

**NO TIME TO WAIT:
PROPOSALS TO LOWER
PRESCRIPTION DRUG COSTS**

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TUESDAY, APRIL 12, 2022

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Phoenix, Arizona.

The committee met, pursuant to notice, at 10:58 a.m., at ASU Collaboratory on Central at the Westward Ho, 618 North Central Avenue #100, Phoenix, Arizona, Hon. Mark Kelly, member of the committee, presiding.

Present: Senator Kelly

**OPENING STATEMENT OF SENATOR
MARK KELLY**

Senator KELLY. Good morning, everybody, and thank you. Thank you for joining us here this morning at the Westward Ho. We chose this hearing here because hundreds of Arizona seniors call this place home, and I would like to thank Arizona State University for hosting us here in their downtown campus.

I am very excited to be here today to chair a United States Special Committee on Aging hearing. This is my first field hearing, and I cannot think of a more important issue facing Arizona's seniors than the one we are here today to examine, and that is, how do you lower the cost of prescription drugs?

You know, right now, supply chain issues are driving up the cost of everything, from a pound of ground beef to a gallon of gas, and when you live paycheck to paycheck, or especially when you are on a fixed income, these rising costs make everything harder. They make your life harder, but when you add on top of that, paying for your prescription drugs as well, and we are talking about medications that people need to survive, Arizona families and seniors are facing choices that nobody should ever have to make.

Across Arizona and across the country, this is the reality for far too many people. Now I have heard this directly from my Senior Citizens Advisory Group. Now we get together about every 3 months, and this is a problem that gets raised every 3 months, and as it should be. You know, and it is that 34 percent of seniors here in Arizona are concerned that their household won't be able to afford their needed prescription drugs in the next year, and those concerns, they are not unfounded.

Last year, more than 1 in 10 Americans aged 65 and older skipped a pill because of the cost. One in eight older Americans re-

port to have delayed their retirement because of the cost of their prescription medication. Now I have heard from Arizonans across the State who are seeing the costs of their prescriptions continue to climb or spike or even double in a year, and that is unacceptable, and the data backs this up.

Medicare spending on prescription drugs is rising. Spending on Medicare Part D, the prescription drug benefit, has doubled over the past decade, and it is expected to grow faster than most other areas of Medicare spending in the years to come. Now this is going to result in both greater spending, greater spending for the Federal Government, and greater spending for Arizona seniors out of their pockets, and this is a problem.

The data shows that spending is going to go up, but not because seniors are accessing more prescription drugs, but because the drugs are becoming more expensive. From 2012 to 2017, the average cost of a prescription drug treatment in Arizona increased by almost 58 percent. The costs are going up, and this should alarm all of us, but that is why we are here today, and that is why I have worked on solutions to drive down the costs of prescription drugs. Just in the past couple of weeks, the House of Representatives passed a bill which I am a co-sponsor of that would cap the out-of-pocket cost of insulin at \$35 a month.

Now, as many of you know, insulin is a drug that is not optional if you are a Type I diabetic, you need it to survive, and many people have to take it for decades and they do it. Yet Americans, we pay 10 times more than folks in many other countries for insulin, so we are working to change that. I have also worked to negotiate a plan that would lower out-of-pocket costs for seniors, drive down prescription drug prices, and prevent price gouging from drug companies.

Under this plan, for the first time ever, Medicare would be able to negotiate directly with drug companies to get a lower price on the most expensive drugs on the market. Now, this plan would also prevent drug companies from raising the prices of these drugs faster than the rise of inflation, or if they still choose to do that, it would require that they pay a rebate, and it would restructure the Part D benefit so that seniors on Medicare Part D pay no more than \$2,000 annually out of their pocket, and it would also allow the costs to be spread out, that \$2,000 out of their pocket to be spread out over the year. Now these reforms will drive down the price of prescription drugs, lower out-of-pocket costs for seniors, and make our country more financially secure, saving hundreds of billions of dollars over 10 years, and I will keep pushing this proposal forward in the Senate, and I will continue to make the case to my colleagues that we need to act now, not next month, not next year.

Arizona seniors cannot and should not wait any longer, so today we are going to bring D.C. to Arizona, to hear directly from Arizonans about how rising prescription drug costs are impacting them and discuss the urgency to act on solutions, and I would like to ask each of our witnesses to please keep your remarks and questions to 5 minutes—you see how I did that. We got a clock right there, and now I will turn to introductions, I am pleased to introduce our witnesses. Our first witness is Ms. Dana Kennedy, who currently

serves as the State Director for AARP. She has spent more than 20 years as a leading advocate for working families, retirees, and women, and has long worked with nonprofit organizations in the State focused on disability and aging.

Thank you, Ms. Kennedy, for being here today and sharing your experience and your expertise with this committee. Our next witness, Dr. Suganya Karuppana—did I get that right?

Dr. KARUPPANA. You got it.

Senator KELLY. Alright, I practiced. She is the Chief Medical Officer at Valle del Sol Community Health. She also serves as a Chief Medical Operations Officer. Dr. Karuppana has more than 20 years of experience in health care and a decade in physician leadership in community health. Thank you, Dr. Karuppana, for being with us today and for sharing your work with this committee.

Next, I would like to introduce Ms. Dora Vasquez. She is the Executive Director of Arizona Alliance for Retired Americans and has more than 25 years' experience in local and State Government. In her role, Ms. Vasquez works to advance public policy that strengthens the health and retirement security for older Americans, so thank you, Ms. Vasquez, for being here today and for sharing with the committee.

Next, I will introduce Ms. Jenny Peña, Associate Manager of Pharmacy Patient Advocacy at the Banner MD Anderson Cancer Center. Ms. Peña has over 19 years' experience in the pharmacy career field. Her work as a patient advocate allows her to hear firsthand from patients who struggle to afford their health care and prescribed cancer treatment.

Thank you, Ms. Peña, for being here with us today and for sharing your work with the committee, and last but not least, my new, good friend, Ms. Judy Wilson. Met her at her car outside. Ms. Wilson is a recently retired Medicare enrollee who is living with multiple sclerosis. She is also Rotarian for 22 years, the volunteer for the MS Society, and a mentor for the Community Health Mentor Program, and a grandmother of four.

Thank you, Ms. Wilson, for being here today and for also sharing your story. We will now turn to our witnesses for their statements, so we are going to begin with Ms. Kennedy, so Ms. Kennedy, you can begin, and we have got the clock there. If you go over by a minute or two, not a big deal. If you go under, we will you pass the time down the line.

Ms. Kennedy.

**STATEMENT OF DANA KENNEDY, STATE DIRECTOR,
AARP ARIZONA, PHOENIX, ARIZONA**

Ms. KENNEDY. Great. Thank you, Senator. AARP, on behalf of our 38 million members, over 890,000 members in Arizona, and all older Americans nationwide appreciates the opportunity to submit testimony on this important hearing of the Senate Aging committee. High prescription drug prices hit older Americans particularly hard.

On average, Medicare Part D enrollees take between four and five prescriptions per month, often for chronic conditions that will require treatment for the rest of their lives. At the same time, Medicare beneficiaries have a median annual income of just under

\$30,000. One-quarter have less than \$8,500 in savings. In Arizona, the average annual cost of prescription drug treatment increased 26.3 percent between 2015 and 2019, while the annual income of Arizona residents only increased 15.6 percent.

This population simply does not have the resources to absorb the rapidly escalating prescription drug prices, and many are facing the reality of having to choose between their medications and other basic needs such as food and housing. In the case of one of our members, Leona G., age 74, she has maxed out her credit cards to afford her blood thinner Eliquis. She only received Social Security benefits and a small pension check each month. Unfortunately, Leona isn't alone.

We know the one reason someone doesn't fill a prescription is because of the cost. For years, prescription drug prices increases have dwarfed even the highest rates of general inflation. If consumer prices had risen as fast as drug prices over the last 15 years, gas would now cost \$12.20 a gallon, milk would be \$13 a gallon.

Just in January, the drug industry raised prices on over 800 prescription medications just as they increased prices for decades, including three-quarters of the top 100 drugs with the highest spending in Medicare Part D. AARP is mindful that high and growing prescription drug prices are affecting all Americans in some way. Their high cost is passed along to everyone with health coverage through increased health care premiums, deductibles, and other forms of prescription drug spending and other public programs like Medicare and Medicaid.

These escalating costs will eventually affect all of us in one form of health care costs, higher taxes, cuts to Medicare or Medicaid, or all of the above. In other words, every single American taxpayer is paying for high prescription drug prices, regardless of whether you are taking medicine or not. Fortunately, there is action the Senate can take right now. There is longstanding and overwhelming bipartisan support among voters for Medicare to negotiate with drug companies for lower prices.

The policies before the Senate that the Senator Kelly is leading on include Medicare negotiations, capping out-of-pocket costs under Medicare Part D, and penalizing drug companies that increase their prices faster than inflation, will provide long overdue relief to older Americans across the country. These policies, taken together, will help reduce drug prices and out-of-pocket costs. This is important because real relief for seniors and all Americans must include policies that get to the root of the problem, the high prices set by drug companies. American seniors aren't the only ones who stand to benefit.

Lowering prescription drug prices will also save Medicare program and taxpayers hundreds of billions of dollars every year. Medicare spends more than \$135 billion on prescription drugs. Last October, a survey commissioned by AARP Arizona conducted by OH Predictive Insights showed Arizonans across the aisle agreed on the need for affordable medication and action by Members of Congress.

An overwhelming majority of Arizonans agree Congress needs to tackle high prescription drug costs because some people can't afford to buy medicine or pay their necessities. Eighty-nine percent of

those surveyed agreed. The survey results showed a vast majority support for each proposed measure being discussed in Congress to reduce drug prices. The most favored initiative was allowing Medicare to negotiate for the price of drugs, winning over ninety-four percent of Arizonans.

Further, two-thirds, sixty-six percent of Arizonans surveyed do not believe that innovation will suffer if Medicare is allowed to negotiate for lower prices. Clearly, Americans are fed up with paying three times what people in other countries pay for the same drugs.

More than 4 million people across the country, including over 113,000 in Arizona, are joining AARP to sign a petition to demand lower prices for prescription drugs. There will never be a better time to lower drug prices than the historic opportunity in front of Congress right now.

