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Meaningful Lives As We Age

GSA On Aging: GSA Policy Profile Podcast

The Latest in Alzheimer's Disease and Related Dementias Research & Policy

Transcript

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Speaker

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Patricia D'Antonio:
Hello! Thank you for joining this Policy Profiles podcast installment, which will explore the latest research and federal policies around early detection, risk factors, and treatments for people living with Alzheimer's disease and related dementias and their caregivers. This is Trish D'Antonio, Vice President of Policy and Professional Affairs here at the Gerontological Society of America. Joining us for our discussion today is Ian Kremer, who since 2012, has served as the Executive Director of the LEAD Coalition, and that's leaders engaged on Alzheimer's disease.
This organization is the uniting voice of over 260 member and allied organizations, including GSA, along with hundreds of university-based researchers. This coalition works collaboratively through federal public policy to improve quality of life for all people facing dementia, while advancing the social and biomedical sciences to prevent, detect, treat, and ultimately cure all forms of dementia. Currently, Ian serves on the CMS Medicare Evidence Development and Coverage Advisory Committee, the NIH Alzheimer's Disease Related Disorder Summit Subcommittee on multiple etiology dementias Research for Implementation of Discoveries into Practice, GSA's Public Policy and Aging Report Editorial Board, and on steering and advisory committees for eight NIA and CDC supported projects, the Alzheimer's Disease Patient and Caregiver Engagement Initiative, the Foundation for the National Institutes of Health's Alzheimer's Disease, Blood-Based Bio Signature for Predicting Clinical Progression Consortium, the Digital Medicine Society's ADRD Core Digital Clinical Measures Project, and the Dementia Friendly America Initiative. Wow! Ian holds degrees from Washington University in St. Louis and University of Michigan School of Law. Ian has worked on federal, state, and local dementia advocacy for over 28 years, and is a friend and a close colleague to GSA. Ian, I'd like to welcome you to this discussion on a topic that most likely has touched everyone who's listening to our conversation today.

Ian Kremer:
First, thanks for the invitation and opportunity to visit yes, indeed. Good friends with GSA, and you and I go way back and, kudos for being able to get through that unnecessarily long list of things I'm involved in. I'm not a clinician, I'm not a researcher, but a whole bunch of clinicians and researchers have seen their way clear to let me be at the table and try to be a voice for people that have lived experience with these disorders and just bring a little bit of non-expert point of view to the work that they're doing to try to make the world a better place for people at risk for living with dementia. And it's a pleasure always to partner with you and with GSA in this fight.

Patricia:
Well, why don't we jump in? Could you discuss a little bit more about the goals and priorities of the LEAD Coalition and maybe some of the advancements the coalition is seeking to champion in the fields of Alzheimer's disease and related dementia's research and policy?

Ian:
Sure. Happy to do that. So, we're organized as a U.S. Federal Public Policy Coalitions. So, we're trying to protect existing laws and regulations and federally-funded and federally-driven programs, and we're trying to strengthen them along the way and innovate for new ones. Obviously, we're living in very challenging times where the position of the federal government about how to address health and wellbeing of Americans it is undergoing dramatic change. And so, while in all candor, I will say normally we have a much more affirmative kind of set of issues we work on. We are now in a position where we're having to play defense on a lot of issues where I think most of our community would've been able to take those issues for granted. In the past, it was always about building a stronger NIH. Now we're trying to defend what's left of an NIH that is being actively eroded by the current federal government, and we're going to work with our friends.
We are working with our friends both in the House and the Senate, Republicans and Democrats alike who believe in maintaining and building on the strength of the National Institutes of Health, the Food and Drug

