Featuring:
Washington State Representative Cindy Ryu, Chair, Women In Government Board of Directors (moderator)
Dr. Debra Patt, M.D., PH.D., MBA, Executive Vice President of Texas Oncology and a practicing oncologist and breast cancer specialist in Austin, Texas
Hilary Gee Goeckner, MSW, Senior State and Local Campaigns Manager - Access to Care, American Cancer Society Cancer Action Network

Washington State Representative Cindy Ryu:
Welcome to today’s event on “The Role of Biomarker Testing in Personalized Healthcare and Addressing Disparities in Cancer Care and Survival.” I’m Washington State Representative Cindy Ryu, chair of Women in Government. I’m excited to be joined by so many lawmakers and some great speakers to talk about this important issue.

I’d like to thank Amgen for sponsoring today’s event, and their partners at the American Cancer Society Cancer Action Network, or ACS CAN, for organizing the briefing.

Progress in improving cancer outcomes increasingly involves the use of precision medicine, which uses information about a person’s own genes or proteins to prevent, diagnose or treat diseases like cancer. Biomarker testing is an important step to accessing precision medicine treatments, including targeted therapies that can lead to improved survivorship and better quality of life for people with cancer.

Biomarker testing is so important for connecting patients with the most effective treatments and clinical trials – not only for cancer care but soon, for many other conditions as well.

Targeted treatments have come a long way in recent years – but not everyone is benefiting from the latest advances.

There is currently limited and disparate access to biomarker testing. Improving access to biomarker testing and thereby access to targeted therapies is a strategy to reduce health disparities and improve outcomes for people with cancer.

To kick things off, we’d like to show a short, animated video from ACS CAN to explain a bit about today's topic – biomarker testing.

**Video:**
**Narrator:**
Imagine - scientists have developed a new way to use information from your own genes or proteins to help doctors diagnose or treat disease and improve survival and quality of life in 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 health care 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 advanced health equity for all.

Washington State Representative Cindy Ryu:
Next, we’re excited to hear from a provider on the front lines of cancer care and cutting edge research – Dr Deborah Patt, an oncologist, breast cancer specialist, and Executive Vice President at Texas Oncology in Austin. Dr. Patt is in clinic today, so we recorded her remarks in advance of today’s event.

Dr. Deborah Patt, MD:
Hi, my name is Dr. Deborah Patt, and I serve as an Executive Vice President of Texas Oncology. I’m a breast cancer specialist, and I live in Austin, Texas. I have the privilege of talking to you today about a lot of development in cancer care, how next generation sequencing and biomarker testing has really evolved the landscape in cancer care. I think it’s incredibly important for our policy makers to understand all of the developments in cancer care and how your decisions and the policies that influence health care can change them over time.

Cancer in 2021: None of you are spared from cancer. One out of two men and one out three women in their lifetime will be diagnosed with cancer. It’s very common. 1.7 million persons are diagnosed with cancer in this country every year. 18 million cancer survivors currently live in the United States. We spend about $157 billion in costs for cancer, and the AARP estimates about a $150,000 cost per cancer diagnosis.
We know there are many factors that contribute to one’s risk of cancer. Some of them are preventable, and certainly screening is some of the best prevention that you can have to prevent cancer. But the big difference that we have in cancer now too is that we have more effective therapies. Therapy has really evolved over the last 20 years, and I’d like to spend some time talking to you about that.

As I think about cancer therapy in three sort of buckets, there’s the blunt instruments from 1900 to 2000. Those are really important, and we still use them today. There are things like surgery and radiation and general chemotherapy that opts to kill cells that are rapidly dividing. But we’ve had some more specific changes over time because of our understanding of the molecular basis of disease, and so that’s targeted therapy. That really started in 2000. Then, also immune therapy that has really been present since 2015. They’ve been real differentiators in cancer care.

