Addressing the Burden of COPD in Rural America from the NACRHHS – 02/26/19

Kristine: Hello, everyone. I'm Kristine Sande, and I'm the program director of the Rural Health Information Hub. I'd like to welcome you to today's webinar addressing the burden of Chronic Obstructive Pulmonary Disease in rural America. We're happy to be doing this webinar today in conjunction with the National Advisory Committee on Rural Health & Human Services, and I will quickly run through some housekeeping items before we begin. We do hope to have some time for your questions at the end of today's webinar, so if you do have questions for our presenters, we ask that you submit those at the end of the webinar, using the Q&A section that will appear on the lower right-hand corner of your screen following the presentations. We've provided a PDF copy of the presentation on the RHI Hub website, and that's accessible through the URL that's on your screen, and we will also share that in the chat function. For technical issues during today's webinar, we ask that you call Webex support at 866-229-3239.

Our first speaker today will be the Honorable Ronnie Musgrove. He has served as the chair of the National Advisory Committee on Rural Health & Human Services since 2010. He is also the former governor of Mississippi, serving from 2000 to 2004, and he was the Lieutenant Governor prior to that. Governor Musgrove has dedicated his life to serving the people of Mississippi. For more than two decades, he has taken a leading role in the state to improve education and expand economic development. Governor Musgrove will provide some background information on the committee, introduce the webinar presenters, and set the stage for why the committee chose to focus on addressing the burden of COPD in rural America. With that, I'll turn it over to you, Governor Musgrove.

Ronnie: Thank you, Kristine, for that introduction. I would like to take this opportunity to welcome our audience to today's webinar on addressing the burden of Chronic Obstructive Pulmonary Disease, or COPD, in rural America by the National Advisory Committee on Rural Health & Human Services. In this webinar, we will provide an overview of the committee, cover rural-urban disparities in COPD outcomes, review the committee's recommendations, and hear from a patient's perspective on the disease.

I would like now to provide some brief background on the committee, especially for those joining us today on the webinar who do not know who we are. The committee is a federally chartered independent citizens' panel whose charge is to advise the Secretary of the US Department of Health and Human Services, or HHS, as we all call it, on healthcare challenges that affect rural Americans. The committee consists of 21 members, including the chair, and the experiences and expertise they bring reflects a wide variety of rural issues in public health, medicine, nursing, human service delivery, hospital administration, childcare, research, finance, law, and business.

The committee was formed in the late 1980s in response to a large number of rural hospital closures. Since then, the committee has continued its work to address and examine pertinent issues that affect the health and wellbeing of rural Americans, and to also hear directly from rural stakeholders. Following its meetings, the committee produces policy briefs to the HHS Secretary with recommendations on policy or regulatory matters under the Secretary's purview.

For its 84th convening in September of 2018, the committee met in Charlotte, North Carolina, and focused on COPD in rural areas as one of two topics. During the meeting, the committee examined the delivery and quality of COPD care and treatment, payment for pulmonary rehabilitation services, and COPD surveillance. Over the two and a half day meeting, the committee first heard from subject matter experts, two of whom you will hear from during this

webinar. The subcommittee tasked with this issue then visited a Grace Anne Dorney Koppel Pulmonary Rehabilitation Center at the Happy Valley Medical Center located in Lenoir, North Carolina. We have hyperlinked to the brief if you click on the cover of this policy brief. You can also find it, along with others, at the link provided at the bottom of the slide.

Why COPD? 2015 data published by the Centers for Disease Control and Prevention, or the CDC, show that the prevalence of COPD among rural counties was almost twice as high as that of urban areas. As you can see on the map, additional research has documented that the highest quartile of reported COPD prevalence is often concentrated in Appalachia or the South. Those areas tend to be geographic regions that have states with high rural populations. One of our speakers will go more into data around rural and urban outcomes. To add onto that, a 2018 Johns Hopkins study showed a higher estimated COPD prevalence among rural poor communities. This suggests that rural residence and poverty are independent risk factors for the disease.

The trends we see alone are concerning, but when you factor in the aspects of living in a rural area, the issue becomes even more pressing. Because of a lack of access to and availability of transportation services, specialty care, and treatment options, the disparity in COPD outcomes may even be more pronounced between rural and non-rural areas. Furthermore, exposures to certain rural-related risk factors, such as higher rates of smoking and a greater likelihood of being exposed to environmental and occupational hazards from farming or coal mining, may explain in part these disparities.