Administration, the Centers for Disease Control and Prevention, making sure that we still have an Administration for Community Living (ACL), that this administration has proposed eliminating. We want to make sure not only that ACL continues to exist, but that it is strengthened and its ability to meet the needs of people all across this country -- that ability is strengthened as well. And I can say that for a variety of other federal agencies and the support that they deserve from the administration and from Congress, we're going to fight for all of them, understanding we're not going to win all of those fights, right? We'll win some in whole, we'll win some in part. And sadly, we're going to lose some of those fights.
But we are going to fight everywhere, every day for the people across this country and indeed around the world who need us to be their voice and their power in Washington for the benefit of everybody who's facing these absolutely atrocious diseases that we put under the umbrella of dementia. So, we're going to fight for federal funding. We're going to fight to protect the civil servants who have dedicated their careers in a selfless way to non, in a nonpartisan way, advancing the interests of the American people. We're going to be in their corner and make sure that members of Congress, Republicans and Democrats alike know that the community of citizens throughout this country support their work to protect these vital public health and science programs.

Patricia:
Well, and Ian, we certainly appreciate the activities of the coalition and bringing us all together to be able to support those efforts. I was wondering, as you know, as we're talking about this, there have been some things in care services and supports for people with Alzheimer's disease and related dementias that we've all worked on. And last year, we saw the bipartisan, bicameral effort to pass what's called the Building Our Largest Dementia (BOLD) infrastructure for Alzheimer's. We commonly refer to it as the BOLD Act. And then Congress also reauthorized the National Alzheimer's Project Act, or as we all, you know, have to have our abbreviations, we refer to as NAPA, which calls for that National Plan for Alzheimer's disease, dementia, and related disorders with input in a public-private way where we have the Advisory Council for Alzheimer's Research Care and Services. So, I was just wondering for our listeners, could you talk a little bit about the significance of the BOLD Act and activities there, as well as the National Alzheimer's Project Act, the significance of this, the policy provisions, and maybe what we seek to achieve through those?

Ian:
Sure. Great questions, and I'll, if it's all right, I'll throw a third reauthorization in. That was also really, really important from the last Congress, again, unanimous bipartisan support. And that was reauthorizing. Something that in layman's terms is called a Bypass Budget Provision, where Congress -- by law -- has ordered the National Institutes of Health every year to put out a scientific report, updating the Congress and the country on progress in fighting Alzheimer's disease, social science, as well as biomedical science, and to project for the next fiscal year ahead of Congress in its process, how much money would be needed from Congress for NIH to continue pursuing the science around the goals of the National Alzheimer's Project. Now both NAPA and this so-called bypass law were reauthorized for an additional 10 years through 2035. So, let's, let's take these in order, BOLD, then NAPA, then Bypass Budget.
The BOLD Act, as you said, it's about public health, it's primary, secondary, and tertiary levels of prevention. We're trying to reduce risk. We're trying to do a better job detecting and diagnosing, identifying individuals who are facing cognitive impairment, and we're trying to better serve them and the people in their ecosystem, both paid and unpaid care partners for people living with Alzheimer's Disease and related disorders. BOLD does a lot of things. But more than anything else, I think the most important thing it does is focus the nation's energy and attention and some resources, some congressionally appropriated resources on fighting all three of those levels of public health to try to reduce what in the scientific lingo we call the burden of Alzheimer's disease and related disorders. Burden is obviously a very loaded word in plain speaking. And, not everything