This is a timeline that looks at cancer care innovation, and you can see historically there have been multi-agent chemotherapy in the 1960s, other systemic chemotherapies that have improved survival. But it really wasn’t until the year 2000 that we have our first molecular profiling and the approval of Gleevec or Imatinib Mesylate in Chronic Myeloid Leukemia (CML) that was our real first understanding of the molecular basis of disease and how treatment could dramatically change the outcome. I speak to that because this is really the first targeted therapy that was approved but this is when Chronic Myeloid Leukemia, which is a disease that impacts about 5,000 Americans per year, went from an average survival of five years to having 95% of people survive at five years overnight with the innovation of this targeted therapy.

And the thought of targeted therapy in general in this space is that if you can stop the way that cells communicate and tell each other to grow, then you can render cancer as a chronic disease like hypertension or diabetes. This is really the dream of modern cancer therapy that cancer can be chronically controlled - if not cured. So, when we think about targeted therapy, that’s really evolved. As we look at the distribution of biomarkers in non-small cell lung cancer (NSCLC), you can see this is a distribution of frequent known genetic mutations that in non-small cell lung cancer that drive therapeutic decisions.

When I finished my training at the MD Anderson Cancer Center in 2006, we treated non-small cell lung cancer largely with chemotherapy. And I would say while chemotherapy is still very important in the treatment of non-small cell lung cancer, most patients today are now either eligible for immunotherapy or some kind of targeted therapy, and how we treat that cancer more chronically in a way that is less toxic to patients has really evolved over time.

So, this is the promise of modern cancer therapy, and this is a complex slide, but really this is a way to talk about how molecular mechanisms of disease work in the way that cells talk to each other. We call this signal transduction, but really what this kind of communication is is intercellular mechanisms that tell cells that it’s time to grow or it’s time to stop growth, and there are many different genes and proteins that influence those choices that cells make. And so, if we can upregulate or down regulate them based on our understanding of molecular profiles of cancer, we can cause cancer to chronically
not grow. And that’s really what we want is a chronic state of non-growth in cancer cells that render cancer in remission for many years and allow patients to have long-term survival.

So, cancer and healthcare policy is really important because not every patient has access to these life-saving treatments - to these wonderful therapies that could potentially render their cancer a chronic disease. And they don’t have access to these life-saving treatments because they don’t have access to the testing that identifies that those life-saving treatments would be helpful.

Sometimes the burden is simply because of insurance status. So, we know that many states have lower insurance rates, and that limits people’s access to care. It limits our ability to treat cancer effectively. When that happens, we see the survival for cancer is dramatically reduced. This looks at years of survival after first diagnosis with any malignancy by insurance type, and we see that insurance is a main determinant of that. In Texas, where we have a large percentage of patients that are uninsured and adults that are uninsured, this a large problem. You can see that mortality substantially tracks to insurance status.

A problem, though, that we have is that it’s not just an issue of if someone has insurance or not but also with many insurance plans. Their benefit design does not cover specific molecular testing for specific cancers. Just because someone has insurance, we can’t guarantee that they necessarily have access to these different tests to determine if they would be eligible for certain treatments for cancer.

We have done some looking at disparities in this patient population, and we know that low-income individuals and individuals that live in high poverty locations in general have less access to testing. This was a study that was published in the Cancer Epidemiology Biomarkers and Prevention in 2019 that looked at testing for Erlotinib for patients with metastatic non-small cell lung cancer, so they needed a specific molecule marker to determine if they were candidates for a particular pill-based therapy. This looks at testing among those patient populations. What we can see is living in a low-income area or high poverty location was a risk to not be tested.

Policy also dramatically impacts this. This is a study that looked at the trends in next generation sequencing in patients with solid tumors by race and ethnicity after implementation of the national coverage determination for Medicare where we looked at demographic differences in next generational sequencing by race, ethnicity, region, insurance, age, sex, and tumor type before and after the national coverage determination. What we can see is that the national coverage determination that permitted the use of some next generation sequencing increased the compliance with appropriate next generation sequencing and testing among all patients - but still there was variability. I would argue that we need to have continued policy to promote insurance coverage, both private insurance coverage and also Medicaid, and expand the use of Medicare for testing for patients as this drives therapeutic opportunity and promotes good patient outcomes.

