

NYU BOLD PARTNER SPOTLIGHT:



Please include a brief bio here.

Ian N. Kremer, JD, has worked on federal, state, and local dementia policy since 1996. Since 2012, Kremer has served as Executive Director of the LEAD Coalition (Leaders Engaged on Alzheimer's Disease: <http://www.leadcoalition.org>), the uniting voice of over 200 member and allied organizations. The LEAD Coalition accelerates transformational progress in care and support to enrich the quality of life of those with dementia and their caregivers, detection and diagnosis, and research leading to prevention, effective treatment, and cures. The LEAD Coalition has helped to secure historic funding increases for the National Institutes of Health (NIH), expand Medicare services for people with dementia, protect dementia-relevant components of Medicaid and the Patient Protection and Affordable Care Act, expand the role of people with dementia and their care partners in medical product development, build a nationwide network of dementia-friendly communities, and worked with a dozen federal agencies to overcome health disparities, clarify regulatory pathways, combat elder abuse, and improve cognitive impairment detection and diagnosis, clinical care, and access to home and community-based services.

Kremer serves on the Centers for Medicare and Medicaid Services (CMS) Medicare Evidence Development & Coverage Advisory Committee (MEDCAC) and served on the steering committees for the NIH's 2017 and 2020 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers. He also serves on the CDC Healthy Brain Initiative's (HBI) Leadership Committee (co-chairing the cross-sector linkages workgroup) that is developing the 2023-2027 Public Health Roadmap, the Food & Drug Administration (FDA) Prescription Drug User Fee Act (PDUFA VII) Stakeholders Working Group, the Public Policy & Aging Report editorial board, and on steering and advisory committees for the National Institute on Aging (NIA) IMbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory, the CDC-funded NYU School of Medicine BOLD Public Health Center of Excellence on Early Detection of Dementia and University of Minnesota Public Health Center of Excellence on Dementia Caregiving, the CDC National Healthy Brain Initiative Tribal Project (American Indian and Alaska Native Resource Center for Brain Health), the NIA-funded Hopkins' Economics of Alzheimer's Disease and Services (HEADS) Center and the WeCareAdvisor Study, the UCLA Dementia Care Study, the Alzheimer's Disease Patient and Caregiver Engagement (AD PACE)

initiative, the Dementia Friendly America initiative, the Davos Alzheimer’s Collaborative Champion’s Cabinet, the Brain Health Partnership, the Alzheimer’s Disease Partnership for Evidence and Value (AD EVAL), Dementia Alliance International and the Adira Foundation board of directors. Kremer was an external reviewer for the 2021 National Academies of Science, Engineering, and Medicine report, “Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward.” Previously, Kremer has served on steering and advisory committees for a wide variety of organizations and projects including the International Collaboration for Real-World Evidence in Alzheimer’s Disease in the US (ICARE-AD-US) Study, the CDC Healthy Brain Initiative Roadmap (2018-2023 edition), the FDA PDUFA VI Stakeholders Working Group, the Gerontological Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, and the PCORI Dementia Research Methods project. Kremer holds degrees from Washington University in Saint Louis and the University of Michigan School of Law.

Please start by telling everyone a little bit about the work that you’re doing.

While our coalition is organized around promoting federal public policy to make life better for people facing dementia while advancing the science to end dementia, we have a strong and interwoven emphasis on building collaborative relationships among stakeholder organizations outside of purely federal policy projects. Those relationships advance the mission-focused priorities of each participating organization and build their capacity to effect federal policy results.

What’s the story behind why you’re doing what you’re doing?

The Hebrew “Tikkun Olam” translates roughly to “repair of the world.” I believe all people have a duty to make the world more just, peaceful, inclusive, and equitable. We may do so at an individual level, community level, national level, or global level. We do so through kindness and empathy, care and support, education, charity, political action, or by other means. What we cannot perfect, we can improve. What we cannot complete, we can begin. What we cannot do alone, we can do together.

Tell us about some parts of your projects that you’re working on now that you are really excited about.

I cannot elevate one project over another. It all matters, it all is interconnected.

For people who want to know more about your current work and programs, what are 1-2 pieces of information that you think is important for them to know?

Nothing happens in a vacuum, so parsing credit or blame among stakeholder organizations (governmental and non-governmental) doesn't help anyone who is facing dementia. We should celebrate all successes and learn from all failures, no matter their sources.

What would you tell someone who wanted to start a similar program like yours in their own setting (e.g., another state, county, or city)?

Real coalitions are non-hierarchical. No one organization "owns" the coalition. If the priorities genuinely are shared, the decision-making genuinely will be shared, the work genuinely will be shared, the results genuinely will be shared, and no one will need to claim or disavow responsibility.

Where else can people look to find out more about all the great work that you're doing?

<http://www.leadcoalition.org>
https://twitter.com/LEAD_Coalition

What is one thing that you wish people knew more about early detection of dementia?

No one wants to have dementia, no one wants to hear that they (or a loved one) have dementia. But if detection and diagnosis are done in a Timely, Accurate, Compassionate, and Actionable (TACA) way, then most people will be glad they learned the truth about what health condition they do have (and, by extension, what health condition they do not have) and what they can do to maximize their quality of life and – through research participation – the lives of people who may face dementia in the future.

Thank you so much for your time and for all the great work that you do!