should be viewed through the prism of loss and pain, though there is more than enough loss and pain to go around in Alzheimer's disease and other forms of dementia.
We want to remember people can have a very high quality of life if they are well supported, and the diseases erode that quality of life over the course of years or decades, not over the course of minutes, hours, days, or weeks. So, we want to do everything we can in a proactive way to support and maintain quality of life as much as possible for as long as possible. And that takes a strong, unified public health commitment, along with the partnerships of state and local public health departments throughout the country. And BOLD creates an infrastructure to help us do that. We can't do it without BOLD and BOLD is not the be all and end all. But among other things, the BOLD Act provides, at this point, I believe, don't hold me to this, I apologize. I think about $30 million a year through the Centers for Disease Control and Prevention to fund three Public Health Centers of Excellence that are located at specific institutions but are meant to serve the entire public health community with expert evidence-based guidance on how to promote public health.
One of the Public Health Centers of Excellence led by the Alzheimer's Association is on risk reduction and public health strategies to reduce the number of people with Alzheimer's and related disorders, and to forestall when the people who get it actually develop symptoms. The second led by the University of Minnesota is a Public Health Center of Excellence around caregiving. So, to improve the quality of caregiving and to reduce, again, here's that word, I hate -- the burden of caregiving. There are people, and I will say in my own experience as a care partner for my dad, people who find tremendous meaning and purpose, and sometimes a measure of joy in being able to give care to someone that they love. I got to give back to my dad a bit over five years of what he had given me in the previous 50 years of my life. So that was a joy and a privilege, even as we together went through a very painful experience. We want to make sure that people who are giving care and offering support are as equipped as possible to do it well for the person they are giving that care to, and to sustain their own wellbeing as much as possible in very different difficult circumstances.
And then the third Public Health Center of Excellence led by New York University, but again, serving the entire country is a Center of Excellence on detection and diagnosis of cognitive impairment, in this case, Alzheimer's disease and related disorders. So that we do a better job of identifying people who may be experiencing these symptoms, figure out what is causing their symptoms, and then move them into a stage of clinical care and support where we do what we can do for them. If it's not actually dementia, figure that out and treat what they do have, if it is Alzheimer's disease or another disease that causes dementia, provide both clinical and nonclinical supports to those individuals. And then there are a series of smaller grants that are going to individual state or local public health departments and other organizations and forgive me, I don't remember, maybe GSA included to sustain that, those other sort of experiments in advancing public health around Alzheimer's disease and related disorders.

Patricia:
Right. GSA is involved with each of the Centers. Got it. And so, GSA members are part of steering committees and part of executive committees. And then even GSA staff have been invited to be part of the executive committees of some of these the BOLD Centers. So certainly it's a pretty big endeavor that we're happy to be participating in and happy to be contributing.

Ian:
NAPA was passed about 12 years ago for the first time or came into legal functioning within the federal government about a dozen years ago, and it got reauthorized last year. So, we've got at least 10 more years working with it. NAPA, as you said, sets up this Federal Advisory Council. About half the members of the Advisory Council are from federal agencies with expertise in various aspects of addressing Alzheimer's and related disorders. So, National Institutes of Health and Centers for Disease Control and a variety of other federal agencies have a representative on this council to bring their expert perspective to the work. But there

are an equal number of non-federal members, people like you and me, and folks living with Alzheimer's, people who have been caregivers or are caregivers, people who run nonprofit or for-profit services, providing agencies at a community level, and people from the state and local public health departments, and others who come together to try to give advice--no mandates, no dictates -- just advice to the federal government, principally to the Secretary of Health and Human Services on an annual basis, what should be the National Plan to address all things dementia.

And that includes risk reduction, detection and diagnosis, caregiving, clinical, and nonclinical supports everything under the sun that the federal government and its public and private partners might do to be part of this fight and to make the world a better place. So, the National Plan has six goals, and this is all available online. And, and perhaps toward the end of the podcast, we can share the URL for where they can find that full annual report and its updates. But, the Advisory Council just advises. They have no power, no authority, but they have a lot of wisdom, a lot of experience, and a lot of expertise with experience, as well as professional accredited kind of experience. And it's all to inform the judgements of the Secretary of Health and Human Services about what should and maybe shouldn't ultimately be in that annual plan for how the country's going to do better in tackling Alzheimer's and related disorders.

And, and when I continually refer to the related disorders by statute established by Congress, the related disorders that this plan focuses on, in addition to Alzheimer's disease, specifically, it's frontotemporal degeneration, Lewy body and mixed dementia, which is an umbrella that includes any combination of causes of dementia, but principally under that mixed dementia, you would be looking at things like vascular dementia, like people that have had a bunch of mini strokes or big strokes may develop cognitive impairment that that can manifest ultimately in dementia. So, that would be covered there too. There are literally a hundred things that can cause dementia, but principally it's those four big buckets, Alzheimer's, FTD, LBD, and then this category of mixed dimensions. That's the focus under law of the National Alzheimer's Plan, the work of the advisory council. And then that annual plan literally has hundreds of things that the federal government, state governments, local governments, and non-government actors can and should try to do to address the myriad of challenges of Alzheimer's disease and these related forms of dementia.