So, in summary, cancer is a common problem that impacts all of us. One out of two men and one out of three women will be impacted by cancer. Cancer progress is unprecedented, but we need the tools to manage optimally. Next generation sequencing and molecular marker testing have been some of those tools that have been critically important in rendering cancer a chronic disease, especially in
patients with advanced cancer - with stage 4 cancer. Sometimes in patients with even earlier cancers, but especially patients with stage 4 cancer. Molecular testing with next generation sequencing or biomarking testing are some of these tools that are really important to preserve and protect. Disparity exists regarding access to these tools. If you have insurance or don’t, if you have Medicaid or Medicare or private insurance and even among private insurance payers that all have variable coverage determinations around molecular profiling and next generation sequencing, we really need policies to cover testing and provide access to improve patient outcomes and allow effective cancer treatment to be a reality.

I want to thank you for listening to me and for your time today and let you know that I have the great privilege of serving as a leader in a large organization in cancer. Empower me to be a better cancer specialist by giving my patients access to the tools they need. Thank you for your time.

**Washington State Representative Cindy Ryu:**
That was fantastic. Now we’ll move into some discussion of what policy solutions exist to help expand access to this important testing. You can submit questions anytime using the Chat Box on the right side of your screen.

At this time, I’m excited to introduce Hilary Gee Goeckner with ACS CAN to talk about legislative opportunities in this area. Hilary?

**Hilary Gee Goeckner:**
Thanks so much, Representative Ryu. ACS CAN is proud to be working alongside many state and national partner groups representing patients, health care providers and others to advance equitable access to biomarker testing. One big barrier for patient access, as Dr. Patt mentioned, is lack of insurance coverage for needed biomarker testing. Last year, both Illinois and Louisiana passed laws to align insurance coverage with robust medical evidence, including clinical treatment guidelines. Here’s a short video from Illinois that talks about the law and features a few of the policymakers involved.

**Video:**
**Alecia Mandal (Cancer Survivor):**
My name is Alecia Mandal. I’m originally from Minnesota, but I’ve lived in Hawthorne Woods, Illinois for 24 years. Met my husband 30 years ago in Minnesota. He was a resident, and I was a nurse, and it’s that story-we fell in love. Had a few kids. Moved here. Life’s been great. A year ago, I was diagnosed with cancer.

Basically, I had stage four colon cancer. Over Labor Day of 2020, I had three rounds of chemotherapy, and then after that - I think it was October or November - Dr. Kircher gave me a call and said, “Hey guess what? Great news!” And I’m like, “What’s great news? My cancer is gone?!” And she’s like, “No but you know we did that biomarker testing,” and I’m like, “Yep, I remember that.” And she goes, “You qualified to get immunotherapy.” And then she called me last Friday and gave me the amazing news actually that I’m sharing now publicly for the first time because only my children know and my husband that everything in my colon is gone. I had 49 – yes, 49 - positive lymph nodes in my body, and I have zero. So, right now I’m not calling it cancer free. I’m just saying they have no signs of cancer in
my body. I would not be sitting here if it weren’t for God and if it weren’t for immunotherapy and biomarker testing.

**Dr. Jan Kitajewski (Director of the University of Illinois Cancer Center):**
So, think of it - biology and marker. Your body is a biological entity, and there are markers of normalcy and normal aspects of your body and abnormal. So, biomarker testing is looking for those abnormal aspects of your body that would indicate cancer or guide a process for treatment of cancer.

**Theresa Mendez (Cancer Survivor):**
I am a two-time thyroid cancer survivor. And that’s how they detected the cancer came back the second time in my lymph nodes was after having that test.

**Dr. Jan Kitajewski (Director of the University of Illinois Cancer Center):**
I think the real big impact is personal knowledge about what you’re facing, and in many cases that knowledge is going to overcome the fear and lead to success.

**Theresa Mendez (Cancer Survivor):**
Which in my case they did the test. They found that it was in a couple of the lymph nodes. We went back in, we removed the lymph nodes, and now it’s gone, and the markers are not there anymore.

