rates and better quality of life for people with cancer, and those better health outcomes could lead to lower healthcare costs. But private and public insurance plans are failing to keep pace with this progress.

As biomarker informed care continues to advance, ensuring equitable access to biomarker testing by improving coverage will be key to preventing new health disparities and dismantling barriers that prevent too many patients from benefiting from these innovations.

So even if you're not a doctor or a scientist, you can help bring the promise of biomarker testing to all Americans who need it, by supporting a law to extend coverage for biomarker testing and by educating friends, family, and policymakers about the importance of biomarker testing. Join ACS can in supporting policies that will ensure coverage of testing for patients, including those insured through Medicaid, improving access to biomarker testing

can lead to better patient outcomes and advance health equity for all.

>> James: Great. So, hopefully that -- do you guys --

>> Dennis: It explained things well, James.

>> James: This is one of those situations my kids would just laugh at me and say, dad, what are you doing? Can you all -- I'm back on camera, correct?

>> Chase: We can see you now, yeah.

>> James: Great. I think that's a pretty good overview, and I think what was important in that video is the rural and the economic inequities of biomarker testing. And that's why a piece of legislation in Texas is so important. Getting legislation passed that really requires a level playing field for state regulated insurance companies to reimburse for biomarker testing is going to be so important.

And many of the access issues that we have faced, or cancer patients have faced in the last 30 years have been really because of the success of public policy. Interestingly, back in the '80s, well before my time, if you talk to someone in my seat, they would tell you they were advocating for mammograms to be covered in state insurance. That issue has been fought and won, and some of the greatest achievements we've had in improving access for cancer patients have been through public policy.

We see this as one more step in the direction of providing access, and really creating more equity in the fight against cancer. So making sure that individuals, cancer patients in rural communities have access and get reimbursed for biomarker testing, make sure those on Medicaid here in Texas get coverage for biomarker testing.

So, we are working with a broad coalition, and really appreciate the support of the coalition. And Dennis and Chase in helping us educate elected officials, bring together diverse group of stakeholders to really put a face and a voice to this issue, and get the legislature to do what they know needs to be done, that is legislation that will provide this for Texans, so they know when the time comes to make a decision with their doctor and what treatment is best for them, there are no barriers

s on whether or not testing becomes an option.

I'm probably well over time, but again, I'm happy to answer any questions. Love to keep you updated as we go through the next session. Mandates are never well-received in the Texas legislature, as you all know. But when we do what you all do so well, and that is put a face and a voice to the issue, it becomes a very different discussion. So that's what we are doing in this campaign, and I'm glad you guys are part of it.

>> Chase: And James, this is something that we've all discussed over the years, that when patients get put first, and we get early treatments, people have better health outcomes, that is how you make an actual cost effective healthcare program in Texas. Instead of being a reactive healthcare program, which is currently where we're at.

This moves us to that next step of really the potential of all that research that we've been doing to really improve health outcomes, and to do that, we have to make sure it's available for everyone in Texas, and that's where y'all are working -- y'all currently have some legislation being drafted or worked on to bring this issue to the next session, and that's where we can all support y'all and make sure that these voices and everyone's voice -- because I'm sure everyone on this call proba

a rare disease, or many of the things that we could be helping people improve their health, this will affect in the near future.

So if there's anything we can do for y'all, please let us know.

>> James: Appreciate that, and you explained it really well. This has got to be a decision between the patient and their family and physician in terms of what treatment they pursue, and having the appropriate data in making that decision is critical to their quality of life.

>> Chase: Perfect. Well, thank you, James, for getting on. I'm going to turn it over to Dennis, who's going to continue on this theme of health equity and how it affects us all in a bigger, more general area.

>> James: Thanks, everybody. Have a good afternoon.

>> Dennis: Thank you, James. Thanks, Chase. So, I'm Dennis. I am an anglo male with gray hair, gray beard, gray jacket, gray eyes. Just think of me as your friendly elephant.

I wanted to talk to you about health equity in a larger sense than medicine. But before I do, I want to tell you, as I was listening to James talk, I was reminded of an example of health equity legislation related to prescription drugs that we succeeded on.

And it was a drug that was made out of -- and this is true. I'm not making this up. It was made out of the saliva of Gila monsters -- right? Hela monsters. You know what those are? They're like those creatures, you know, in the desert, kind of big lizard things with very strong jaws. You don't want them biting on you. Yeah, that is a Gila monster. Believe it or not, there's a medicine made out of there that was very effective, but it was not available to many people. And we had to pass leg

and other medicines of those kinds, which are now called biologics. You might have heard that term a lot more frequently now. That term is now common.