And then the third piece is this Bypass Budget, which is NIH spending literally about 11 months a year developing a set of recommendations along with cost estimates for what it would encourage Congress to consider investing through the annual appropriations process to continue the scientific part of the journey of meeting the obligations of the National Alzheimer's Plan. So that includes, again, and I'll stop after this, that includes both biomedical and social sciences. So part of what has come of the National Alzheimer's Project Act, and part of what helps us make the scientific judgements about where to invest and how much to invest in biomedical and social science, is that NIH now every year holds a summit, a scientific research summit, focused on Alzheimer's disease and or the related dementias. In year one of the every third year cycle, it's a focus on Alzheimer's disease.

Year two is a focus on the related dementias, including mixed dementia, which of course sometimes means Alzheimer's and FTD or Alzheimer's and vascular dementia, et cetera. And then the third year, I'm particularly proud of this one because we don't pat ourselves on the back, a lot of the LEAD Coalition, but we'll pat ourselves on the back for this one, the LEAD Coalition spent a great deal of advocacy energy in the mid-2000s, persuading the federal government to have that third summit be devoted to dementia care and services research. The Care Research Summits were 2017, 2020, 2023, and the next one will be in 2026.

Patricia:

There you go.

Ian:
The Summit that's coming up at the end of April 2025, which is virtual only for logistical reasons, that summit is on the related dementias. So, Alzheimer's Plus, or in the absence of Alzheimer's, any other combination of dementias or the standalone FTD or LVD.

Patricia:
There was a lot packed into that response there. And before I go on, I just wanted to, you talk about a National Plan. So, can you tell me when we talk about a National Plan, or we talk about federal plan, like the importance of this being a National Plan for Alzheimer's?

Ian:
Yeah, thank you. That's a terrific question. So, there was a very conscious decision made by Congress with the support of the advocacy community that this should not be a federal plan. None of us believe that all the solutions are held solely in the domain of the U.S. federal government. The U.S. federal government is an essential, indispensable player in getting us to a world ultimately without dementia. But, in the meantime, a much better world for people who are facing dementia and along the way, to have fewer people face dementia, we need the full power of the federal government to be as effective as we need to be. But the federal government will never be able to do this alone. It takes all of us in this fight on behalf of all of us. And that's whether we're talking about a social safety net, whether we're talking about advances in biomedical science, whether we're talking about public health or just simply caring better and more for each other, that has to involve other levels of government.
And, as important, it has to involve non-governmental actors that can be each of us as individuals taking on responsibility for what is within our reach and our capacity, and what our heart motivates us to do -- trying to be better to those around us and look out for each other. But that also involves the private sector, both nonprofit and for-profit. We need industry, drug discovery, device discovery, clinical providers, clinical care providers, social service providers, nonprofit organizations, others, to all step up where they can and to do it in as coordinated and efficient a way as possible. And, you know, for all the good things in terms of biomedical innovation that the pharmaceutical industry and the biotech industries are capable of doing, they'll be the first to tell you that very little in the way of innovation starts and ends in their own private laboratories.
So, much of it starts with, just to go back to this example, the National Institutes of Health, doing basic research that then creates opportunities for the ball to be carried forward by private industry. NIH should not be doing drug discovery soup to nuts. That's not their responsibility, and it's not their skillset. Industry is really not in a position to do the basic biomedical research that sets the foundation, but they are in a position to carry it forward, to make the enormous private investments in trying to take basic discovery in through the process and translate it into meaningful medical products and services for human use, and then marketing that and taking the marketplace risks of having done it. So that's an example, but it's certainly not the only example of where we need the public and the private sectors to work collaboratively and in a coordinated way, but understanding their distinct roles in the process.