**Dr. Jan Kitajewski (Director of the University of Illinois Cancer Center):**
Biomarker testing is routine for certain populations and game changing for the course of their cancer - whereas other populations for a variety of reasons are not able to equally access this.

**Illinois State Representative Mary Flowers:**
So many people - because they didn’t have the right type of income, didn’t live in the right ZIP code, didn’t know the right person - unfortunately, they didn’t get the same type of care that other people may have gotten that had means.

**Alecia Mandal (Cancer Survivor):**
And I don’t think that’s right. It can’t be right. It can’t be the world we live in. Why should I get something that somebody else doesn’t? I don’t deserve any more than anyone else does.

**Dr. Jan Kitajewski (Director of the University of Illinois Cancer Center):**
So, this bill is really designed to prevent that new technology from widening the disparities.

**Illinois State Senator Tony Munoz:**
When the American Cancer Society brought this to my attention, I realized that this can help people throughout the state of Illinois.

**Illinois State Representative Mary Flowers:**
This is everybody in, and no one is left out. That’s what I love most about this legislation.
Illinois State Senator Tony Munoz:
I am very proud to say I was part of this. I think it is a very proud moment for the state of Illinois.

Dr. Jan Kitajewski (Director of the University of Illinois Cancer Center):
Illinois is serving as a leader, and I imagine that many other states will follow that lead soon to onboard biomarker testing.

Alecia Mandal Cancer Survivor:
Why wouldn’t everybody want this? Why wouldn’t every state in the United States say, “Let’s do it”? Look at what it’s done for people. We could actually get a handle on cancer treatment. I mean come on this is what people have been waiting for years.

Theresa Mendez (Cancer Survivor):
Less treatment. Less pain. Less sickness. I feel this eventually will end the suffering and the death caused from cancer.

Illinois State Representative Mary Flowers:
I want to thank the American Cancer Society for helping to put forth this legislation and for their tenacity and their hard work and never giving up.

Dr. Jan Kitajewski (Director of the University of Illinois Cancer Center):
ACS CAN is the real deal. I have not met a harder working, more dedicated group of people that are fighting on behalf of cancer patients. They fight, and they fight hard, so I’m very impressed and really pleased to partner with them.

Illinois State Representative Mary Flowers:
So many people’s lives will be made better as a result of this legislation. Not that we found a cure - but it’s about the closest things that we can get, and we’ll take that for now.

Washington State Representative Cindy Ryu:
Thank you so much, Hilary. If anyone who has any questions, please be sure to ask your question in the Chat Box. In the meantime, I have some questions for you, Hilary.

How are targeted therapies different from more conventional cancer treatments?

Hilary Gee Goeckner:
I love that visual Dr. Patt uses with the hammer. Chemo and radiation - kind of what everyone pictures when you think of cancer treatment, are very blunt tools, and chemo targets fast growing cells. So, that also hits a lot of cells that aren’t cancer. That’s why chemo can cause hair loss and have other significant side effects.

Targeted therapies are going after the specific mutations that can be identified through biomarker testing that are causing an individual patient’s cancer to grow. They often have fewer or sometimes no side effects. What’s really exciting about these targeted therapies - instead of treating a patient based
on where the cancer was found in their body - for a really oversimplified example, let’s say you have breast cancer, and so these are the five or six treatment options we can choose from. Instead, doctors are able to look at the mutation, and so, regardless of where we found this cancer in your body - whether it’s breast or prostate or melanoma - if you have this mutation, we know that this treatment might work really well for you.

Washington State Representative Cindy Ryu:
And that must be where the late stage came in because it must have metastasized to other sites from breast cancer, or in my friend’s case, from her lung to her spine to everywhere else.

So, what kinds of disparities do we see in biomarker testing? And what do you think can be done address these disparities?

Hilary Gee Goeckner:
That’s a really important question. A lot of the disparities we see in cancer outcomes - whether that’s by race, ethnicity, income, insurance - are also seen in the biomarker testing rates, so improving access to biomarker testing is really important for advancing health equity. The research shows that people of color, particularly Black people, are not benefitting from biomarker testing at the same rates as white people. Additionally, people insured through state Medicaid programs are less likely to receive appropriate testing. We also see that people in rural communities receiving care in non-academic medical centers are less likely to benefit from biomarker testing.