Now is the time to get it done. Thank you.

Senator KELLY. Thank you, Ms. Kennedy.

Dr. Karuppana?

**STATEMENT OF SUGANYA KARUPPANA, M.D.,
CHIEF MEDICAL OFFICER, VALLE DEL SOL
COMMUNITY HEALTH, PHOENIX, ARIZONA**

Dr. KARUPPANA. Okay. Thank you, Senator Kelly and members of the Special Committee on Aging for inviting me to speak today on this vital topic, the high and ever rising cost of medications for our seniors. My career has been dedicated to serving communities with health disparities. I spent 6 years at UCLA's County Hospital. I was a Clinical Professor at the David Geffen School of Medicine, training our next generation of doctors. Since moving to Phoenix, I have worked exclusively in federally qualified health centers.

As Chief Medical Officer at Valle del Sol Community Health in Phoenix, we serve a large number of Latinos, African-American, Asian, Pacific Islanders, and Native American patients, all of whom are disproportionately impacted by high cost medications. As you know, within the Part D prescription drug program standard benefits, patients must pay the initial \$480 out-of-pocket deductible before the initial coverage phase begins.

Regrettably, for many patients that initial deductible is enough of a barrier for them to choose not to purchase a prescription and forgo needed treatments. While some patients can qualify for premium and cost sharing assistance, many are not forthcoming with their health care providers about their financial limitations because they are embarrassed, some even choose not to return to their provider when they cannot afford their medications for fear of reproach.

Community health centers like Valle del Sol are starting to realize the need to screen for financial challenges and other social determinants of health upfront to address them early, rather than waiting to discover these problems after a patient develops complications due to lack of treatment. Unfortunately, screening and additional subsidies are not enough to solve today's problems.

These are the types of scenarios we see day in and day out in community health centers and other facilities that treat our seniors on fixed incomes. Patients who have grown to trust their health care providers often turn to us for help. I can't tell you the number

of times I have heard my patients say, doc, or doctora, please look at all of my meds and tell me, what can I skip? It costs me too much each month and I need to stop at least two or three of them, but when a patient has had a heart attack with a stent, breast cancer, and a blood clot, every one of her meds is critical to keeping her alive.

These are hard decisions for patients, but also medically and ethically difficult for doctors and other health care providers who routinely face these circumstances. Another scenario we often see play out involves patients who can afford their regular daily meds and the initial out-of-pocket deductible, they can also meet the initial coverage phase where they are responsible for 25 percent of the medication costs, but when they have reached the Federal \$4,430 threshold, the Medicare coverage gap, better known as the infamous donut hole, the patients are then still on the hook for 25 percent of the cost until they hit \$7,050 in out-of-pocket spending when catastrophic coverage takes effect, and then, even after spending that much on medication, these seniors are still responsible for 5 percent of the cost of their meds without a cap until the year ends and the cycle begins again. For patients with complex conditions like rheumatologic disorders and cancers that require specific high cost medications, the coverage gap and no limit on how much they may have to pay out of pocket causes real problems.

Many patients who have moderate financial resources are unable to get treatment because medications totaling thousands are putting those treatments out of reach. In some cases, patients ask for treatment regimens that are not evidence based in order to make it affordable. Those same patients with moderate resources may ration their treatment in order to make it affordable, so how do we address these issues? There are several prescription drug policies proposed by Senator Kelly that could improve the lives of my patients. For example, allowing the Federal Government to negotiate prices for high cost drugs covered under Medicare Part B and Part D, redesigning the Part D benefit to create a \$2,000 cap on out-of-pocket costs is much more reasonable than today's coverage gap, and capping co-pays on insulin at \$35 will make life saving diabetes treatment more accessible.

I close today with this, I believe we have a duty to care for our Nation's seniors, especially those who cannot care for themselves. Our seniors are not only our parents, our grandparents, the people who care for us, they nurtured and raised us, they are the reason we are all here today and we should remind ourselves we will be in their position later on. You don't need a physician to tell you that none of us escapes the aging process, and as such, we may soon find ourselves in facing the very difficulties I have described today. In that sense, our duty to our society and our seniors is our duty to ourselves. I thank the special committee for allowing me to speak today, and I am willing to answer any questions.

Senator KELLY. Thank you, Dr. Karuppana.

Ms. Vasquez?

**STATEMENT OF DORA VASQUEZ, EXECUTIVE DIRECTOR,
ARIZONA ALLIANCE FOR RETIRED AMERICANS,
PHOENIX, ARIZONA**

Ms. VASQUEZ. Thank you, Senator Kelly. Good morning. Thank you for holding today's field hearing in the great State of Arizona and for inviting me to testify. I am Dora Vazquez, Executive Director of the Arizona Alliance for Retired Americans. The Arizona Alliance for Retired Americans is a grassroots organization representing more than 48,000 retirees and seniors statewide, working to advance public policy that strengthens the health and retirement security of older Americans.

It is a pleasure to be here with you all today as we discuss ways to bring the skyrocketing cost of prescription drugs under control. There truly is no time to wait to lower prescription drug prices. The Arizona Alliance strongly supports efforts to eliminate waste and reduce drug costs in Medicare's prescription drug benefits plans and the system's finances overall and opposes proposals that shift any additional cost to beneficiaries.

We support the fundamental goals of this hearing, namely, to demonstrate the harm that exceedingly high prescription drug prices cause seniors citizens and the American economy. Senator Kelly has been a leader in the effort to lower the cost of prescription drugs through Medicare negotiation, out-of-pocket caps, and a Part D redesign that includes a cap on the price of insulin. All of these tools are needed to reduce the cost of prescription drugs. Americans pay the highest prices in the world for prescription drugs, and prices of hundreds of drugs have already increased by 5 percent in 2022, far outpacing inflation.

According to a March 9th, 2021, report by the Government Accountability Office, in 2020, Americans paid two to four times more for 20 brand name drugs than people in Canada, France, and Australia. Seniors who take the most prescription drugs to stay healthy bear the brunt of these high cost, because of this terribly excessive cost of prescription drugs, a quarter of Americans and 20 percent of seniors report not being able to afford their prescription.

As a result, millions of Americans do not take their prescriptions as prescribed by their doctor and instead are not filling them, skipping doses, or taking fewer doses than directed. This should not be tolerated in a Nation as wealthy and resourceful as the United States. The Arizona Alliance strongly believes that the Secretary of Health and Human Services must be allowed to negotiate lower drug prices under Medicare.

According to the Congressional Budget Office, Medicare price negotiation would not only assist seniors to afford their medicine, it would also save the U.S. Government billions of dollars. The CBO estimates that Senator Kelly's proposal to allow negotiations would lower spending by \$78.8 billion over 10 years. This would create savings that could be reinvested back into Medicare for greater or improved coverage.

Another contributing factor to the casual effect of high drug prices is the abusive practice of drug companies that take advantage of the U.S. patent system. The Arizona Alliance strongly believes that legislation needs to be enacted to curb these often egre-

gious abuses. Pharmaceutical corporations use numerous tactics to extend patent terms, costing Medicare billions of dollars.

For example, and AbbVie Pharmaceutical reached an agreement through a pay for delay deal with its competitors, Novartis and Amgen, to delay the entry of those companies biosimilars in the United States until 2023, a delay agreement that is costing American taxpayers \$19 billion. Last, the Arizona Alliance for Retired Americans strongly supports meaningful drug price reforms in the plan supported by Senator Kelly that passed in the House.

The most important of these include capping co-pay for insulin at \$35, setting a \$2,000 annual out-of-pocket cap for seniors' medication in Medicare Part D, and creating new price gouging penalty for drug companies that raise prices faster than inflation. I want to thank you again for providing me with the opportunity to present testimony on behalf of the Arizona Alliance for Retired Americans on this critical issue, and I would be pleased to answer any questions you may have. Thank you.

Senator KELLY. Thank you, Ms. Vasquez.

Ms. Peña?

**STATEMENT OF JENNY PEÑA,
ASSOCIATE MANAGER OF PHARMACY PATIENT ADVOCACY,
BANNER MD ANDERSON CANCER CENTER, PHOENIX, ARIZONA**

Ms. PEÑA. Thank you, Senator Kelly. My name is Jenny Peña, and I am the Associate Manager of Pharmacy Patient Advocacy at Banner MD Anderson Cancer Center, specializing in oncology. Banner MD Anderson is part of Banner Health, one of the largest secular nonprofit health care systems in the country and largest private employer in Arizona.

I am also an Advisory Board Member of the National Health Career Association and was named next generation pharmacist, pharmacy technician of the year honoree in 2021. I would like to express my gratitude to Senator Kelly and the Senate Special Committee on Aging for providing this opportunity to testify on behalf of the patients I serve each day. As a patient advocate, I help patients who are facing life altering cancer diagnosis access financial assistance to cover costs of the drugs they have been prescribed.

I work in oncology, these drugs are even pricier than other non-specialty drugs. An average oral drug to begin treating breast cancer at cost about \$1,100. For pancreatic cancer, the average is around \$5,500. The cost of starting oral treatment for chronic myeloid leukemia has an average cost of \$32,000.

These drugs are clearly incredibly expensive. According to the National Cancer Institute, most cancer drugs launched between 2009 and 2014 were priced at more than \$100,000 per patient for 1 year of treatment. Once a patient has been prescribed treatment, it is my job to find out what their insurance will cover of those amounts and what will be left on their bill to pay out of pocket.

I am extremely protective of my patients, and mama bear comes out when I am working back end of these claims with the insurance plans. I always fight to make sure my patients get the coverage they deserve, but even with good insurance coverage, my patients can still be left with thousands of dollars to pay out of pocket. I am the one who makes the phone call to let the patients know

their insurance has approved their treatment, but that they are going to be left with a high co-pay.

When my patients hear the amount they are on the hook for, I typically get one of two reactions, some people are angry. They have already faced countless doctors, tests, diagnosis, and other stressors. Now they are faced with costs that may impact their ability to seek treatment. Others are just sad—now they are faced with costs that may impact their ability to seek treatment. They feel hopeless, the costs are too high, and they surrender to their unknown fate.