So, sometimes health equity comes piece by piece. And what I wanted to talk to you about today is, again, a little bit larger. Can we move more into health equity on a just overall, without doing this every inch by inch along the way.

So, health equity is achieved when everyone, everyone has the opportunity to be as healthy as possible. And those inequities, when there are inequities or disparities, it shows up in length of life, quality of life, rates of disease, disability, preventable early death, severity disease, and access to treatment.

Now, let's be real, folks. Do we think everybody in the United States has equal access to healthcare, medicines, treatments? The answer is no, they don't. Okay? And those folks on this call right now may be thinking, we're going to talk a lot about people with disabilities, and we are. But it also impacts people who may live in rural areas versus urban areas, people of color, people of low income, people of perhaps different sexual preferences, all these kinds of things,

where people through no fault of their own have less access to health. We used to call that health disparities, instead of health equities. And in my mind sometimes that makes it more sense to call it disparities.

But the common term today is "health equity." I get that. It's a positive term. An what do we want to do, we want to reduce these inequities, so we want to increase health equity, including for people with disabilities of all ages, of whatever disability they are, of whatever ethnicity they might be, wherever they might live.

And so why is that important? Well, I did have some data on this. It's from 2019, so it's a couple of years old. If you compare people with disabilities to people without, and sure enough, this is not going to surprise many of you, the people with disabilities had less access to healthcare. They have more depression and anxiety, engage more off in risky health behaviors such as smoking, perhaps drinking alcohol beyond moderation, and are less physically active.

So, you know, some of those things might be personal choices, but some of those things are not. They're what you're told you have to live with.

James was talking about biomarkers. I think you got the idea that these biomarkers, which are pretty new on the scene, are really good things if you have cancer, to have access to. It's like getting on a highway instead of being stuck on the dirt road along the way. You just go directly to where you might need to be as far as the kind of medical intervention.

And that's a good thing, but we know -- and this is why Chase and I will be working shoulder-to-shoulder with James and many other advocates, to say that these biomarkers need to be available in Medicaid, okay? So if Medicaid recipient has cancer, let's give them to biomarker so we can direct them to the efficacy of treatment. Which frankly, is getting better.

I used to think -- you know, I'll be honest, my mom died prematurely from cancer, so I hate cancer. And there was a long time ago, and I always thought, well, cancer is going to be cured. You know what? It's been almost 40 years now that cancer still isn't cured. So we've got a ways to go on that. But we've come a long ways, too.

Okay. So, I wanted to tell you all that legislation can result in health equity. And I'm going to tell you a true story about CTD advocacy that resulted in a piece of health equity.

Okay. So I am showing you a very ugly-looking thing. How would you like to have a bunch of those things in your liver? Well, that would be bad. That would be really bad. Because what that is a hepatitis C molecule. Hepatitis C is a terrible, terrible disease that is progressive, it takes a long time, it's hard to detect in early stages, but when it gets further on, it destroys the liver and can result in death or having to have a liver transplant.

Now, this is particularly difficult in, believe it or not, women. Why? Because women used to be given blood transfusions upon childbirth to restore some blood, and at one time, the blood supply in the United States wasn't checked for Hep C. And so a lot of women are discovering in their late 50s or 60s that they've been carrying a Hep C problem, these molecules in their liver, for decades, and it's now causing them serious problems and threatening the shortening of life.

So, it's a terrible, terrible disease. So, what is the health equity in this? Well, it turns out that CTD became aware that a medicine was developed to cure hepatitis C, to cure it. That was almost unknown of. That was like, you know, these biopharmaceutical researchers, this is what they lived for, to find a cure for something that's never had a cure before. And that became available in 2014.

But you know what? It wasn't allowed in the preferred drug list in Texas Medicaid. Okay? This is a cure. And this would replace -- keep this in mind. A cure would replace the need for a liver transplant or the progression of the disease. It would also keep people from having to take lifelong medicines just to try to keep it under control. So this medicine was great.

We presented this information to the Texas sunset advisory commission, not the legislature, the sunset advisory commission, and recommended that they, the sunset commission, recommend the laws be changed to include this medicine and Medicaid. And it took a little while, but, in fact, we were able to succeed in that. And this medicine became available in Medicaid.

But, you know, it's never as easy as it should be. So what happened is the Health and Human Services Commission said, well, you know, we're going to take our time, we're going to add it, but we're going to delay adding it.

So we started pressuring the Health and Human Services Commission, whose executive commissioner at that time was a physician. And, you know, it was kind of interesting because it didn't take him too long to actually agree. Because he knows it was expensive medicine, it was cheaper than a liver transplant. A lot cheaper, actually. But he wasn't going to do it. But he did after we kind of advocated to him that this is what we needed to do.