There are a number of barriers to access to biomarker testing - certainly patient awareness, providers feeling like they can stay up to date on the latest testing recommendations, but one big opportunity that can make a really big difference in this area is insurance coverage of biomarker testing, as Dr. Patt was describing. So, this is looking at people who have some kind of health insurance, whether that’s through Medicare or Medicaid or an employer sponsored insurance plan or something they purchased through the marketplace. Does their insurance cover the biomarker testing that their doctor thinks they need and that these clinical treatment guidelines like those from the National Comprehensive Cancer Network (NCCN) say are appropriate for understanding their cancer and their disease?

Most oncologists report that they look to things like NCCN’s clinical treatment guidelines for determining what to do with each patient. So, does this patient need further testing? What treatments should we consider? A lot of insurance plans say that they look to those treatment guidelines in determining what to cover, but unfortunately, a lot of biomarker testing that is recommended by those treatment guidelines is not covered by insurance.

This is an opportunity where state policy can have a big impact to make sure that everyone who meets the clinical treatment recommendations is able to get that appropriate testing because the alternative is either people who have- so typically Medicare and employer-sponsored insurance plans have better coverage of biomarker testing, but that leaves out people who have Medicaid for their health insurance or a plan they purchased on the marketplace or a small employer-sponsored plan. Those people are less likely to have coverage for biomarker testing.
You’re left with a scenario where only people who can pay out of pocket are able to get it, and if that’s the case, we’re just going to see the existing disparities by income or race increase as cancer treatments get more precise and more effective. We want to make sure everyone is able to benefit from those.

**Washington State Representative Cindy Ryu:**
What does insurance coverage of biomarker testing currently look like? Who and which states are benefitting from these tests?

**Hilary Gee Goeckner:**
Yeah, so that builds a little bit on my last answer. Typically, what we see is that Medicare - which is regulated at the federal level, although there are some local coverage determinations as well – generally, Medicare patients are able to get the biomarker testing their doctors want for them. We did a survey about two years ago, and 91% of cancer survivors who responded and had biomarker testing while covered by Medicare were able to get the testing that they needed.

Then, large employer-sponsored plans are more likely to have robust coverage of biomarker testing. There we saw about 75% of patients with employer-sponsored insurance able to get the testing that they needed. And then, patients who bought their own insurance through a marketplace in their state - about 60 or 63% were able to get biomarker testing.

There’s a range, and the good news is many patients are able to get the testing that they need, but there’s also room for improvement to make sure everyone’s able to get the latest and most effective testing and treatment for their cancer.

**Washington State Representative Cindy Ryu:**
Thank you. So, can you speak to the importance of biomarker testing as it relates to clinical trials?

**Hilary Gee Goeckner:**
Sure. Biomarker testing is becoming increasingly important for enrollment in clinical trials, and for many cancer patients, clinical trials offer them the best opportunity to treat and beat their cancer. Similar to how a lot of new targeted treatments are just based on the mutation, and it doesn’t matter what kind of cancer you have or where it started, a lot of clinical trials are enrolling people based on the biomarkers that are in their cancer. Instead of having a clinical trial for Melanoma, instead they’ll be enrolling people with all different types of cancer who have X mutation. Those mutations are usually noted by a four-letter number combination like EGFR or ROS1.

**Washington State Representative Cindy Ryu:**
Thank you. What opportunities for biomarker testing existing outside of cancer care – other applications for other diseases?

**Hilary Gee Goeckner:**
Sure. Right now, the overwhelming majority of applications for biomarker testing are in oncology, especially lung cancer. There’s really advanced research, lots of targeted therapies in lung cancer, lots
of exciting research happening for other cancer patients, but also lots of research happening for other disease areas.