Of course, some people don't even know—don't want to know what the co-pay is because they know they can't afford it. On these phone calls, you must have a lot of compassion. You are going to have patients with different emotions, but I sympathize. This is a very personal issue to me as well. Both of my parents are from El Salvador and my father is a cancer survivor.

Thankfully, his diagnosis prompted many others within our community to get screened, including myself. I know that not everyone is able to take these proactive measures, and not everyone can maintain their treatment, especially in communities of color. Black and Hispanic individuals are more likely to report cost related non-adherence to their treatment.

My goal is to help prevent anyone from foregoing their medication due to cost. To do this, I help my patients access the resources available to assist with these financial concerns, including foundation grants, free trials, manufacturer free drug programs, and voucher programs. However, the process of finding these resources is time consuming and complicated, time that many of the cancer patients do not have.

Additionally, my Medicare patients are limited in the assistance they can receive, despite typically being the population who needs the most financial help. While I am typically successful in helping my patients, if I was mama bear before, my papa bear personality comes out, when I am working to turn over every stone to find a solution for these patients. I recognize that many medical facilities do not have roles like mine designated to patient advocacy.

My role in helping patients access their medications is extremely important, and it is something I am so passionate about, but to be honest, this should not be necessary. I believe that everyone deserves access to affordable prescription drugs despite their age, income, socioeconomic status, or race.

Congress has to do more to make sure people can access the care and treatment that they need. I am encouraged by the fact that I am here today to advocate for solutions. Thank you again for the opportunity to speak today, and I am happy to answer any questions.

Senator KELLY. Thank you, Ms. Peña. We will wrap up the opening remarks with Ms. Wilson.

**STATEMENT OF JUDY WILSON,
MS PATIENT, PHOENIX, ARIZONA**

Ms. WILSON. Senator Kelly. My name is Judy Wilson, and I am a recently retired. I am on Medicare. I returned for 22 years—I volunteer for the MS Society, I mentor for Community Health Mentor

Program and, most importantly, a grandmother of four wonderful children, and I am also living with multiple sclerosis. MS is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and the body.

I was diagnosed in 2010 after experiencing tingling in my fingers, lack of balance, depression and anxiety, inability to write, and incontinence. With the help of my general practitioner and many specialists, I was able to address many of my symptoms. Even still, I have lost much of my hearing, have no sense of smell, my eyesight is compromised, my gait is off, my number of falls has increased, and I have constant nerve pain in my feet and hands.

Disease modifying treatments have proven to be the best way to manage the MS disease course. There are more than 20 on the market, and it is common for people with MS to move through several different treatments throughout their life. After some trial and error with several disease modifying treatments, or DMTs, my neurologist prescribed Copaxone, a self-injector that I take three times a week.

When I transitioned to Medicare, I was able to get assistance from a charitable foundation, and they paid \$3,272 co-pay for the first 2 months of the year and then \$250 per month after that, making my treatment affordable for me. Charitable foundations like the one I used exist for Medicare beneficiaries to apply to for assistance supporting their medication, but the need is far greater than supply.

Unfortunately, in 2021, the foundation I relied on ran out of money. I am unable to afford the over \$7,000 per year without financial help, so I reached out to my neurologist for help. After discussions with my doctor, I decided to go off my medications. I didn't have any other options and have so far been very lucky that I haven't had any relapses or any setbacks, but I want to emphasize that the decision to stop my medication was based on money, not medicine.

If I could afford to go back on Copaxone, I would. MS is an extremely unpredictable, and just because I have been healthy so far doesn't necessarily guarantee that I will not have a relapse in the future. For most living with MS, a gap in medication could mean disease progression, and that would lead to permanent loss of mobility or cognitive function. This is a risk I take daily. No one should have to take this risk because they cannot afford medications they need.

It seems ridiculous that I have to need a charity assistance to afford my medications, even though I am already paying \$2,040 per year for health insurance through Medicare. I know I am not alone. A National MS Society survey found more than 70 percent of people with MS have received financial assistance for their DMT, and 40 percent of people with MS alter the use of their DMT due to cost, including stopping, skipping, or delaying treatment.

As a volunteer self-help group leader for people living with MS in the Phoenix area, I hear firsthand how difficult it is for people to afford their medications. There are two others in my group who have discontinued use of their medications. One has recently gotten out of the hospital after a 2-weeks stay.

Congress must pass legislation immediately that establishes an out-of-pocket cap in Medicare and a structure that allows beneficiaries to spread their costs throughout the year so that seniors like me can afford to take their needed medication. It is also critical that Congress keep drug price increases at the pace of inflation and allow Medicare to negotiate better drug prices on behalf of its beneficiaries.

When I first began to take Copaxone in 2014, it was priced at approximately \$60,000 a year. It is now at \$75,000 a year. That is an increase of \$15,000, or 25.6 percent, in just 8 years for the same medication.

There is no single policy solution that will address the high cost of prescription drugs, but these policies are an important step in the right direction and would immensely improve the quality of life for many seniors, including me. Thank you for the opportunity to share with you today.

I look forward to working with you to address the high cost of medication.

Senator KELLY. Thank you, Ms. Wilson. Now we are going to go back to Ms. Peña because she was going to deliver her remarks in Spanish as well.

Ms. PEÑA. Gracias, Senador Kelly. Mi nombre es Jenny Peña y soy la Gerente Asociada de Defensa del Paciente Farmacéutico en Banner MD Anderson Cáncer Center, especializada en oncología.

Banner MD Anderson es parte de Banner Health, uno de los sistemas de atención médica sin fines de lucro más grandes del país y el empleado privado más grande de Arizona. También soy miembro de la junta asesora de la Asociación Nacional de Profesionales de Salud y fui nombrada técnico de farmacia del año, the next generation pharmacist, homenajeada en 2021.

Me gustaría expresar mi gratitud al Senador Kelly, y al comité especial del Senado sobre el Envejecimiento por brindar esta oportunidad de testificar en nombre de los pacientes que atiendo cada día. Como defensor del paciente, ayudo a los pacientes que enfrentan diagnósticos de cáncer que alteran sus vidas al acceder a asistencia financiera para cubrir los costos de los medicamentos que le han recetado.

Debido a que trabajo en oncología, estos medicamentos son incluso más caros que otros medicamentos que no son de especialidad. Un medicamento oral promedio para comenzar a tratar el cáncer de mama cuesta alrededor de \$1,100. Para el cáncer de páncreas, el promedio es de alrededor de \$5,500. El costo de iniciar un tratamiento oral para la leucemia crónica tiene un costo promedio de \$32,000.

Estos medicamentos son claramente increíblemente caros. Según el Instituto Nacional del Cáncer, la mayoría de los medicamentos contra el cáncer lanzados entre 2009 y 2014 tenían un precio de más de \$100,000 por paciente por un año de tratamiento. Una vez que a un paciente se le ha recetado un tratamiento, es mi trabajo averiguar que cubrirá su seguro de esos montos, y que quedará en su factura para pagar de su bolsillo.

Soy extremadamente protectora con mis pacientes, y esa mamá sale cuando estoy trabajando en la parte final de estos reclamos con los planes de seguro. Siempre lucho para asegurarme que mis

pacientes tengan la cobertura que se merecen. Pero incluso con una buena cobertura de seguro, mis pacientes aún pueden quedarse con miles de dólares para pagar de sus bolsillos.

Soy la que hace esa llamada telefónica para informarle al paciente que su seguro a aprobado su tratamiento, pero que se quedara con un pago alto. Cuando mis pacientes escuchan la cantidad por la que están endeudados, normalmente obtengo una de dos reacciones. Algunas personas están enojadas. Ya se han enfrentado a innumerables médicos, pruebas, diagnósticos, y otros factores estresantes. Ahora se enfrentan a costos que pueden afectar su capacidad para buscar tratamiento. Otros simplemente están tristes. Se sienten sin esperanza. El costo es demasiado alto y se rinden a su destino desconocido.

Por supuesto algunas personas ni siquiera quieren saber cuál es el monto de copago porque saben que no pueden pagarlo. En estas llamadas telefónicas debes tener mucha compasión. Vas a tener pacientes con diferentes emociones, pero simpatizo. Este tema también es muy personal para mí. Mis padres son del Salvador, y mi padre es sobreviviente de cáncer.

Afortunadamente su diagnóstico hizo que muchos otros de nuestra comunidad se hicieran la prueba, incluyéndome a mí. Se que no todos pueden tomar estas medidas proactivas y no todos pueden mantener su trato, especialmente en las comunidades de color. Las personas Hispánas y de color son más propensas a no informar sobre su tratamiento relacionada los costos.

Mi objetivo es ayudar a evitar que alguien renuncie a su medicamento debido al costo. Para hacer esto, ayudo a mis pacientes a acceder a los recursos disponibles para ayudar con estas preocupaciones financieras, incluidas subvenciones de fundaciones, pruebas gratuitas, programas de medicamentos gratuitos del fabricante, y programas de vales. Sin embargo, el proceso de encontrar estos recursos lleva mucho tiempo y es complicado, tiempo que mucho de esto pacientes con cáncer no tienen.

Además, mis pacientes de Medicare están limitados en la asistencia que pueden recibir a pesar de que por lo general son la población que más ayuda financiera necesita. Si bien normalmente tengo éxito en ayudar a mis pacientes y antes era mama oso, y personalidad de papa oso aparece cuando trabajo para remover cada piedra para encontrar una solución para estos pacientes. Reconozco que muchas instalaciones médicas no tienen roles como el mío destinado a la defensa del paciente.

Mi papel en ayudar a los pacientes a acceder a sus medicamentos es extremadamente importante, y es algo que me apasiona. Pero para ser honesta, esto no debería ser necesario. Creo que todos merecen acceso a medicamentos recetados accesibles independientemente de su edad, ingresos, nivel socioeconómico, o raza.

El Congreso tiene que hacer más para asegurarse de que las personas puedan acceder a la atención y el tratamiento que necesitan. Me alienta el hecho de que estoy aquí hoy para abogar por soluciones. Gracias nuevamente por la oportunidad de hablar hoy, y estaré feliz de responder cualquier pregunta.