So now we start with the sunset commission, and then we're into the Health and Human Services commission. All advocacy is not necessarily in the legislature, but it can be.

And I'll continue on that. As this medicine became available in Medicaid, they set up a criteria that said you have to be really sick before you could get the medicine. And after years of struggle, we finally got them to relax it so you could be in an early stage of the disease when the medicine could be more effective. So notice the steps.

And I'm going to finish up with what we were able to achieve in the last legislative session, 2021. That was to make this medicine available to the early disease stage and fund it. And we were able to do that with a Senate resolution 31 to make access to this Hep C cure available at an early stage, and funding it for $51 million.

And you know what? We were the only consumer advocacy that worked on this legislation. We need more work.

So I'm getting to the point where I'm supposed to -- oh, I have just a few more minutes. So, I told you the background. I gave you an example. So the next thing -- and I'm going to get rid of this ugly molecule. That's much better. I know I look better than that molecule.

So, let's look forward in the next legislative session. There will be a bill filed called the Office of Health Equity bill. This was filed in the last session by Representative Coleman Out of Houston. There used to be an office called the elimination of disproportionality and disparities. In other words, it was the Health Equity Office, and it helped the Health and Human Services commission to identify if they were certain groups, ethnicity, rural areas, parts of the state, communities such

who didn't have access to certain healthcare, and help HHSC devise plans to make healthcare available.

That office was closed in 2017. Yeah, that was not a good idea. So this legislation would restore it and change the title to Office of Health Equity, a positive, a progressive, positive thing. And in addition to helping HHSC plan to eliminate these disparities, we helped them implement them. And hopefully, my thought is it would help reach out to advisors from the various communities. When I say advisors, I'm talking about people with lived experience. So people living with disabilities

could talk about how access to certain medicines, certain treatments, certain cares better.

And by the way, that does include long-term services and supports. Equal access to community attendant services is a health equity issue.

This is also going to talk about social determinants of health, which are things that -- it means if you're poor, if your housing isn't good, if you don't have transportation, those are social determinants of health. They make you less healthy.. if you have less money, if you liver in poverty. This is long overdue.

I think it's kind of an embarrassment that the state had such an office in place and then closed it. Well, it's time to restore that, and the way to do that is with this legislation. It will be filed. Now, Representative Coleman has retired, so he won't be coming back. But, I was able to confirm this week that another State representative is taking it on and filing that bill. So that's a good thing. So that will be filed. So we will keep you posted. On how that happens.

So, Laura, let me ask you this. Do you want to give the breakout etiquette, or do you want me to give the prompt first? Because we're going to go into breakouts here, folks.

>> Laura: Right. Before we do that, I see that Lira has a question.

>> Dennis: Oh. Yeah, go ahead, Lira.

>> Laura: It's in the chat. She says, do you know why they had stated that they closed the office?

>> Dennis: Thank you, thank you. By the way, Lira, I'm so glad you're here. Lira is a UT student who is getting involved in advocacy. How cool is that? And going to drag along a bunch of other UT students, too. Right, Lira?

Do you know why they stated that they closed the office? Yes, I do. They stated that they didn't think it was worth the money it was costing. And I'll tell you, we have a saying among advocates, when something is really cheap compared to how much money they spend, we call that -- I'll sprinkle my fingers here, budget dust. It's like a grain of dust in the total budget.

So what was the real reason they closed that office? Was it really money? I don't think so. I think they just weren't -- I think they weren't invested in the idea of health equity. I think they were -- they recognized that these disparities existed, and maybe that office was pointing that out a little too much for their comfort level.

I can't say for sure, but they blamed it on budgetary problems. But when something, as I say, is a grain of dust in the total budget for the Health and Human Services Commission, that's the kind of explanation that to me doesn't ring true.

Breakout discussions

>> Dennis: I'm going to touch on several things that came up in our group, and then ask if anybody had other things regarding health equity. And so things we heard about.

Doctor wandering. You've got to go to multiple doctors before you go to your diagnosis. A GP, specialist, then another specialist. That's a barrier.

Interest list for community attendant services. Sometimes 16 years long. That's a barrier. You know, like Betty was just talking about how she was responsive to the biomarker conversation earlier about how great that is for people with disabilities, because cancer does strike people with disabilities more so than others. Why? Because of unequal access to things like oral healthcare.

So the roots of health disparities are almost like multipliers, it goes around.

Transportation. Disadvantages in transportation. Just getting to healthcare results in a lack of health equity. Cost. Physical accessibility, sometimes getting into a healthcare place, getting on an exam table, getting through a narrow doorway. A good comment about people with visual impairments trying to use technology, like touch pads. What if you don't have an iPhone? Tools that have become common in accessing healthcare are really not equally accessible.