Now, it is important to point out that while there is no current cure, prescribed medications, pulmonary rehabilitation, oxygen therapy, and surgical procedures are several treatments that can help alleviate COPD symptoms. Moreover, as the committee, we believe that robust and aligned federal efforts to address the disease burden can help to decrease prevalence and overall deaths.

To transition us into learning more about this disease, I want to briefly introduce the rest of the team presenting on today's webinar. First, we will hear from Tony Punturieri, which is the reason I'm going to call him Tony from now on. He is program director in the Division of Lung Diseases at the National Heart, Lung, and Blood Institute, or the NHLBI. NHLBI is one of 27 institutes and centers of the National Institutes of Health, and it is the primary institute investigating the causes, treatments, and cures for both common and rare lung diseases.

Tony participates in the development of programs that aim to address the pathophysiological understanding, prevention, and design of therapeutic avenues for COPD. In this capacity, Tony administers a varied portfolio of grants covering basic research to clinic research networks and contracts in the area of COPD and the environment. In this webinar, Tony will go over the rural-urban disparities in COPD outcomes and provide a brief overview of the COPD National Action Plan.

Following Tony will be Kathleen Dalton, a current committee member. In addition to being a researcher, Kathleen's experience in healthcare finance spans multiple roles as a manager, consultant, and hospital trustee. Following a 20-year career in healthcare finance, she earned her doctorate in health policy from the School of Public Health at the University of North Carolina. After completing a CMS-funded dissertation on payments to teaching hospitals under the Medicare Prospective Payment System, she remained at the university for five years as a

research faculty member, where she was a frequent investigator with their program on rural health policy and conducted multiple studies under contract to the Medicare Payment Advisory Commission. Kathleen will transition over to discuss the committee's recommendations and spotlight the committee's site visit to Happy Valley Medical Center.

Our last speaker for the webinar will be Grace Anne Dorney Koppel. She was diagnosed with very severe COPD in 2001, which led her on the path to COPD patient advocacy and activism. Since 2006, she has devoted her training, knowledge, and professional life to achieving better outcomes and quality of life to those with COPD symptoms. She is president of the Dorney Koppel Foundation, which provides startup funding and strategic guidance for pulmonary rehabilitation centers in areas of high COPD prevalence, primarily in rural America, that have no access to such services. To date, 12 Grace Anne Dorney Pulmonary Rehabilitation Centers are now in operation in Kentucky, North Carolina, West Virginia, Louisiana, and Maryland, with 11 of them being in rural areas.

Grace Anne is also a past president of the COPD Foundation, presently serves on its board of directors, is current chair of its advocacy and public policy committee. The COPD Foundation is dedicated to lead initiatives that result in expanded services and a cure for COPD through research, education, public policy, and advocacy. Grace Anne will wrap up by providing patients' perspective on the disease. With that, I will turn it over to you now, Tony.

Tony: Thank you, Governor, and thank you, everybody, for tuning in. As the governor said, I go by Tony, because it's my first name and last name are a mouthful, and that's the way that I connect with people in the best way. Let's go on the first slide that goes to what actually is COPD, for those that don't know it. The name is a mouthful, of course, but it also describes what I usually call a horrible disease. It's a horrible disease, but it's also a preventable and treatable disease, so we can do something about it. I think that's message number one from today's talk, and we all can do something about it.

As you know, the air needs to go in, down into our lungs, so that we get oxygen in the blood, and the oxygen goes all the way to feed all our organs. If you have a problem with the conducting pipes, with the airways, as we call it, like it happens on the panel that says airway in bronchitis, what happens in COPD, you may have restriction of that. You have a restriction of mucus, so you have swelling, and so the air has trouble getting in, but the error that you see of the airflow, it goes also the other way around, also getting out, leading to what is called hyperinflation, so some parts of the lung get bloated and the air that is in there is stale, so it makes very difficult to exchange oxygen in that way.

The other part of COPD is on the panel on the right, the one that says emphysema, where instead of having at the bottom, a little picture of the nice alveoli that are like a grape, you can see about it, that they are just now on the top, just one structure. The tissue has been destroyed, and this also make very difficult to exchange the oxygen. In most patients, there is a combination of both diseases. Some have more airway disease, some have more emphysema, more tissue destruction. Now, asthma is also a disease where it's difficult to empty the air in and out of the lungs, but asthma is not included in the definition of COPD, although a person with COPD has frequently in his or her background, some degree of asthma.