Senator KELLY. Well, thank you. Thank you, everybody, for their initial testimony here. We are going to start off with our round of questions, and again, we will try to keep the answers to 5 minutes per person here. We are going to start with Ms. Vasquez. In your initial testimony, you talked about, and hopefully we can get to this in your answer, talked about some of the ways that pharmaceutical companies can keep the cost up. Pay for delay is what you mentioned.

There is also other ways of getting around the patent law, but let me start by saying that there are more than 1.3 million Arizona seniors on a Medicare plan, and in 2018, tens of thousands of seniors spent enough money on their prescription drugs to reach the catastrophic coverage, which based on the threshold in that year meant they spent more than \$5,000 on medication.

That has since gone up. That number is now over \$7,000, and the average out-of-pocket costs for an Arizona senior on a Medicare Part D plan was \$3,450 for the year. This is unacceptable, and for seniors, it is not sustainable, but today we are here to talk about solutions.

Ms. Vasquez, what are some of the solutions that you have seen that can make prescription drugs more affordable for Arizona's seniors?

Ms. VASQUEZ. Well, thank you, Senator Kelly. You know, as mentioned, we pay more than any other country for the same prescription drugs that members of the Alliance,

Arizona Alliance urge the members of the U.S. Senate to pass the drug pricing agreement that you, Senator Kelly, support.

There is no substitute for the real comprehensive drug pricing legislation from Congress to make health care more affordable for retirees, and we hear this time and time again, Congress must allow Medicare to negotiate lower drug prices and include provisions that cap out-of-pocket prescription drug costs at \$2,000 per year under Medicare Part D.

Senator Kelly, you worked on cap—to cap the price of insulin at \$35 per month, and the agreement that you worked on creates a new price gouging penalty for drug companies that raise prices faster than inflation. In addition, we strongly encourage Congress to extend APTCs, the tax credits you get to take advantage—advance to lower your monthly health insurance premiums, and those need to be extended through 2025.

The current subsidies in the American Rescue Plan benefit about 9 million people, and those will expire in 2022. Thank you.

Senator KELLY. Thank you. Then we also need to do something on the patent reform.

Ms. VASQUEZ. Absolutely.

Senator KELLY. As well. You mentioned, one pharmaceutical company paying another to not bring a generic right to market, and that just hurts everybody.

Ms. VASQUEZ. Right. Absolutely.

Senator KELLY. Ms. Kennedy, you know, during your initial testimony, the thing that, you know, that I really did notice was—I mean, gas prices are high now, but if they went up at the rate of prescription drugs, you said \$12.20 a gallon. That is remarkable, so that shows you how fast the price of drugs rises every single

year, so lowering the cost of prescriptions, it is one of my top priorities and it has been while I have been in the

U.S. Senate for 14, 15 months now, so Ms. Kennedy, AARP has been advocating for policies to reduce drug costs like those Ms. Vasquez just mentioned for many years, and AARP has 890,000 members in the State of Arizona.

Ms. KENNEDY. We do.

Senator KELLY. You have got to be like the biggest organization in the State.

Ms. KENNEDY. One of the largest.

Senator KELLY. Yes—in the country with the number of members—

Ms. KENNEDY [continuing]. membership organizations.

Senator KELLY. What do you hear from those 890,000 members? Can you share with us—you know, what are your members—what do they say about this topic?

Ms. KENNEDY. I mean, they are frustrated. I am frustrated. I actually started working on this issue in 1998. My first job out of college was working on this issue, and I have worked for the National Council of Senior Citizens, I worked for the Alliance for Retired Americans, and now seven and a half years with AARP, and so there is just a tremendous amount of frustration that, you know, year after year, we promise to get something done and we don't get something done, and of course, we did get an AARP supported Medicare Part D, the drug benefit, but unfortunately there are still—you know, we knew that there was still was some unfinished business, so actually getting the House version done in the Senate would be very helpful, but you know, what we hear from our members is, you know, they do cut their medications in half.

They are very resourceful with what they do. They fill their prescriptions and try to make it last until they get their next Social Security check. There is a tremendous amount of guilt if a spouse has a certain terminal illness or chronic condition, and they simply can't afford it. We got a letter from a member and his wife, you know, suffered from a stroke and he feels very guilty that he can't afford her medications, and so there is just, you know, so many things that people are doing to be resourceful, but at the end of the day, they are just frustrated that something doesn't get done, and you know, we have the opportunity right now to get this done, and I really appreciate you championing this issue, and let's get it across the finish line.

Senator KELLY. Yes. We don't always have the opportunity, and right now we do. I mean, there is really no excuse. I remember speaking to a senior at Prescott, they told me about how the price of a certain drug went up 3x, you know, 300 percent in a year with no explanation. Do you ever have—does anybody ever tell you that a pharmaceutical company at least tried to explain why the price of the drug went up? Is that something you have ever heard?

Ms. KENNEDY. Sometimes they try and say that they offer some type of benefit to ask their physician if they could get some samples, but as far as them explaining why they are raising the prices, I haven't heard a reason for why they raise it the way they do.

Senator KELLY. With 890,000 members, nobody has ever said, hey, at least the pharmaceutical company told me why the prices doubled.

Ms. KENNEDY. No.

Senator KELLY. No explanation.

Ms. KENNEDY. No. I mean, the other thing is people go to great lengths to do the research during open enrollment and figure out like, what medications do I have and what is going to be the best plan for me? Then they could do all their research and sign up, and then there is, you know, some switching that goes around or they do fall into the donut hole as well, so that is something we need to fix. You know, once they actually hit that catastrophic benefit, it is very generous, but how much money do they have to spend to actually hit the catastrophic benefit?

Senator KELLY. I want to ask you about insulin here. You know, so we got the House. The House passed this bill to cap at \$35 a month per patient for folks with Part D commercial insurance plans, so can you describe what a difference this monthly cap would make to millions of seniors who are—happen to be Type I diabetics?

Ms. KENNEDY. Well, what I do know is we know families all across the country are struggling with outrageous prices of insulin and many other drugs, and just in January, prices went up yet again on 75 percent of the most prescribed drugs in Medicare, and that is why AARP remains laser focused on urging the Senate to pass a comprehensive prescription drug reform already passed by the House that will finally let Medicare negotiate for lower prices.

It will cap out-of-pocket costs for millions of Americans, seniors, as well as cap monthly insulin costs, and AARP members have listened for decades as politicians have promised these commonsense reforms, and it is time for Senators to keep their promises on the voters, so definitely the insulin cap would help, but we definitely need comprehensive prescription drug reform.

Senator KELLY. You know, the negotiation part of this is so important. The argument that some folks will try to make for pharmaceutical companies is they need these enormous profits in order to develop the next drug, and that is fundamentally not the situation. I mean, part of this negotiation, if enacted, would be, you know, there would be—that would be a topic of discussion.

You know that we, the Federal Government, understands that companies need to make a profit and they need to have the resources, but when you see these prices going up, you know, 26.3 percent between 2015 and 2019 is the number that you stated, when income is only going up 15 percent, that is unsustainable.

Ms. KENNEDY. Absolutely.

Senator KELLY. I mean, you cannot—it is unfair now, but if those two rates, I mean, they will continue to diverge, nobody will be able to afford their prescription medications, so thank you.

Ms. KENNEDY. Thank you.

Senator KELLY. Ms. Peña, so thank you for sharing your experiences with us today, and your work is important because I agree with you that we should be tackling the problem of high drug costs comprehensively at the source, not just asking you to have to patch this up with your patients, and I want to thank you for all the hard

work that you do on behalf of people that, you know, are just in such a horrible situation.

You know, as we heard today, patients on Medicare Part D pay 25 percent of their drug costs until they hit \$7,050 in out-of-pocket spending, but I think what it is, is they are paying between—when they hit \$480, it is \$0 to \$40 and then it is 25 percent up to \$4,000 and something, and then it is nothing right up to \$7,050, and then it is covered with a 5 percent out-of-pocket after that, so you could see how this gets really expensive very quickly, so how long—could you give us an example how long it might take one of your patients to rack up \$7,050 in drug costs, and would that necessarily take multiple drugs and several months, or could that be in one single treatment? Based on your testimony, I think we all know what the answer is here, but I want to hear from you.

Ms. PEÑA. Yes. If you are a patient that can afford the co-pay, depending, of course, on your insurance plan, it could take roughly about 3 months before you hit that \$7,050, but if you are a patient on limited income or low income, and then you are out there seeking support from grants or foundations, and then again, assuming that you qualify based on your diagnosis and that there is even funds available in the grant because they do tend to run out, you maybe never reach that \$7,050 because you will never be able to accumulate that amount of money because of the high costs.

Senator KELLY. Yes, so you pointed out that somebody who has pancreatic cancer, their drug costs, you said, was \$5,500 and I think you meant \$5,500 per month, per month, so there are many scenarios where they are—it is just unaffordable.

Ms. PEÑA. Correct.

Senator KELLY. Like, they are never going to—they are never going to get there because they can't afford the first month of medication.

Ms. PEÑA. Correct. Yes.

Senator KELLY. However, if we restructured the Part D benefit program and there was a \$2,000 cap, that maybe for some of these patients it would be realistic if we could spread that \$2,000 over 12 months.

Ms. PEÑA. I think any cap that is lower than what it is today would be very beneficial to all patients out there and in our communities.

Senator KELLY. Okay. Thank you, and this next question is also for you, Ms. Peña. In your testimony, you mentioned the various reactions you get when you call your patients to help plan the next steps of how they are going to afford their treatment.

You mentioned that every patient has a different reaction when you tell them. You said some of them are sad, some of them are angry. Some of them just realize they can't afford it, so I guess for them it doesn't even matter, but obviously everybody has a different and unique situation, and we know that the impact of these costs hits some Arizonans harder than others, and the high costs are not equally distributed, so can you describe the disproportionate impact of high drug costs on Latinos and African-Americans and the Native American patients that you deal with?

Ms. PEÑA. Sure. I think part of it is culture. Growing up in a Hispanic household, you are taught to grow up on, you know, home

remedies, a lot of old wives tales, right, and so we tend not to go to our providers to get treatment, but also in some research that I did when I was looking into cost related nonadherence in those communities of color, I found that a lot of it has to do with them not even being able to go see a provider.