We might hear a lot, especially in marketing from medical providers, about personalized medicine and precision medicine. This is really taking information from your own body - so your genes and mutations in your cells, to understand what treatments will work. This isn’t just about cancer. There’s lots of research happening in cardiology, neurology, Alzheimer’s. Some current applications actually targeted therapies available for some autoimmune diseases like Rheumatoid Arthritis. Cancer is certainly the cutting edge and where most research has advanced historically, but it’s really exciting to see that there could be future applications.

One important note about the legislation that passed in Illinois last year is that it’s disease agnostic, so it says insurance plans need to cover biomarker testing when it meets these criteria to show that there’s really robust medical and scientific evidence to support that application. And that’s not limited to cancer patients. So, as other treatments and targeted therapies come to market for other conditions, those plans will have to cover those as well.

**Washington State Representative Cindy Ryu:**
Great! I would love to see that bill and also the fiscal note, but it sounds like we've come a long way over the last 20 years. So, this sounds expensive. Will biomarker testing increase costs?

**Hilary Gee Goeckner:**
That’s a great question and a perfect follow-up to your note about fiscal note. Milliman just put out a study in the last couple weeks looking at cost implications of this type of legislation and what this would mean for premium impact on insurance plans. They projected somewhere from $0.14 to $0.50 per member per month for private insurance plans.

What’s really important is that this accounts for the potential increase in use of biomarker testing but this doesn’t count any avoidance that you can get with biomarker testing. Without biomarker testing, often oncologists are kind of guessing and trying out different treatments to see what will work and those treatments can be really expensive. Ask anyone’s who’s been treated for cancer or knows someone who’s been treated for cancer. There can be enormous costs for treating that, even with good insurance.

Biomarker testing, the test itself, can range anywhere from under $100 if you’re just testing for a single gene or thousands of dollars if you’re looking at a larger panel to identify more mutations. But that helps doctors say, “Actually, that $80,000 worth of chemotherapy that we would have prescribed you if we didn’t know about this mutation, we’re not going to do that because we know that won’t work,” or “We know this other treatment will work better.”

It’s really important to look at the biomarker testing and the targeted therapies in the context of a cancer patient’s treatment options. You’re able to avoid treatments that would be perhaps ineffective and more quickly get on a treatment that will work and avoid complications.
Something I’ve heard over and over again talking to patients who benefitted from targeted therapies based on their biomarkers is that they are able to keep working and living their lives. Unlike someone who’s going through chemo or radiation, who maybe is tired all of the time and missing work, a lot of people with targeted therapies are able to continue living their life. They take a pill or get an infusion once a month to keep that cancer in check, but other than that, they don’t feel really sick all the time, which is really exciting.

**Washington State Representative Cindy Ryu:**
Yes, definitely for quality of life as well as of course surviving the cancer itself. Can you explain the difference between genetic testing for an inherited cancer risk and biomarker testing for a patient’s specific tumor?

**Hilary Gee Goeckner:**
Sure. One way to kind of simplify this is to think of genetic testing as something that might happen before someone’s diagnosed with cancer and genomic or biomarker testing happening after they’re diagnosed with cancer. I’ll get into a little bit of nuance there.

Genetic testing is looking for inherited mutations - so something you got from your parents - to see if you’re at higher risk for getting certain cancers or if you could potentially pass on those risks to your children. That’s looking at inherited mutations, things you got from your parents, and what that means for how often you should be getting screened or if you might want to take some other preventive measures because you are at high risk for certain cancers.

Biomarker testing, or what people sometimes call genomic testing, is looking after you’ve been diagnosed for cancer. How aggressive is this cancer? Will it respond to these targeted therapies? Many of those mutations are acquired, so you didn’t have them at birth, they didn’t come from Mom and Dad, but you’ve had these mutations evolve in your cells over time that are now driving this cancer to grow aggressively. It’s looking more after someone’s been diagnosed with cancer at which treatments will work or what can we say about your cancer.

Though certainly after people get diagnosed with cancer, they might also get genetic testing to see what this means for other cancers or for my children or grandchildren’s risk.

**Washington State Representative Cindy Ryu:**
Excellent. As a brand new Grandma, I do pay a lot more attention to people who get really scared when somebody is diagnosed with cancer and then they worry for their own health as well.