Now, getting, as the governor mentioned, more into the details, into the differences between urban and rural COPD. This panel shows more collated data for leading causes of death from '99

to 2014. The solid line is rural and the dotted line is urban. The first three panels here are heart disease, cancer, and stroke, and you see that the lines are ... There is a little gap in between them, and we can talk why there is the little gap, but they're all going in the same direction. There is diminishment of death for all diseases.

However, when we look at two other leading causes of disease in this panel, unintentional injuries here and chronic lower respiratory disease here, you see there is a striking difference. In the first panel, the two lines are parallel and there is a bigger gap. We kind of understand that, because of course, working in rural environment exposes to more injuries, and so you expect to see that kind of gap. However, for chronic respiratory disease, we have two lines that are not going in the same direction. The dotted line is going down. That means mortality in urban areas is diminishing, whereas there was no change in mortality in rural setting.

The next slide shows also who is dying of COPD. It's the fourth leading cause of death in the United States after heart disease, cancer, and accidental death. In this slide, you see on the left panel, division of women and men, death of women and men by age up to 74, and you see that no matter how you slice it, they are basically overlapping lines. The big difference is on the right panel, where you can see more women, and that's since the year 2000, die of COPD than men, and this is the biggest toll that we pay in COPD deaths, so people over 75. A good slice of the rural population is in this data.

Overall, COPD is the fourth main cause of disability. We pay altogether 32 billion with a B a year related in care for COPD. The prevalence is 6.5% of the people, which translates in 16 million people that have been diagnosed with the disease. We know that there are millions out there that do not have it, and we will talk about it along the webinar, for the reason of this. We know the rural population had the greater risk of COPD in 2015, as also the governor mentioned.

Another important thing to know about COPD is that it's not just a disease of the lung. This panel shows what other diseases people with COPD have, and you see there is a constellation, basically, around COPD of different diseases that are from cardiovascular all the way to anxiety, to breast cancer, for example, depression, diabetes. This tells us in short that a patient with COPD is not just a patient with a bad lung disease, but it's a patient most likely with other diseases, and this has other implications we will address later in the talk.

This is a map similar to the one that the governor showed, and what is important here is the concept that if we do not know where COPD is, who it's affecting, there's very little we can do about it, and that's why our institute, the National Heart, Lung, and Blood Institute, partnered with the Centers for Disease Control to try to put COPD on the map, and working with the state health department, and reach people, and get ideas on where the disease is. This, of course, effort enabled us to put COPD literally on the map, so we can have now outreach efforts that are targeted, and it provides foundation to build focused state action plans.

Drilling deeply, more deeply into the disparities, I'm going to show you two slides of recent data collected by CDC and published in one of their publications, MMWR in 2018. The columns in the red refer to COPD in rural environment, and the others are COPD, especially those to the left, in a urban setting. You see there is almost doubling of doctor diagnosed COPD in rural environment compared to a urban environment, and the same is true not only for diagnosis, but also for death rates. It's almost doubled in rural environment compared to metro environment, and hospital discharges for COPD are also higher in a rural environment.

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Another important thing that emerges from knowing where the disease is and relating it to what we can do about it is the access to pulmonary rehabilitation. We're going to talk a little bit more along the webinar about pulmonary rehabilitation and its benefits for COPD, but what this slide shows is where pulmonary rehabilitation is located on the map. If you compare that with the map of where COPD is, you see that there is no direct correlation. In addition to this, the programs are very few. It has been calculated that actually to satisfy the requests for all COPD patients, one of these dots should see about 18,000 patients, which is clearly unrealistic.

Other data are telling us the relationship between COPD patients and providers. Only 73% of people with COPD symptoms, not diagnosed, but just symptoms, talk to their physician, and only 40% were given a breathing test. The best breathing test is called spirometry, and that helps with the diagnosis of the disease, so there is this gap of communication. Only 71% of primary care providers evaluated COPD with spirometry. Only 68% acknowledge pulmonary rehabilitation that were available in their area, and only 38% routinely prescribe pulmonary rehabilitation for patients diagnosed with the disease.