Patricia:
Well, that leads me to so much of the work of our GSA members who are conducting this research all the way from the basic biology through the practical application and biomedical research and health and also the behavioral and social science issues that we need to think about as we are considering all that we need to do around Alzheimer's and related dementias. It makes me want to just share a little bit again about GSA's activities, our interest groups that that really inform some of this work. And the KAER Toolkit, the KAER Framework for Brain Health that I know you were involved from our very start. You know, we developed that early on. It was probably like 2013, 2014, 2015.

And for those of you who are listening who aren't familiar, when I reference KAER, it's KAER because it's how we kickstart the conversations -- kickstart the conversation in primary care that we think about early detection, how do we think about that? And then A is assess for cognitive impairment, E for evaluate for dementia, and then the R, which I think is so important, because it's the piece that we all need to understand is referral. And that's not only to other healthcare practitioners, it's also to the community resources that are available and that we all need to support us as people with dementia, as well as people who are caring for loved ones and, recognizing those services and supports. And how often are we finding that in our own communities? People are knocking on the door saying, don't you work, you work in aging? Can you help me with this? And, quite often making references for how you can learn more about the community resources for us all. And for our listeners, we'll have links in the show notes to our KAER Framework, our KAER Brain Healthcare toolkit, and that's at KAERBrain.org. But we'll have links in the show notes for you.
You know, Ian, I'm just thinking about this when we're talking about federal policies regarding treatment and risk reduction, which is newer when we talk about risk reduction for Alzheimer's disease and related disorders, do you see any more discussion around that this year being introduced or are there other policies that LEAD Coalition's advocating for that you want to raise today?

Ian:
Yeah, so, you know, I started out by saying we're a federal policy coalition, but, I should maybe round out by saying, I don't love silos and working in narrow lens and to do federal public policy, you have to pay attention to and care about a lot of things that others might not see through a policy lens. I can, you know, it's a little like six degrees of Kevin Bacon, that game that we all have played in under one name or another, I can connect anything to being about federal public policy. I just don't need other people to see it through the same prism I do. So, if something like risk reduction is seen by clinicians as not being about public policy at all, that's fine. If it's seen by the members of the general public who we want to engage in risk reduction, relevant personal choices and activities, they don't need to see that through public policy.
It's OK if I do, they don't need to. So, I will give you a couple of practical examples. And again, I'll tie this back to policy, but it's fine if others don't. NIH funded a tremendous amount of absolutely world-class scientific research to figure out ultimately that aggressive management of hypertension was proven to reduce risk, not eliminate the potential, but reduce risk for individuals who had serious hypertension reduce their risk of developing dementia. So, it's not a lock-solid guarantee that if you have hypertension and it's aggressively managed, you absolutely will never under any circumstances get Alzheimer's. That's not the promise we're making. What we're saying is, your chances of getting dementia are much, much lower. If one of your primary drivers is hypertension, and we can get it under control, we can give you a better chance, a significantly better chance, of not developing dementia that took investments over decades by Congress in a bipartisan way in supporting basic science research at NIH and working with the private sector clinicians, patients, others, to develop the evidence and prove whether it was true or untrue. Thankfully, it turned out to be true. So now public health advocates, doctors, patients, others can use that advice to make America healthier. That's good. We're on the cusp of findings probably this summer from another major set of studies that will give us more information about what does, or hopefully this is not going to be the case, what might not work to reduce risk around other lifestyle interventions.
So, there's a huge multinational study with a major U.S. sub study coming out this summer. It's called U.S. POINTER Study. And I apologize -- as much as I love acronyms -- I can't remember what all the letters in U.S. POINTER stands for, but what that's testing is certain dietary and exercise modifications to one's own lifestyle and what that can do, hopefully, to reduce risk for dementia. We'll find out this summer if the evidence is strong for prevention or if it turns out it's weaker than we suspect, but I think it's going to be a positive study. And if it is, then we'll be able to go directly to doctors' and their teams and have them go directly to their patients and say, "I'm telling you to eat healthier, exercise more, et cetera, et cetera. Not just because it's good for your waistline, not just because it's good for your heart, but because it's also good for your head." And