Why would we tie this coverage requirement to national guidelines and recommendations? Why not say, “We know it works for these particular cancers, so let’s just cover those and reduce that fiscal note”?

**Hilary Gee Goeckner:**
That’s a great question. The Illinois legislation, as well as bills under consideration in several additional states now, spell out a couple sources of evidence for when biomarker testing should be covered. So,
that’s FDA-approved tests or companion diagnostics for FDA therapies, CMS (Centers for Medicare and Medicaid) coverage determinations. When Medicare decides that this should be covered for Medicare beneficiaries, other plans should follow that evidence. And then nationally recognized clinical practice guidelines like I mentioned earlier, NCCN, the National Comprehensive Cancer Network.

What’s really exciting in this area is there’s so much happening, and we want to make sure that this coverage keeps pace with the science. Not getting ahead of the science - only when the testing is proven to be really helpful for patients and helpful for shaping their treatment decisions. Then, it should be covered. As you know, changing laws can be challenging, and we don’t want to have to go back year after year after year and update the statutes and say, “Oh, last year it was really good for non-small cell lung cancer melanoma but actually there’s all this new research now about pancreatic cancer.” We want to make sure those patients benefit too.

It’s an efficient and forward-thinking process to tie the coverage requirements in statute to those really robust sources of evidence going forward so that patients can benefit.

**Washington State Representative Cindy Ryu:**
There’s also something called rulemaking by the agencies.

A question we have here is whether ACS CAN has resources for the state legislators to basically copy - it’s the finest form of flattery – to introduce and pass policies on health insurance including biomarker testing for cancer patients?

**Hilary Gee Goeckner:**
There are a couple of resources linked on the event page now. So, you can click on some fact sheets on biomarker testing generally and biomarker testing and health equity.

There’s more information at [fightcancer.org/biomarkers](http://fightcancer.org/biomarkers).

I will also add that we are working in many states – not quite every one yet, but soon on this issue specifically. ACS CAN is working in every state and territory on policies to help prevent and treat cancer. This is a really exciting priority for us because it’s so important to helping patients get the best treatment for their cancer. We are working in coalition to educate lawmakers through events like this about the exciting opportunities around biomarker testing but also to advance legislation like that passed in Illinois.

I’m happy to call out our friends in Arizona where the House unanimously passed coverage of biomarker testing just last month, and that is now under consideration on the Senate side. There are bills introduced in several other states as well.

As we’ve covered in the last 30 or 40 minutes, this is a complicated issue. There’s a lot of nuance to it. We are trying to be thoughtful about educating lawmakers and partners and potential opponents of this about what this issue is, what it means for patients, and what the legislation would do.
We aren’t running or asking lawmakers to carry bills in all 50 states at once. We are trying to work through this thoughtfully and soften the ground, educate lawmakers, and build up champions to help advance this issue throughout the country.

**Washington State Representative Cindy Ryu:**  
Women legislators are very willing to step up. The last question: Is there any targeted therapy at this time for Alport Syndrome that you’re aware of?

**Hilary Gee Goeckner:**  
I’m not aware. I would have to look into that one. I’m not sure exactly but happy to give it a Google.

We’ve had a few questions about slides and recordings, and we will work with Women in Government to get the recording shared with everyone. So, if you weren’t able to catch the first few minutes or if you want to share it with colleagues, we encourage you to do that, and we will get that out in the next day or two.

**Washington State Representative Cindy Ryu:**  
Thank you so very much, Hilary. We are out of time for today, and I really appreciate you organizing this and joining us. Thank you, everyone, for joining today’s conversation. I’d like to thank our speakers and Women in Government for hosting us.

Let’s keep the conversation going. Please check out the resources linked on the right side of your screen, and you can learn more at [fightcancer.org/biomarkers](http://fightcancer.org/biomarkers).

And please join Women in Government again for our next event, an upcoming webinar on “Preserving and Promoting Professional Certifications” on Monday March 28th at 2:00pm Eastern / 11:00am Pacific. The details are on [womeningovernment.org](http://womeningovernment.org)

Thank you again, and we’ll see you soon.