COPD, it's a big problem, and we have known this for a while, and thanks to patient organizations and other stakeholders, Congress pushed us and the Centers for Disease Control to move along and create what is now the first ever COPD National Action Plan. This was launched in 2017, and it's the first one, let's say booklet that provides a comprehensive framework for action. The plan hinges on five major goals, and it was the product of more than 200 stakeholders that gathered together here in Bethesda and gave us directions on how to structure it. It is not a top-down approach plan, but it's definitely a bottom-up. It came from the patients, their families, from the providers.

The five, I'm not going to read what each one of the goals is, but in short, the first goal is directed to the patients and their caregivers, their families, and wants to empower them with knowledge about the disease, what they can do about it, recognize the symptoms if they have early stages of the disease. The second is addressed to those that instead provide healthcare, so to improve knowledge in these people of the disease so that they can intervene early, and they can help the patients along the course of the disease. The third, and you heard me hammering on this, it's important that we know where COPD is, who's affected and so on, and so the importance of collecting data and making data available to everybody so that we can act upon it.

The fourth, of course, it's important also to know what we can do in terms of therapies, for example, and so it's important to know how the disease comes about, what are all the causes of it, what are, for example, your genetic predispositions to it. Basic knowledge about how the disease comes about is fundamental to therapy and management of the disease. The fifth one hinges instead upon putting together all the products of the previous four goal, and translate it into recommendations for research and public healthcare actions.

We are now ... This is part of it. What we are doing today with this webinar is absolutely one of the fundamental part of it, is we now need to move along and make the plan a living thing. It can't be a thing that stays on a shelf and gathers dust, of course, so all the COPD stakeholders have a possession of the plan and need to have an active role in its implementation. You'll see I listed here all the partners, and it's like a big puzzle that needs to get together to give resolution of the plan.

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One of the effort that we are doing specific to rural health, in addition, of course, to all that you are going to be hearing about today, is also diffusing the word about COPD and the plan in the rural communities and in the rural healthcare community. We just recently published a summary of a workshop that we held, specifically targeting the COPD National Action Plan into rural health, in a journal that reaches the healthcare providers that directly interact with the rural world. At this point, I'm going to pass the mic to Kathleen, that is going to talk to you more specifically about the policy recommendation from the site visit. Thank you all.

Kathleen: Okay, can everyone hear me? Yeah? Thank you, Tony, for providing more context on the rural-urban differences in COPD outcomes, and also for the introduction to the COPD National Action Plan. This is Kathleen, and I'm delighted to present our recommendations, our policy recommendations to you, but before we go there, I'd like to talk a little bit more about our site visit on the second day of the meeting.

The group from the committee traveled an hour or two, I think, into the mountains, up to Happy Valley Medical Center. This is a federally qualified health center. It was established in 1985, and it operates one of the 11 current Grace Anne Dorney Pulmonary Rehab Centers, all of which are funded by the Dorney Koppel Foundation in partnership with some other funders. While we were there, we had an opportunity to tour the facility, and we also heard from several COPD patients and from their physicians and their other providers. See if I can get this moving. Okay.

During those conversations, a recurring theme that arose was about the need for better education, both for primary care providers and for the patients. From the providers who spoke with us, we heard about the lack of pulmonologists practicing in rural areas and the resulting need to decentralize COPD expertise from the tertiary care centers down to the community level. Primary care providers are on the front lines of seeing and treating the individuals with COPD symptoms, and they need to be trained on how to properly diagnose the disease, including the appropriate use of spirometry, and also how and when to make timely referrals for effective treatments.

COPD patients on our meeting described feeling empowered after learning more about the disease, and they spoke about the social, as well as the physical benefits gained from participating in the rehab program at Happy Valley. One of them emphasized the value of the program in knowing simply that he is not struggling in isolation. As he said, "When you're in the COPD class, you're with other people who are going through the same thing, and it makes you feel like you're not alone."

Another patient we heard from spoke quite passionately about her life-changing experience with pulmonary rehab. In her own words, "It's the best decision I've ever made. The program focuses on what each individual can accomplish, and there's one-on-one attention from the respiratory therapists. They take good care of you." She ended by saying that, "The pulmonary rehab gave people with COPD, like me, some hope."