wouldn't that be another powerful tool driven by NIH investments in science and driven by private sector investments in science, all credits referenced at the Alzheimer's Association, who have also invested private charitable dollars in the science to partner with the NIH in advancing us to a point of scientific discovery where we'll get those answers. What diet, what exercise does? Make what degree of difference in dementia risk? We need to be able to quantify that for all Americans, not just some Americans. So, it's really important, I'll end on this note, really important that science is being done in an inclusive and representative way so that we get science for all, not just science for some.

Patricia:
You know, you raise a great point and we'll put a link to the POINTER Study for our listeners in the show notes. And when you think about that, you and I think alike in the policy realm here. And my family and friends joke that it usually only takes me 10 minutes in a conversation before I say, "You know, here's a policy thing about that." As you're talking about this, and I'm like, I know you're already thinking about it, it's like, okay, so then what other policy in nutrition and in just for states and for public health departments in cities and counties and what we would want to be sure is available for all as far as nutrition, and then education. And there's just a whole bunch of things that start to keep in mind which are so important to recognize that interrelationship of the importance of how research translates into practice and policy and our goal is for evidence to inform those practice and policies that are developed. So, that's such a great point, and I really, I appreciate you for bringing that up.

Ian:
Can I just make a quick point on the, on the public health implications of, of this particular study as an example of that broader point policy? Let me reiterate. You know, we all have our political points of view, but in the fight against Alzheimer's, we should all be non-partisan and apolitical -- the right thing to do is the right thing to do. And so, there are people that we may oppose on 10 issues and support on 10 issues, and it's the individual elected official or government official, and that's fine. And, so let me be clear, the Alzheimer's community is going to have beef with Secretary Kennedy on a lot of things that he is doing at HHS, but if Secretary Kennedy can take evidence from things like the POER trial or the study a few years ago that gave us the conclusive evidence about aggressive management of hypertension. If he can do things to aid average, everyday citizens across this country in addressing hypertension, diabetes, smoking cessation, food desserts, avoiding excessive intake of sugar, et cetera, we will be his greatest champion on those things. We have no permanent friends and no permanent enemies. We don't have enemies in this fight. We only have current allies and potential greater allies, and we want Secretary Kennedy to be arm in arm with us in fighting Alzheimer's disease in every evidence-based way we can for all people in this country. Again, not for an elite few who can afford whatever the latest and greatest may be, but a strong, robust public health system where all of us have access to the best information and the best tools to protect ourselves against dementia. And then if God forbid, we develop dementia to have the best quality of life with the best support for ourselves and all the people in our ecosystem who help us preserve our quality of life as much as possible, and I think Secretary Kennedy could be a tremendous friend to our community on many of these fights. That said, I'll reiterate again where he's wrong on things. We'll go to him and say, "We disagree with you respectfully, and here's why, and here's the evidence, and here's what we'd like you to do about it."

Patricia:
Right, right. You know, I think that we'll invite you back for another discussion around the three Ps, the policy, the politics, and the process, right? You know people will say, :Well, how are you working with this member of congress or this department or this agency?" And it's like we work with the people that are going to help us advance the evidence to improve practice and policy. And, sometimes there are issues that we will agree on, and sometimes there are issues that we will not agree on, and we will make sure that we stand by the science,

right? That's what our work at GSA is. And I know our work and our coalitions, like the LEAD Coalition, evidence shows this is how we move forward. So, we so appreciate that. Thinking about the politics and thinking about the process that needs to inform all of this is also very important for us all to ultimately benefit our goal here in ending Alzheimer's disease and related dementias. I mean, that ultimate goal that we all seek.