They can't even afford the co-pay to go get a diagnosis, go to urgent care, or see their primary care physician, and so they have to go through that first hurdle. If they do find the means to see a provider, they have a second hurdle, which is, can they afford that prescription medication that they just got prescribed for their diagnosis? It is just this consistent, vicious cycle of unattainable medication that they can never get for treatment, and so that really goes toward that cost related nonadherence for our communities of color.

Senator KELLY. Then I think it is important that we point out when a patient doesn't take the medication that they need, that somewhere down the line they often wind up being hospitalized.

Ms. PEÑA. Correct.

Senator KELLY. The overall cost, you know, could be even higher for the Federal Government by not having individuals take the medication they need for whatever condition they have.

Ms. PEÑA. Correct.

Senator KELLY. Thank you. Dr. Karuppana, you know, nobody in our country should have to make the decision whether or not to buy groceries or pay rent or utility bill and take a pill, but in your testimony, you mentioned your experience with patients who are forced to ration or stop their medication because of cost, and could you share some examples of when the high cost of prescription drugs has not only led to hard choices, but do you have any examples of like harmful health outcomes, which was what I was just alluding to?

Dr. KARUPPANA. Sure. I have two examples I can share. One is similar to what you were just referencing. I had a patient of mine who had diabetes, and she was previously well controlled, but she came in for followup with me and that particular day her sugars were very high, and I asked her, you know, what changed? She told me that she had to choose between paying for her insulin or paying for gas for her grandchild to go to work, and her grandchild was the breadwinner for the household and the rent was due, and so that was the obvious choice that she had to make, so that is a common one.

Senator KELLY. Do you remember what her insulin cost was?

Dr. KARUPPANA. Her insulin costs was like \$250 or \$300 a month. Another example I have is a patient of mine who had ulcerative colitis, so that is an inflammatory bowel disease that causes bloody diarrhea and can often lead to colon cancer, so without her treatment, she was having about 10 bloody stools a day. However, thanks to a disease modifying antirheumatic rheumatologic drug, her disease was well controlled, and the blood had stopped.

Unfortunately, the specialized medication became too expensive, so she started to take her medication every few days. The blood in her stool was reduced to only three to four times a day, which she thought was better, but she didn't understand that that was still putting her at risk for colon cancer. She ended up needing to get

a blood and iron transfusion, and she ended up being hospitalized because of her chronic blood loss, and all of that could have been avoided if she could have just stayed on her prescription.

Senator KELLY. How is she doing now?

Dr. KARUPPANA. I think she is doing great. I mean, she was eventually able to get on an assistance program that was able to keep her on her medication, but it took a long time to figure out a solution for her, and you know, she has suffered a lot of consequences in the interim.

Senator KELLY. Do you think these policy solutions we have been talking about today will help your patients?

Dr. KARUPPANA. Absolutely. From my first example, if there was a \$35 cap on her insulin instead of the hundreds that she was paying every month, I think she would have been able to stay on her insulin and help her grandchild get to work, and in my second example, the patient who was paying the high amount for her medication for her ulcerative colitis, I think if there was an option to reduce the cost of that medication through the Federal Government negotiating the prices of those specifically high cost medications, and if there was that \$2,000 cap that was spread out over the course of the year, both of those things would have allowed her to stay on her medication and avoid those health outcomes.

Senator KELLY. What do you think her hospitalization cost are?

Dr. KARUPPANA. Hospitalizations can run to hundreds of thousands of dollars. I think she was in for about 4 days, if I remember.

Senator KELLY. Well, thank you. Ms. Wilson, I want to thank you for being here today and sharing your experience. I think it is really important for folks in my position to hear stories like yours to fully understand how these policies impact people's lives.

As we have discussed today, I put forth a plan to reduce the cost of prescription drugs by allowing Medicare to negotiate directly with drug companies to bring down prices, and then to also limit how quickly those companies can then raise the price from year to year without a penalty. There is a provision in here for—to provide rebates if they raise them quicker, which is kind of like a penalty, but it would also cap the out-of-pocket cost of insulin at \$35 per month, and for those on Medicare Part D plans, there would be a cap of \$2,000 on out-of-pocket expenses, so Ms. Wilson, can you describe how these types of policies, like capping your out-of-pocket prescription drug costs at \$2,000 per year, would impact you and your family?

Ms. WILSON. Sure. Thank you for the question, Senator Kelly. Although even \$2,000 per year out of pocket is a lot of money, capping what I would have spent on prescription drugs at that amount would allow me to afford to get back on Copaxone, and I wouldn't have to worry about my MS progression because I am not on a disease modifying therapy.

I would also love to see a policy that would allow me to spread out that \$2,000 over a year, so I don't have to worry about paying all that at once in the first few months. Policies like this would be a relief to me and so many other seniors, and that would immediately improve my quality of life.

Senator KELLY. Well, thank you. I am going to continue to work as hard as I can on this, you know, to make sure we get that cap,

that it can be spread out, that pharmaceutical companies can't, you know, keep increasing the prices, and then if we do that, I hope to hear next time I see you that you were, after we do this, that you were able to get back on the Copaxone that you need for your MS. Let me close here by saying, I want to thank all of our witnesses here today for contributing your time, your experiences, your expertise, and I especially want to thank Ms. Wilson because it is always hard for people to talk about their personal story, especially when it is health care related, so I want to thank you personally for doing that and sharing that.

As we have heard today, congressional action to reduce the cost of prescription drugs both for the Federal Government and for Arizonans is long overdue. I mean, this is not only savings—remember this, this is not only savings of the patient, this is savings for the Government as well. We have got a plan. We know what to do.

We have got to allow Medicare to negotiate the cost of the most expensive drugs. I mean, that is clear. The Veterans Administration does this already. This is not unprecedented, but Medicare, because of current law, they don't—they are not allowed to do it, and it is essentially to, you know, make sure the pharmaceutical companies have very high profits, but the capping the out-of-pocket expenses at \$2,000 for Medicare Part D plans, I mean, we have to get this done, and insulin that has been around for over 100 years, I don't know, 100 years? I think maybe more than that. Insulin has been around a long time. Why does it cost hundreds of dollars per month? You know, we have got to get that across the finish line, and then, you know, this legislation will also prevent pharmaceutical companies from increasing the price of their products at more than the price of inflation.

Let me say that this is just like also like a fundamental question of fairness. I mean most of these drugs, correct me if I am wrong, but most of these drugs are developed and manufactured in the United States, and it is unfair that Americans have to pay two to three maybe four times more for certain prescription medications than, let's say, our, you know, friends on the other side of the border in Canada or any other country for that matter. It is just fundamentally unfair.

I am going to continue to work with my colleagues to put this plan into place, and if the witnesses, if you have additional statements or something else you want to add that you didn't get to share today, the hearing record will be open for seven more days until Tuesday, April 19th.

Thank you so much for participating today, and this is, just to finish, this is incredibly valuable for me and for the Senate Committee on Aging, so thank you, and I conclude this hearing.

[Whereupon, at 12:04 p.m., the hearing was adjourned.]

APPENDIX

Prepared Witness Statements

**NO TIME TO WAIT: PROPOSALS TO LOWER
PRESCRIPTION DRUG COSTS
STATEMENT of DANA KENNEDY
State Director, AARP Arizona**

AARP, on behalf of our 38 million members, over 890,000 members in Arizona, and all older Americans nationwide, appreciates the opportunity to submit testimony on this important hearing of the Senate Aging Committee.

High prescription drug prices hit older Americans particularly hard. On average, Medicare Part D enrollees take between four and five prescriptions per month, often for chronic conditions that will require treatment for the rest of their lives. At the same time, Medicare beneficiaries have a median annual income of just under \$30,000. One-quarter have less than \$8,500 in savings. In Arizona, the average annual cost of prescription drug treatment increased 26.3% between 2015 and 2019, while the annual income for Arizona residents only increased 15.6%. This population simply does not have the resources to absorb rapidly escalating prescription drug prices and many are facing the reality of having to choose between their medication and other basic needs such as food or housing.

In the case of one of our members, Leona G (age 74) has maxed out her credit cards to afford the blood thinner Eliquis. She only receives Social Security benefits and a small pension check each month. Unfortunately, Leona isn't alone. We know the number one reason someone does not fill a prescription is because of the cost.

For years, prescription drug price increases have dwarfed even the highest rates of general inflation. If consumer prices had risen as fast as drug prices over the last 15 years, gas would now cost \$12.20 a gallon, and milk would be \$13 a gallon. Just in January, the drug industry raised prices on over 800 prescription medications—just as they have increased prices for decades—including [three-quarters](#) of the top 100 drugs with the highest spending in Medicare Part D.

AARP is mindful that high and growing prescription drug prices are affecting all Americans in some way. Their high cost is passed along to everyone with health coverage through increased health care premiums, deductibles, and other forms of cost-sharing. We have also seen massive increases in prescription drug spending under public programs like Medicare and Medicaid. These escalating costs will eventually affect all of us in the form of higher health care costs, higher taxes, cuts to Medicare or Medicaid, or all of the above.

In other words: every single American taxpayer is paying for high prescription drug prices, regardless of whether you are taking medicine yourself.

Fortunately, there is action the Senate can take right now. There is long-standing and overwhelming bipartisan support among voters for allowing Medicare to negotiate with drug companies for lower prices.^[4] The policies before the Senate that Senator Kelly is leading on – including Medicare negotiation, capping out of pocket costs under Medicare Part D, and penalizing drug companies that increase their prices faster than inflation – will provide long-overdue relief to older Americans across the country. These policies, taken together, will help reduce drug prices and out-of-pocket costs. This is important because real relief for seniors and all Americans must include policies that get to the root of the problem: the high prices set by drug companies.

^[4] <https://www.aarp.org/research/topics/health/info-2021/drug-prices-older-americans-concerns.html>

America's seniors aren't the only ones who stand to benefit. Lowering prescription drug prices will also save the Medicare program and taxpayers hundreds of billions of dollars. Every year, Medicare spends more than \$135 billion on prescription drugs.