Now, for those of you who may not know, let's give a quick definition of pulmonary rehab. It is an evidence-based multidisciplinary comprehensive intervention. It's designed to reduce chronic respiratory symptoms, to optimize functional status, to reduce healthcare costs, all of this through patient assessment, exercise training, education, nutritional intervention, and psychosocial support. The American Thoracic Society and the European Respiratory Society have reported a number of benefits gained for COPD patients who undergo an organized pulmonary

rehab program. These include patients experiencing improvements in exercise capacity, in health-related quality of life, and functional status. Patients also report reductions in hospitalizations and unscheduled healthcare visits, and in symptoms such as shortness of breath and leg discomfort.

Despite the evidence supporting the effectiveness of pulmonary rehab, the American Thoracic Society and the European Respiratory Society report that payer awareness, and by payer, they mean both public payers and insurance companies, payer awareness of pulmonary rehab is poor. In the US, payment is quite low, which discourages hospitals and communities from operating organized rehab facilities. Do you know? I skipped a slide. You'll have to just run with me. I was thinking about it and forgot to get through it, but we've been through that slide.

Our committee came up with three policy recommendations. One focuses on education, one on payment, and a third addresses staffing and workforce issues. The conversations we had during our site visit certainly helped inform these recommendations. We also find that the recommendations were nicely aligned with the congressionally mandated COPD National Action Plan that Tony discussed. In fact, I would say that that also helped inform our recommendations.

Our recommendation one, regarding education. The committee recommends the Secretary in HHS undertake a national campaign to educate rural primary care providers and individuals with COPD about rural-urban disparities in COPD outcomes, with an emphasis on the need to do more screening and referral to effective treatments to help manage the disease. Now, the committee envisions a campaign that is similar to one the HHS ran that was undertaken on chronic care management, or CCM. It happens that under Section 103 of the Medicare Access and CHIP Reauthorization Act, which was back in 2015, Congress required HHS and the Secretary to, quote, "Conduct an education and outreach campaign to inform professionals who provide Part B services and beneficiaries of the benefits for chronic care management services and to encourage individuals with chronic care needs to receive such care." End quote.

This campaign was specifically aimed to educate providers and patients in rural and underserved areas. For a similar campaign that we envision for national COPD, the committee encourages the Secretary to include the CDC, CMS, the Federal Office for Rural Health Policy, National Heart, Lung, Blood Institute, and the Administration for Community Living, all in the campaign's development and its implementation.

Second recommendation, and this regards payment. Our second recommendation addresses current Medicare reimbursement for pulmonary rehabilitation. The current payment rates are simply not sufficient to sustain provision of services. I should say it's roughly ... At the moment, I believe it is around $56 per session, and that's for everything that happens in that session, in that multidisciplinary session. Since 2010, when pulmonary rehab was first recognized as a covered service, Medicare payment rates have varied, due at first to a scarcity of hospital cost data, and then later on to an uncertainty about the types and volumes of services that should be included in a rehab, organized rehab visit.

The committee is concerned that low reimbursement will discourage health systems in rural areas from investing in cost-effective pulmonary rehab programs. Therefore, committee recommends that prior to the next reevaluation of outpatient prospective payment rates, this is an annual occurrence for setting Medicare outpatient payments, HHS should consult with experts in pulmonary treatment to refine the definition of rehabilitation services and review

Medicare cost reports to confirm that there is adequate accurate data on this service to be used as a basis for setting the rate. Oops. Let's go back one. There you go.

Recommendation three. In addition to reimbursement, the Medicare program imposes certain staffing regulations that are potentially burdensome for rural health facilities that offer pulmonary rehab services, specifically with regard to who can provide direct supervision for such programs. By law, Medicare requires ... By law, that means that Congress has passed it. By law, Medicare requires that a physician be available for each pulmonary rehab session, thus precluding physician assistants and nurse practitioners, or what we call non-physician practitioners or NPPs, to serve in a supervising role.

The committee is concerned that such a requirement may actually be difficult for rural facilities to fulfill. However, since the availability of non-physician providers reflects the existing clinic resource and reality in the rural areas, the committee believes that direct physician supervision needs to be expanded to include other primary care providers. Hence, the committee recommends the Secretary work with Congress to expand the direct supervision of pulmonary rehabilitation to include physician assistants, nurse practitioners, and other primary care providers who are under the general supervision of a physician.