Any other comments? Raise your hand or unmute.

>> Chase: Dennis, this is Chase. One thing that came up in ours that I think really kind of struck me, I thought about it in the past, but May said, when you're looking at the waivers and you have people receiving -- especially those that are receiving a really robust package, and at age 21 they lose their around-the-clock nursing care and stuff like that, where we kind of have set these age limits of when you can get care up to.

And it's kind of like the dental program used to be in Medicaid, where you had a full dental package for kids, but at age 21, there's absolutely nothing.

So, it's not like people's teeth have healed or they need less care at the age of 21, but we basically have created for aging Texans, and if we consider 21 and one day aging now, where you lose a lot of the coverage you might have had as a child earlier on in your life.

So age can play a role in equity, in a way that we probably haven't even thought about.

>> Dennis: Any other comments about health equity, health disparities that came up in your groups that you want to share?

>> One thing that we talked about in our group was kind of a subset of the cost issue where sometimes co-pay assistance and other such cost help is available. But either the doctor's office that's writing the prescription doesn't know about it, or the pharmacy doesn't know about it, and you have to be pretty savvy to actually find, if there's assistance available for a particular kind of drug, there's some people that they'll get a drug, and they'll have a bill facing them

that's seven hundred and they need this drug, but they don't know how to pay for it, not knowing that there is actually help there. They just -- you know, sometimes getting that help, you have to do an application with a manufacturer. Sometimes you have to go through your insurance. Sometimes there's a coupon out there that you didn't know was out there. Sometimes it's simple like through Good Rx. Sometimes it isn't.

Sometimes there's third party assistance available through a foundation, and not having access to that information, not knowing how to comb through those systems, not having just a simple concentrated resource for all this information is a major barrier for people that are facing high cost associated with their drugs.

>> Dennis: Yeah, yeah. There's a high cost, and then you don't have access to the information to help you navigate those costs. That's a good one.

There's one in the chat that came in from Jolene's group. Lack of access to prescribed services under Medicaid or a self-funded plan. My guess is an example of that would be the ABA services for autism, which are in Medicaid theoretically, and in self-funded plans, theoretically, but are not all that easy to really get to. In fact, pretty darn hard.

Just because something is said to be available, said to be equitably available, it doesn't always mean that it is.

Anybody else -- we're going to wind it up here. Marianne? Sure. Unmute yourself.

y Ann? Sure. Unmute yourself.

>> Related to that last one, you know, people might think, oh, Austin, there's great equity. One issue that's been going on for quite a while in Austin is that psychiatrists are declining to participate in private insurance, let alone Medicaid, and unless you have the money to pay them out of pocket, you're out of luck if you need psychiatric care, you know?

And that's a big issue. That's a big issue for a lot of people, not just people with mental health issues, but for people with autism, for example.

>> Chase: Marianne brought up a good point in our group about that, where if you need certain medications prescribed that have to be prescribed by a psychiatrist, but you can't afford to pay to get them to sign that, that becomes a barrier that you can't get the access to the medications, because you can't afford to pay.

>> Yeah, and I think this brings up a -- this is something that CTD cares very much about and we've been working on for a while. Mental health and IDD and being able to access mental health services. Oftentimes there are things like IQ thresholds to be able to access mental health services or, you know, these two services are not talking to each other.

So we have the local mental health authorities and the local IDD authorities, and families are led to believe you kind of have to choose one door to get services, so you either get services for IDD or you get mental health services, and it's just not very well coordinated. We personally have experienced some real struggles. Like Mary had mentioned about having access -- just having access to a psychiatrist, but also if you've got co-occurring diagnoses, it's difficult to get comprehensive c

>> Dennis: Well, thank you all. We're winding down our hour in Raise Your Voice. Really good discussions. A lot of like high level philosophy rather than specifics today, and that was pretty darn cool.

So our next Raise Your Voice roundtable is October 10th. It's going to be about voting, and what is more -- I'll tell you, I can't think of a more important topic right now than voting. So, I also want to thank the fact that we have sponsors that cover all expenses, so no one ever has to pay for Raise Your Voice, and those are Grail, We Work For Health Texas, Amgen, AstraZeneca, touch of class, and United Healthcare, superior health plan, AmeriGroup, and today we had a special session

funded by Bristol-Myers Squibb with some extra support for that.

We appreciate all these folks because they're going to allow us to keep doing this. And we think the fact that you guys show up and spend time and listen, it seems like there's new faces every time. And sometimes there's faces we haven't seen in a couple of months coming back. That's kind of cool, too.