Last October, a [survey](#) commissioned by AARP Arizona and conducted by OH Predictive Insights showed Arizonans across the aisle agree on the need for affordable medication and action by their members of Congress. An overwhelming majority of Arizonans agree: Congress needs to tackle high prescription drug costs because some people can't afford to buy medicine and pay for other necessities (89% of voters). The survey results showed vast majority support for each proposed measure being discussed in Congress to reduce drug prices. The most favored initiative was allowing Medicare to negotiate for the price of drugs, winning over 94% of Arizonans. Furthermore, two-thirds (66%) of Arizonans surveyed do not believe that innovation will suffer if Medicare is allowed to negotiate for lower prices.

Clearly, Americans are fed up with paying three times what people in other countries pay for the same drugs. More than four million people across the country, including over 113,000 here in Arizona, are joining AARP to sign a petition to demand lower prices for prescription drugs. There will never be a better time to lower drug prices than the historic opportunity in front of Congress. Now it's time to get it done!

STATEMENT OF DR. SUGANYA KARUPPANA
CHIEF MEDICAL OFFICER,
VALLE DEL SOL COMMUNITY HEALTH, PHOENIX, ARIZONA

NO TIME TO WAIT: PROPOSALS TO LOWER PRESCRIPTION DRUG COSTS
APRIL 12, 2022

Thank you Senator Kelly, Chairman Casey, Ranking Member Scott, and members of the Special Committee on Aging for inviting me to speak today on this vital topic, the high and ever-rising costs of medication for our seniors.

My career has been dedicated to serving communities with health disparities. I spent six years at UCLA's County Hospital and was a clinical professor at the David Geffen School of Medicine training our next generation of doctors.

Since moving to Phoenix, I have worked exclusively in Federally Qualified Health Centers. As the Chief Medical Officer of Valle del Sol Community Health in Phoenix, we serve a large number of Latinos, African Americans, Asian Pacific Islanders, and Native American patients, all of whom are disproportionately impacted by high cost medications.

As a physician who's cared for families and seniors in medically underserved communities for the past 20 years, I know firsthand that this is an issue that affects the lives of not just many of my patients but also tens of millions of my fellow Americans.

As the members of this Committee know, within Part D prescription drug program's standard benefits, patients must pay the initial \$480 out-of-pocket deductible for medications before the initial coverage phase begins.

Regrettably, for many patients, that initial deductible is enough of a barrier for them to choose not to purchase the prescription and forego needed treatment. The Low-Income Subsidy program, known as LIS, allows some patients facing financial hardships to either automatically qualify or apply for premium and cost sharing assistance, but many patients are not forthcoming with their healthcare providers about their financial limitations because they are embarrassed.

Some even choose not to return to their doctor when they cannot afford to buy their medicine for fear of reproach. Community health centers like Valle del Sol are starting to realize the need to screen for financial challenges and other social determinants of health upfront to address them early rather than waiting to discover these problems after a patient develops a complication due to lack of treatment.

Unfortunately, screening for financial challenges and getting patients to apply for the Low-Income Subsidies is not enough to solve today's problems. The application process is often too complex for patients to navigate. If they do manage to get through the application process, they may find they do not qualify for full benefits. In one instance, a patient I treated had to choose between paying for insulin or buying gasoline to get her grandchild to work because the rent was due and the grandchild was the sole breadwinner in the household.

These are the types of scenarios we see day in and day out in community health centers and other facilities that treat seniors on fixed incomes.

Patients who have grown to trust their health care providers often turn to us for help. I can't tell you the number of times I have heard my patients say, "Doc or *Doctora*, please look at all of these meds and tell me what I can skip. It costs me too much each month and I need to stop at least two or three of them."

But when a patient has had a heart attack with a stent, breast cancer, and a blood clot, every one of her meds is critical for keeping her alive. These are hard decisions for patients, but also medically and ethically difficult for the doctors and other health care providers who routinely confront these circumstances.

Another scenario we often see play out involves patients who *can* afford their regular daily meds and initial \$480 out-of-pocket deductible, and can also meet the initial coverage phase where they're responsible for the 25% of medication costs. But when they've reach the federal \$4,430 dollar-threshold — the Medicare coverage gap better known as the infamous "donut hole" — patients are then still on the hook for 25% of the costs until they hit \$7,050 dollars in out-of-pocket spending, when catastrophic coverage takes effect. And then even after spending this much on medications, these seniors are still responsible for 5% of the cost of their meds without a cap until the year ends and the cycle begins again.

For patients with complex conditions like rheumatological disorders or cancers that require specific high-cost medications, the coverage gap and no limit on how much they

might have to pay out of pocket causes real problems. Many patients who have moderate financial resources are unable to get treatment because of medications totalling thousands of dollars — putting those specialized treatments out of reach.

In some cases, patients ask for treatment regimens that are not evidence-based in order to make it more affordable. Those same patients with moderate resources may ration the treatment in order to afford it. One example I can share is about a patient of mine who had Ulcerative Colitis, an inflammatory bowel disease that causes bloody diarrhea and often leads to colon cancer. She was having 10+ bloody stools a day without treatment. However, thanks to a Disease Modifying Anti-Rheumatologic Drug, her disease was controlled and the blood in her stool eliminated.

Unfortunately, while she could afford the deductible and the 25% share of costs during the initial coverage phase, when she reached the “donut hole” she could not cover the full cost of the specialized medication and could no longer afford her treatment.

My patient saved up enough to fill one month of her prescription, but she started to take the medication every few days. Now she had the bloody diarrhea only three to four times per day, but didn't tell me or her gastro-intestinal specialist. She didn't understand that cutting her dosage put her at increased risk of colon cancer, and she now needed a blood *and* iron transfusion because of her profound chronic blood loss. As a result, she had to be hospitalized, even though all of it could have been prevented if she were able to stay on her medications.

So how do we address these issues?

There are several prescription drug policy changes proposed by Senator Kelly that could improve the lives of my patients. For example, allowing the federal government to negotiate prices for some high-cost drugs covered under Medicare Part B and D. This alone could achieve nearly \$79 billion dollars in Medicare savings over 10 years and help reduce the cost of medications for people with complex conditions like those I previously cited.

Another policy that could have a profound impact on our seniors' lives is the cap on out-of-pocket spending for Medicare Part D enrollees and other Part D benefit design changes. This redesign would continue with the initial deductible, but once you are in initial coverage, you only have to pay a 23% share of the medication costs with a maximum out-of-pocket cost of \$2,000. When you enter into catastrophic coverage, the patient would no longer have a share of the costs. This is a much more reasonable solution to the coverage gap and high-costs that seniors currently face. It could have allowed the patient I referenced to stay on her treatment while avoiding the transfusions and hospitalization.

Something that would be extremely helpful to the millions of seniors with diabetes, including patients I have personally cared for, is the proposal to limit insulin copays for people with Medicare and other commercial insurance at \$35. Significantly bringing

down the cost of insulin and would allow families to plan and obtain life sustaining treatment.

Eliminating cost sharing for adult vaccines covered under Part D requiring adult vaccines recommended by the Advisory Committee on Immunization Practices, or ACIP, be covered at no cost, aligns well with this topic of making medication affordable to prevent complications in the future. It also aligns with other Affordable Care Act provisions like preventative screening being covered if recommended with sufficient level of evidence by the U.S. Preventive Services Task Force.

Additionally, requiring drug companies to pay rebates when they prices increase faster than the rate of inflation aligns with a provision that is already built into Medicaid and has resulted in savings in that program. So it is logical to duplicate the process when it is already in place and effective in another federal program.

I close today with this thought: I believe we have a duty to care for our nation's seniors, especially those who cannot care for themselves. Our seniors are not only our parents and grandparents, the people who nurtured and raised us, they are the reason we are all here today. And, we should remind ourselves, we will be in their position later on. You don't need a physician to tell you that none of us escapes the aging process, and as such we may soon find ourselves facing the very difficulties I've described today. In that sense, our duty to society and our seniors is also a duty to ourselves.

I thank the Special Committee for allowing me to speak today, and I'm willing to take any questions.

STATEMENT SUBMITTED TO THE UNITED STATES SENATE
SPECIAL COMMITTEE ON AGING

HEARING ON

NO TIME TO WAIT: PROPOSALS TO LOWER PRESCRIPTION DRUG COSTS

APRIL 12, 2022

MS. DORA VASQUEZ
EXECUTIVE DIRECTOR
ARIZONA ALLIANCE FOR RETIRED AMERICANS
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Good morning.

Thank you, Senator Kelly, for holding today's field hearing in the great state of Arizona, and for inviting me to testify.

I am Dora Vasquez, Executive Director of the Arizona Alliance for Retired Americans.

The Arizona Alliance for Retired Americans is a grassroots organization representing more than 48,000 retirees and seniors statewide working to advance public policy that strengthens the health and retirement security of older Americans.

It is a pleasure to be here with all of you today as we discuss ways to bring the skyrocketing cost of prescription drugs under control. There truly is no time to wait to lower prescription drug prices.

The Arizona Alliance strongly supports efforts to eliminate waste and reduce drug costs in Medicare's prescription drug benefits plans and the system's finances overall and opposes proposals that shift any additional costs to beneficiaries. We support the fundamental goals of this hearing, namely, to demonstrate the harm that exceedingly high prescription drug prices cause senior citizens and the American economy.

Senator Kelly has been a leader in the effort to lower the cost of prescription drugs through Medicare negotiation; out of pocket caps; and a Part D redesign that includes a cap on the price of insulin. All of these tools are needed to reduce the cost of prescription drugs.

Prescription Drug Prices

Americans pay the highest prices in the world for prescription drugs, and prices on hundreds of drugs have already increased by 5% in 2022, far outpacing inflation. According to a March 29, 2021 report by the Government Accountability Office (GAO), in 2020 Americans paid two to four times more for 20 brand-named drugs than people in Canada, France and Australia. Seniors, who take the most prescription drugs to stay healthy, bear the brunt of these high prices.

Because of the terribly excessive cost of prescription drugs, a quarter of Americans and 20% of seniors report not being able to afford their prescriptions. As a result, millions of Americans do not take their prescriptions as prescribed by their doctor and are instead not filling them, skipping doses, or taking fewer doses than directed.

This should not be tolerated in a nation as wealthy and resourceful as the United States.

Allowing Medicare to Negotiate Prescription Drug Prices

The Arizona Alliance strongly believes that the Secretary of Health and Human Services must be allowed to negotiate lower drug prices under Medicare.