Those are our three recommendations. For more information, we encourage you to read the committee's policy brief. You should all have copies of it. There are further details there, and I will be available, along with the others, to answer any questions at the end of the webinar. With this, I need to pass you on over to Grace Anne, who is going to provide a patient's perspective on this. Thank you.

Grace Ann: Thank you, Kathleen. I am a COPD patient. I was diagnosed 18 years ago with very severe COPD. I have survived for 18 years. My COPD is still severe, but I live and I live well with it. I say to you, Kathleen and Tony, from your lips, from your words on paper to God's ears and at least to the Secretary Azar's ears, because COPD, the third chronic disease killer of Americans, right after heart disease, right after cancer, has really not gathered the kind of attention that it needs, and we don't recognize either its symptoms or its pervasiveness, but we do know, because of the work that the CDC has done, that in rural America, 8.2% of people are diagnosed with COPD, and that really is the tip of the iceberg. It is the undiagnosed, the hundreds of thousands in rural America who have the disease and have not been diagnosed, and that's why it pleases me so much that the National Advisory Committee on Rural Health has focused on this disease, which has been largely ignored.

Dr. Punturieri called it a horrible disease. I can tell you that if you have ever had a respiratory infection and you've done a lot of coughing or you're struggling for breath, you know it's transient. It's going to pass, but for us who live with the disease, and it is a progressive disease and it has no cure, it gets worse year by year, we cannot look forward to the seven days when the cold or flu is largely over. We must adjust to it and live with it, but Tony's also right, because the headline is it's treatable, and it's treatable, and people in rural America do not have the benefit of the treatment or of the diagnosis that people who live in urban America have.

It is a tragedy in both areas. 16 million overall with the disease, 165,000 deaths a year. We must do something about it, and these policy recommendations are a wonderful first step, so I would like to show you, because providers don't ask patients if they have trouble breathing. They don't ask them if they are coughing, if they find they can't do activities they did easily before. I'm

going to ask you, please, to look at the screen. This is an NIH video. The coughing and hacking that is associated with the disease represents the chronic bronchitis aspect of the disease.

Here I am on the left, on the very happy day in May of 2017. I had a press conference, which announced the beginning of the actual implementation of the National Action Plan, and you see I'm clutching a water bottle. I'm clutching that water bottle because I had a respiratory infection, didn't want to miss this great day where we finally have a National Action Plan, and so suddenly I began coughing. People began bringing water to me. I did recover in time to be able to speak, but it's a daily occurrence, and we have tools that can make it possible for people to do well with the disease, but they're not being exploited the way they should in rural America.

In terms of who are we, who has COPD, this is a montage of hundreds upon hundreds of tiny little photos of people. I want you to think of this disease not in the abstract. I want you to think of it in the particular. I want you to look at these faces. They could well be the faces of people in your family, people in your community, someone you sit next to at work, someone you ride the bus with every day or carpool with. We're mothers, and fathers, and grandmothers, and grandfathers. We are not all old. The disease strikes us in middle age, but it's been building for years in our lungs. It does not develop quickly.

The only young faces you see are people who have the genetic form of the disease. They are born with it, and it manifests itself probably when they're earlier in their 40s, but it is a disease that debilitates. Many of us are on oxygen 24/7. I have been there. Right now I only need oxygen when I fly, but I want you to pay attention to the picture of the woman who is exercising in the bottom right. The only reason that I am living 18 years after a diagnosis, when I was expected to be dead within five years, is that I received a prescription from my doctor for pulmonary rehabilitation, an evidence-based program recommended by every professional society and part of the standard of care for people with COPD.

We have three treatments. We have inhaled medicines, and we haven't had a new one in 30 years. We have oxygen, but only if our blood oxygen level is very low, and we have pulmonary rehabilitation. It's the best therapy and the least available in rural America, and that's why my husband and I, in 2009, began finding good foundation partners in rural America, and today there are 12. There are 12 clinics, hundreds and hundreds of graduates, of people who have gotten their lives back, and I want to think that everyone who has the disease that I have has an equal opportunity to get that treatment.

You wonder, what is this? What does this have to do with COPD? Well, it's one of the wonders of nature. It is a murmuration of starlings, and they swell, and pulse, and enlarge, and diminish in an aerial spectacle that is caused by a falcon, a predator near the edge of the flock. The beauty of the murmuration, its movement is a defensive strategy. They gather as a gigantic group to put distance between themselves and the predator. Often they are only a mere feather's width from each other, but they don't collide. They move as one, and it's not a stretch, really, to analogize this murmuration to what we're doing now.