I was wondering, is there any other anything else that you wanted to add? Because, gosh, I just looked at the clock and realized that our time has really flown by here in this discussion. But was there anything else that you wanted to add today, Ian, related to work of the LEAD Coalition?

Ian:

I thank you for that, Trish. I think the challenge of our time today both in this conversation and just the times we all live in is that there are so many worthwhile fights for us all to engage in, to make the world a better, stronger, more unified place in the fight against dementia and beyond that, and there literally aren't enough minutes or hours in the day to speak to all of them or to do all we wish we could on all of them. There are a lot of issues you and I have not touched on today that are critically important to the dementia community. And, it's on me that I didn't get around to mentioning them. So, I'll just mention one in passing. Now, you know, we didn't talk about Medicaid, which is enormously important to our community, and roughly 20 to 25% of people with Alzheimer's disease are on and depend on Medicaid. So, if Medicaid gets cut or weakened, that is enormously damaging and unnecessarily damaging to people who live with dementia and all of us who care about people with dementia. But you know, you and I didn't find time in this conversation to really delve into all the details about that. I promise you there are 50, maybe 100, maybe 1,000 other issues we could have spent time on today. It doesn't mean we don't care, and it doesn't mean we aren't working on it. What it means is that, and, you know, this is the spirit of coalition, whether formal or informal. We all do our part and then aggregate that effort and it comes together to make the world a better place. We can't all do everything, but we do what we can within our power, and we try to support those who are maybe taking the lead where we're taking more of a supportive role.

So, if there's a coalition out there that is working really hard on cancer issues, let's support it as a dementia community. Let's support that cancer community, because you know what? People with dementia get cancer and caregivers for people with dementia get cancer. And if there's a community out there advocating for, let's say for the support of Older Americans Act programs, well, a whole lot of those Older American Act programs support people with Alzheimer's and their care partners. But, even the Older Americans Act programs that are not directly about dementia, they're for the greater good of the community in which people with dementia live and function. So, we need to strengthen everything and not tear down anything. And we can do that together, and we can do it if we give each other some extra grace during difficult times. And if we lend our support to those who are leading, rather than competing over who gets to lead or blaming those who don't raise their hand to lead, it's okay to join even when you're not in a position to lead.

The key is to not sit on our hands and give up. And in advocacy, we don't believe in giving up and in caregiving, we don't believe in giving up. And for those who I know who have faced living with dementia first-person, they don't give up either. They struggle, they struggle mightily, and ultimately they succumb to the disease, but they don't give up. So, none of us get to give up. We do this together, we do it as best we can, and, and we fight as long as we're capable of fighting for the greater good.

Patricia:

I don't even know what to say next to that. Because that felt like the right way to wrap up today.

Ian:

I'll take an amen.

Patricia:
I was going to say amen, but, I didn't know how that would be received, but certainly amen to that. And, I think I heard a couple things. One, an invitation for you to come back so that we could have some continued discussion around some of the policy as the year progresses. Because I think that there's certainly some things that we could. And, you know, you and I always have opportunity to be in rooms together with other colleagues, and we could start to think about some other things. What I would say for our listeners is here's an invitation. If you have some ideas about some of the topics we should be covering as part of this Policy Series, these series of podcasts, let us know. Reach out to us at profaff@geron.org. And, if you have questions for Ian we can get those to him as well. If you reach out to us there or if you just did a Google search on LEAD Coalition, Alzheimer's disease, I know you'll find all the great information that he has there.
I want to thank you for joining us today. It's important that we continue to raise these issues for all of our members and for all of our listeners. So, I want to thank you all for joining us today for this edition of the Policy Profiles Podcast.
Follow GSA's latest advocacy activities at geron.org/advocacy, and on GSA Enrich for more of our podcasts. Have a great day.

Show Notes:

- BOLD Act
- NAPA
- By Pass Budget
- NAPA Annual Reports
- KAER Toolkit and GSA Resources
- U.S. Pointer Study
- ADRD Summit 2025