According to the Congressional Budget Office, Medicare price negotiation would not only assist seniors to afford their medicine, it would also save the U.S. government billions of dollars. The CBO estimates that Senator Kelly's proposal to allow negotiation would lower spending by \$78.8 billion over 10 years. This would create savings that could be reinvested back into Medicare for greater or improved coverage.

Patent Abuses

Another contributing factor to the causal effect of high drug prices is the abusive practice of drug companies that take advantage of the U.S. patent system. The Arizona Alliance strongly believes that legislation needs to be enacted to curb these often-egregious abuses.

Pharmaceutical corporations use numerous tactics to extend patent terms, costing Medicare billions of dollars. For example, AbbVie Pharmaceutical reached an agreement through a pay-for-delay deal with its competitors, Novartis, and Amgen, to delay the entry of those companies' biosimilars in the United States until 2023, a delay agreement that is costing American taxpayers \$19 billion.

Additional Items:

Lastly, the Arizona Alliance for Retired Americans strongly supports meaningful drug pricing reforms in the plan supported by Senator Kelly that passed the House. The most salient of these include:

- Capping co-pays for insulin at \$35;
- Setting a \$2,000 annual out of pocket cap for seniors' medications in Medicare Part D; and
- Creating a new price gouging penalty for drug companies that raise prices faster than inflation.

I want to thank you again for providing me with the opportunity to present testimony on behalf of the Arizona Alliance for Retired Americans on this critical issue, and I would be pleased to answer any questions you may have. Thank you.

STATEMENT OF JENNY PEÑA
ASSOCIATE MANAGER, PHARMACY PATIENT ADVOCACY,
BANNER MD ANDERSON CANCER CENTER, PHOENIX, ARIZONA

NO TIME TO WAIT: PROPOSALS TO LOWER PRESCRIPTION DRUG COSTS
APRIL 12, 2022

Thank you, Senator Kelly. My name is Jenny Peña, and I am the Associate Manager of Pharmacy Patient Advocacy at Banner MD Anderson Cancer Center, specializing in Oncology. Banner MD Anderson is part of Banner Health, one of the largest secular nonprofit health care systems in the country and largest private employer in Arizona. I am also an Advisory Board Member of the National Healthcareer Association and was named Next Generation Pharmacist's Pharmacy Technician of the Year Honoree in 2021. I would like to express my gratitude to Senator Kelly and the Senate Special Committee on Aging for providing this opportunity to testify on behalf of the patients I serve each day.

As a patient advocate, I help patients who are facing life-altering cancer diagnoses access financial assistance to cover costs of the drugs they have been prescribed. Because I work in oncology, these drugs are even pricier than other non-specialty drugs. An average oral drug to begin treating breast cancer costs about \$1,100. For pancreatic cancer, the average is around \$5,500. The cost of starting oral treatment for chronic myeloid leukemia has an average cost of \$32,000.¹ These drugs are clearly incredibly expensive. According to the National Cancer Institute (NCI), most cancer drugs launched between 2009 and 2014 were priced at more than \$100,000 per patient for one year of treatment.²

¹ https://progressreport.cancer.gov/after/economic_burden

² <https://www.cancer.gov/news-events/cancer-currents-blog/2018/presidents-cancer-panel-drug-prices>

Once a patient has been prescribed treatment, it's my job to find out what their insurance will cover of those amounts and what will be left on their bill to pay out of pocket. I am extremely protective of my patients, and Mama Bear comes out when I am working back end of these claims with the insurance plans. I always fight to make sure my patients get the coverage they deserve. But even with good insurance coverage, my patients can still be left with thousands of dollars to pay out of pocket. I'm the one who makes that phone call to let the patient know their insurance has approved their treatment, but that they're going to be left with a high copay. When my patients hear the amount they're on the hook for, I typically get one of two reactions. Some people are angry—they have already faced countless doctors, tests, diagnoses, and other stressors. Now they are faced with costs that may impact their ability to seek treatment. Others are just sad. They feel hopeless—the cost is too high and they surrender to their unknown fate. Of course, some people don't even want to know what that copay amount is because they know they can't afford it.

On these phone calls, you must have a lot of compassion. You're going to have patients with different emotions. But I sympathize—this issue is very personal to me as well. Both of my parents are from El Salvador, and my father is a cancer survivor. Thankfully, his diagnosis prompted many others within our community to get screened, including myself. I know that not everyone is able to take these proactive measures, and not everyone can maintain their treatment, especially in communities of color. Black and Hispanic individuals are more likely to report cost-related nonadherence to their treatment. My goal is to help prevent anyone from foregoing their medication due to cost.

To do this, I help my patients access the resources available to assist with these financial concerns, including foundation grants, free trials, manufacturer free drug programs, and voucher programs. However, the process of finding these resources is time consuming and complicated – time that many of the cancer patients do not have. Additionally, my Medicare patients are limited in the assistance they can receive, despite typically being the population who needs the most financial help. While I am typically successful in helping my patients—if I was Mama Bear

before, my Papa Bear personality comes out when I am working to turn over every stone to find a solution for these patients—I recognize that many medical facilities do not have roles like mine designated to patient advocacy.

My role in helping patients access their medications is extremely important, and it's something I am so passionate about. But to be honest, this should not be necessary. I believe that everyone deserves access to affordable prescription drugs despite their age, income, socioeconomic status, or race. Congress has to do more to make sure people can access the care and treatment that they need. I am encouraged by the fact that I'm here today to advocate for solutions. Thank you again for the opportunity to speak today, and I am happy to answer any questions.

Gracias, Senador Kelly. Mi nombre es Jenny Pena, y soy la Gerente Asociada de Defensa del Paciente Farmacéutico en Banner MD Anderson Cancer Center, especializada en Oncología. Banner MD Anderson es parte de Banner Health, uno de los sistemas de atención médica sin fines de lucro más grandes del país y el empleador privado más grande de Arizona. También soy miembro de la Junta Asesora de la Asociación Nacional de Profesionales de la Salud y fui nombrada Técnico de Farmacia del Año de Next Generation Pharmacist's Homenajada en 2021. Me gustaría expresar mi gratitud al Senador Kelly y al Comité Especial del Senado sobre el Envejecimiento por brindar esta oportunidad de testificar en nombre de los pacientes que atiendo cada día.

Como defensor del paciente, ayudo a los pacientes que enfrentan diagnósticos de cáncer que alteran sus vidas a acceder asistencia financiera para cubrir los costos de los medicamentos que les han recetado. Debido a que trabajo en oncología, estos medicamentos son incluso más caros que otros medicamentos que no son de especialidad. Un medicamento oral promedio para comenzar a tratar el cáncer de mama cuesta alrededor de \$1,100. Para el cáncer de páncreas, el promedio es de alrededor de \$5,500. El costo de iniciar un tratamiento oral para la leucemia crónica tiene un costo promedio de \$32,000.³ Estos medicamentos son claramente increíblemente caros. Según el Instituto Nacional del Cáncer (NCI), la mayoría de los medicamentos contra el cáncer lanzados entre 2009 y 2014 tenían un precio de más de \$100 000 por paciente por un año de tratamiento.⁴

Una vez que a un paciente se le ha recetado un tratamiento, es mi trabajo averiguar qué cubrirá su seguro de esos montos y qué quedará en su factura para pagar de su bolsillo. Soy

³ https://progressreport.cancer.gov/after/economic_burden

⁴ <https://www.cancer.gov/news-events/cancer-currents-blog/2018/presidents-cancer-panel-drug-prices>

extremadamente protectora con mis pacientes, y Oso Mama sale cuando estoy trabajando en la parte final de estos reclamos con los planes de seguro. Siempre lucho para asegurarme de que mis pacientes obtengan la cobertura que se merecen. Pero incluso con una buena cobertura de seguro, mis pacientes aún pueden quedarse con miles de dólares para pagar de su bolsillo. Soy la que hace esa llamada telefónica para informarle al paciente que su seguro ha aprobado su tratamiento, pero que se quedará con un copago alto. Cuando mis pacientes escuchan la cantidad por la que están endeudados, normalmente obtengo una de dos reacciones. Algunas personas están enojadas: ya se han enfrentado a innumerables médicos, pruebas, diagnósticos y otros factores estresantes. Ahora se enfrentan a costos que pueden afectar su capacidad para buscar tratamiento. Otros simplemente están tristes. Se sienten sin esperanza: el costo es demasiado alto y se rinden a su destino desconocido. Por supuesto, algunas personas ni siquiera quieren saber cuál es el monto del copago porque saben que no pueden pagarlo.

En estas llamadas telefónicas, debes tener mucha compasión. Vas a tener pacientes con diferentes emociones. Pero simpatizo, este tema también es muy personal para mí. Mis padres son de El Salvador y mi padre es sobreviviente de cáncer. Afortunadamente, su diagnóstico hizo que muchos otros dentro de nuestra comunidad se hicieran la prueba, incluyéndome a mí. Sé que no todos pueden tomar estas medidas proactivas y no todos pueden mantener su trato, especialmente en las comunidades de color. Las personas hispanas y de color son más propensas a no informar sobre su tratamiento relacionada con los costos. Mi objetivo es ayudar a evitar que alguien renuncie a su medicamento debido al costo.

Para hacer esto, ayudo a mis pacientes a acceder a los recursos disponibles para ayudar con estas preocupaciones financieras, incluidas subvenciones de fundaciones, pruebas gratuitas, programas de medicamentos gratuitos del fabricante y programas de vales. Sin embargo, el proceso de

encontrar estos recursos lleva mucho tiempo y es complicado, tiempo que muchos de los pacientes con cáncer no tienen. Además, mis pacientes de Medicare están limitados en la asistencia que pueden recibir, a pesar de que, por lo general, son la población que más ayuda financiera necesita. Si bien normalmente tengo éxito en ayudar a mis pacientes (si antes era Mamá Oso, mi personalidad de Papá Oso aparece cuando trabajo para remover cada piedra para encontrar una solución para estos pacientes), reconozco que muchas instalaciones médicas no tienen roles como el mío destinado a la defensa del paciente.