We are warding off a predator, COPD in rural America. We've banded together. We are moving as one to achieve a common objective. We represent federal agencies, patient groups, researchers, clinicians, and now we have a National Action Plan for COPD and specific policy recommendations, which I cannot endorse more highly. I want to take those words that are on paper, those words that are in the policy brief that you heard Kathleen describe, the words that

are in the National Action Plan that you heard Tony describe, and I want to make them live. And yeah, the peregrine falcon did not get through and disturb the flight in that video.

I'd like to close with a quote from Governor Musgrove that was certainly articulated in a very different setting. “If you're fortunate in life, age and knowledge breed compassion”, but as a patient and speaking for the patients, I want more than compassion. I want action, because the treatment is there if you will only provide it for us. Now it's over to you.

Kristine: At this time, we'll be opening the webinar up for your questions. You will see a Q&A box that will open on the lower right-hand corner of your screen, and that's where you can enter your questions for the speakers today. To our speakers, thank you so much for sharing such great information and experiences with the folks on the phone today. I really appreciate that, and I just would like to mention, too, that the National Advisory Committee report, there is a link to that on the webinar page on the RHI Hub website, so you can access that report there. It is a good read and really reinforces what all we've heard today. With that, we will wait to see if we get any questions.

Grace Anne, I really enjoyed your point about how this affects real people, and we need to think of it in that personal manner. I think for a lot of people on the webinar today, they can really connect with that, and for a lot of us, we know somebody who has dealt with COPD in a rural area, so thank you for that point. I think it's very important to not have this be an abstract issue.

Here's one question. "My father had COPD and had several pneumonias. He received a high flow device in the home, and pneumonias went down. Has high flow in the home been looked at from a policy angle?" Is anyone aware of that?

Tony: Oxygen is clearly one of the issues here in terms of access to oxygen in rural environment, and clearly that is a problem, and it is even more exacerbated for distances, availability and so on. In terms of oxygen helping, yes, we know that oxygen helps patients to survive, to have a better life, especially those that are at the lower limit of their lung function. We actually recently asked the same question for people that were intermediate in their lung function, and we found that that didn't make any difference, and so it's important that the use of oxygen and the flow of oxygen be tested and individualized for each patient.

Kristine: Thank you. This looks like it's maybe more of a comment, and this says, "I just wanted to comment that this is a wonderful and needed presentation. I hope that the National Advisory Committee incorporates patients into its membership. Patient centricity is so important." All right. Another question says, "55.90 is the outpatient prospective payment system charge, but $28 and $14 are the physician fee schedule charges. This is a killer of FQHC programs, so the OPPS is the hospital, and the PFS is the physician office. Can you explain the facility and non-facility charges of the PFS?"

Kathleen: The facility charge, what the outpatient PPS does is covers the actual clinic and all of the other costs associated with it. The physician charge is on top of it, so if you have a nurse practitioner functioning as a professional, the nurse practitioner would get the nurse practitioner equivalent from the physician charge, but everything else, including the respiratory therapist and all the others and the education, those, I believe would be included all in the 56, 55.90, whatever it is, rate.

Both of those are quite low. They're really very ... You can't do anything that could add up to 55 or $56 in cost that takes an hour in any sort of organized clinic environment. I'm thinking that critical access hospitals would be a bit different. That's a facility where ... I'm assuming if they operated one, it would come under cost-based reimbursement like the rest of their outpatient services, but any other hospital is under the outpatient prospective payment rates. Anyway, the differences between facility and non-facility is simply that the physician gets a professional fee, and then all of the other costs are, in theory, reimbursed to the hospital.

Grace Anne: Kathleen, if you can hear me, it's Grace Anne. The problem, and Dr. Doyle is the one who posed this question, and he is the medical director of the Cabin Creek Grace Anne Dorney Pulmonary Rehab Clinic. It is a fact that pulmonary rehabilitation, and it's addressed, of course, in the policy paper that you've drafted, is reimbursed at approximately half the rate of cardiac rehabilitation, whereas the length of the service and the essentials of the service are almost identical. This is a disparity that has to be addressed, because in order to sustain and create the much-needed pulmonary rehabilitation clinic. We need higher reimbursement, so these clinics, outpatient hospitals, as well as FQHCs operate in the red in order to bring this service to their patients, and we need desperately to do something about this. That's why your policy recommendation number two is so important.

Kathleen: Yeah, I agree with you. I do think it's far too low. I do remember several years back, when the cardiac rehab rates were raised, and people got together and fussed at CMS about it, and fussed over the data, and insisted on it, and I think there's probably nothing else you can do here but the same. We need people willing to make enough trouble for CMS for them to go back and relook at the data. It is hard. I'm not blaming them in the sense that I think there is probably a difficulty with the data from the cross-reports, and it needs someone to analyze what's wrong with that data and convince CMS to make some sort of changes, so that they can get a better understanding of it. I think in our recommendation, we address that briefly and we address also the problem of not having a good handle on the mix of services, so they don't even know what to cost out from a cost report, but it does take fussing. It does take being willing to be a squeaky wheel.

Kristine: Thank you. Another question is, "Given the magnitude of the issue, why is there no policy or so little policy on the federal level to deal with the problem?"

Grace Anne: This is Grace Anne, and I have thoughts. I have thoughts. I believe that our voice has not been loud enough, that we have not, despite our huge numbers, been vocal enough in reaching out to our legislators and to our policy makers, and I think that the community must come together. That's what this National Action Plan is all about, and it will take all of us. To borrow from NIH, it will take all of us to make that happen, but we cannot tolerate this situation any longer. I think it's time for action.

Kristine: Another question. "The increase by state is quite dramatic. Alabama had the 27th highest mortality rate due to chronic lower respiratory disease in 2000, among all of the states. In 2016, we had the 7th highest. The greatest increase was 94% among rural females. Do we have ideas of why there's such an increase in rural females?"

Tony: I think that's actually twofold. One is I think there's more awareness about the disease. Traditionally, COPD was thought of as a men's disease and doctors were dismissing the idea that women could have it, so I think there's more awareness among the providers, and so there's

more questioning about that. The other one is that the peak of smoking, cigarette smoking, I'm talking about here, traditional tobacco combustion, has a gap of about 20 to 30 years between men and women, and that was, if you want, in the 50s and in the 70s, and so we are now paying.

The disease takes 30, 40 years to develop. It's a long simmering process, and so we are now seeing the peak in mortality and disease diagnosis in women because of that. Actually, I want to add a third one, even though I said two. The third one is women live more than men, and so there is, if you want, a selection bias in that. You've seen from my slide on mortality that at the 75 above, that there is a big separation between the two lines, between men and women.

Kristine: All right. Thank you. Here's a question. "What are small things that we can do?" It says, "I'm a nurse in rural upstate New York. What is one small thing that our critical access hospital can do to impact a change? We do have pulmonary rehab." So what's one other small thing that they could do to impact change?

Tony: There are many, many small things. One of them is to make sure that the patients are compliant with their COPD medicines, and also that they know how to use them. I always bring up this example. I was at a chest physician conference a couple years ago, and they had a panel, an exhibit of 20 plus different inhalers that are available on the market in North America, and they were asking physicians if they knew how to use them and to explain their patients how to. That's one thing. Many times, not only patients cannot use what is prescribed to them, but even the physicians can't explain. There are guides online, YouTube videos to fix that. The other one is, yes, rehabilitation is great. Smoking cessation is another one, and smoking cessation doesn't work just with replacement. It needs behavioral cognition therapy also, to be a little bit more effective. Those are the two little things that are available, and they're right there.

Kristine: All right. Thank you so much. There was a couple of questions about what state the at home high flow system was used in, and for those of you asking about that, it was rural Alaska. Then another question is whether the webinar slides will be available. Absolutely, they will be. Within a couple of days, we will make those available on the RHI Hub website, and we'll also be sending that archive, both the recording and the transcript out for folks. I think we, at this point, are out of time, so we will wrap things up. Thanks so much for everybody for joining us today. If you do have any questions, you can contact us at ruralhealthinfo.org. A survey will pop up at the end of the webinar today. We do encourage you to fill out that survey so that we can use that feedback in hosting future webinars. Thanks so much to everyone who participated today, both our speakers and our participants. It was really great information today, and we appreciate your time. Thanks again and have a great day.