Mi papel en ayudar a los pacientes a acceder a sus medicamentos es extremadamente importante y es algo que me apasiona. Pero para ser honesta, esto no debería ser necesario. Creo que todos merecen acceso a medicamentos recetados accesibles independientemente de su edad, ingresos, nivel socioeconómico o raza. El Congreso tiene que hacer más para asegurarse de que las personas puedan acceder a la atención y el tratamiento que necesitan. Me alienta el hecho de que estoy aquí hoy para abogar por soluciones. Gracias nuevamente por la oportunidad de hablar hoy, y estaré feliz de responder cualquier pregunta.

STATEMENT OF JUDY WILSON
MS PATIENT, PHOENIX, ARIZONA
NO TIME TO WAIT: PROPOSALS TO LOWER PRESCRIPTION DRUG COSTS
APRIL 12, 2022

Senator Kelly, thank you for the opportunity to testify at this important hearing. My name is Judy Wilson. I am recently retired, am on Medicare, a Rotarian of 22 years, a volunteer for the National Multiple Sclerosis Society, a mentor for the Community Health Mentor Program and, most importantly, a grandmother of four wonderful grandchildren. I am also living with multiple sclerosis (MS).

MS is an unpredictable, often disabling disease of the central nervous system that disrupts the flow of information within the brain, and between the brain and body. Symptoms vary from person to person and range from numbness and tingling, to walking difficulties, fatigue, dizziness, pain, depression, blindness and paralysis. Nearly one million Americans live with this disease, and most people are diagnosed between the ages of 20 and 50, when they are in their prime working years. The progress, severity and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are leading to better understanding and moving us closer to a world free of MS.

MS is a very expensive disease. The average total cost of living with multiple sclerosis is \$88,487 per yearⁱ. **The total estimated cost to the U.S. economy is \$85.4 billion per yearⁱⁱ**. Disease-modifying therapies (or DMTs) are the biggest cost of living with the disease, with individuals with MS spending an average of \$65,612 more on medical costs than individuals who don't have MS.

I was diagnosed in 2010 after experiencing tingling in my fingers, lack of balance, depression and anxiety, inability to write and incontinence. With the help of my general practitioner and many specialists, I was able to address many of my symptoms. Even still, I have lost much of my hearing, have no sense of smell, my eyesight is compromised, my gait is off, and my number of falls has increased, and I have constant nerve pain in my feet and hands.

Today, evidence shows that early and ongoing treatment with MS DMTs are the best way to manage the MS disease course, prevent accumulation of disability, and protect the brain from damage due to MS. There are now more than twenty DMTs on the market, including generic options, and these medications have transformed the treatment of MS over the last 29 years. The full range of MS DMTs represent various mechanisms of action and routes of administration with varying efficacy, side effects and safety profiles. No single DMT is 'best' for all people living with MSⁱⁱⁱ and, as MS presents differently in each person, every person's response to a DMT will vary. It is common for people with MS to move through several different DMTs throughout their life with MS, as they may "break-through" on a medication, or have disease activity, and need to try a different DMT.

After some trial and error with several DMTs, my neurologist prescribed Copaxone, a self-injection that I took three times a week. When I transitioned to Medicare, I was able to get assistance from a charitable foundation. They paid for my \$3272 copay for the first two months of the year and the \$250 per month after that, making my treatment affordable. Unfortunately, in 2021, the foundation I relied on ran out of money. I am unable to afford the over \$7,000 per year without this financial help, so I reached out to my neurologist for help.

After discussions with my doctor, I decided to go off my medications. I didn't have any other options and have so far been very lucky that I haven't had any relapses or other setbacks. But I want to emphasize that **the decision to stop my medication was based on money, not medicine**. If I could afford to go back on Copaxone, I would. MS is extremely unpredictable, and just because I have been healthy so far does not guarantee that I will not have a relapse in the future. For most living with MS, a gap in medication could mean disease progression, and that could lead to a permanent loss of mobility or cognitive function. This is a risk I take daily. No one should have to take this risk because they cannot afford medications they need.

It seems ridiculous that I needed charitable assistance to afford my medication, even though I was already paying \$2040 per year for health insurance through Medicare. I know I am not alone. A National MS Society survey found more than 70% of people with MS have received financial assistance for their DMT and 40% of people with MS alter the use of their DMTs due to cost, including stopping, skipping, or delaying treatment^{iv}.

As a volunteer self-help group leader for people living with MS in the Phoenix area, I hear firsthand how difficult it is for people to afford their medications. There are two others in my group who have discontinued use of their medications. One has recently gotten out of the hospital after a two week stay due to MS symptoms.

MS DMT prices are too high and still rising—even for DMTs that have been on the market for decades.

The price of MS DMTs has dramatically risen since the first MS disease-modifying therapy was approved in 1993. When the first MS DMT came to market, the price range was \$8,000 to \$11,000 for one year of treatment. The annual median price for MS DMTs has increased nearly \$34,000 in less than 10 years. As of February 2022 (see appendix), the median annual price of the brand-name MS DMTs is close to \$94,000.

Six of the MS DMTs have increased in price more than 200% since they came on market, with nine now priced at over \$100,000. This trajectory is not sustainable for people with MS or the U.S. healthcare system as a whole. Recent analysis of the MS DMTs shows that price increases of brand name drugs are largely driven by year-over-year price increases of drugs that are already in the market vs. new products.^v

When the version of Copaxone that I was prescribed came on market in 2014, it was priced at approximately \$60,000. Today it costs over \$75,000 (see appendix). This is an increase of over \$15,000 (25.6% increase) in 8 years for the same medication.

Seniors with MS Need Medicare Reform

Medicare is the single largest payer of MS-related costs in the United States, and the Medicare program consistently spends around \$5 billion on MS DMTs^{vi}. Like me, many other Medicare beneficiaries with

MS have reported significant difficulty affording their medications.

Unfortunately, recent analysis confirms our experience. Cumulative annual out-of-pocket spending for Medicare beneficiaries with MS was \$6,894 in 2019, including an average of \$352 in out-of-pocket cost per month for those already in the catastrophic coverage phase^{vii}.

Charitable foundations like the one I used exist for Medicare beneficiaries to apply to for some assistance affording their medication, but the need is far greater than supply. From 2018 to 2020, the various nonprofit programs serving Medicare beneficiaries with MS opened for applications only 16 to 20 times for just a total of 87 to 98 days out of the entire year—approximately 25 to 30% of the year. In 2021, these funds opened only four times, for just 25 days out of the year. And to date in 2022, the funds opened only once in January, for just three days.

Policy proposals that redesign Medicare Part D to better work for Medicare beneficiaries by capping out of pocket costs at \$2,000 and allowing beneficiaries to smooth costs within the plan year is important to helping seniors like me afford their medications. \$2,000 is a lot of money, but it is more affordable than the almost \$7,000 that I would have to pay now for my MS DMT.

In closing, I am one of the 85% of people with MS across the United States who want the federal government to do more to control the high cost of MS medications. I urge you and your colleagues to immediately pass legislation that

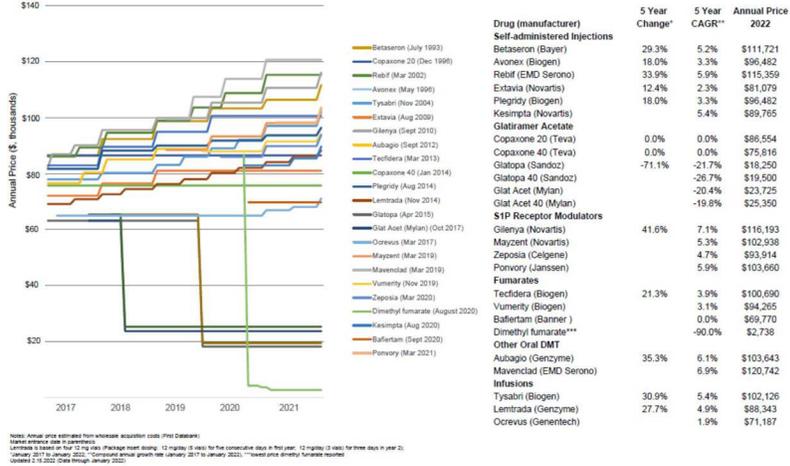
- allows Medicare to negotiate better prescription drug prices on behalf of its beneficiaries,
- establishes a \$2,000 Medicare Part D out-of-pocket cap along with a process that will allow beneficiaries to spread their cost throughout the year, and
- prevents the price of medications from increases faster than the rate of inflation.

These policies will have an immediate benefit on seniors living with MS. There is no single policy solution that will address the high cost of prescription drugs, but the policies that I discussed today are an important step in the right direction, and would immensely improve the quality of life for many seniors, including me.

Thank you for the opportunity to share with you today and I look forward to working with you to address the high price of medications.

Appendix

Trends in annual price for disease-modifying therapies for multiple sclerosis; 2017 to 2022



ⁱ B. Bebo et al. A Comprehensive Assessment of the total economic burden of multiple sclerosis in the United States. ECTRIMS 2021. 15, October, 2021. <https://ectrims2021.abstractserver.com/program/#/details/presentations/557>.
ⁱⁱ B. Bebo et al. A Comprehensive Assessment of the total economic burden of multiple sclerosis in the United States. ECTRIMS 2021. 15, October, 2021. <https://ectrims2021.abstractserver.com/program/#/details/presentations/557>.
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^{iv} National MS Society. Quantifying the Effect of the High Cost of DMTs. Market Research Report. <https://www.nationalmssociety.org/NationalMSSociety/media/MSNationalFiles/Advocacy/NMSS-Research-Report-Full-Access-to-MS-Medications.pdf>. August 2019. Accessed March 10, 2022

^{vvv} Hernandez, Inmaculada et al. "The Contribution of New Product Entry Versus Existing Product Inflation in the Rising Cost of Drugs." Health Affairs. Vol.38, No. 1. <https://doi.org/10.1377/hlthaff.2018.05147>

^{vi} 2019 Data from Medicare Part D and Part B Spending Dashboard. (Accessed May 7, 2021).

^{vii} Daniel M Hartung, Kirbee A. Johnson, Adriane Irwin, Sheila Markwardt, and Dennis N. Bourdette, 'Trends In Coverage For Disease-Modifying Therapies For Multiple Sclerosis In Medicare Part D', Health Affairs, February 2019, Vol.38, No.2.