

THE 2ND SYNDEMIC ROUNDTABLE:

Opioids & Viral Hepatitis Post Meeting Report

PO Box 1748 Oregon City, OR 97045 503-632-9032 www.CaringAmbassadors.org



2nd Syndemic Roundtable Post Meeting Report

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Syndemic: According to the CDC, a syndemic means synergistically interacting epidemics.

Executive Summary

The Caring Ambassadors Program began the Syndemic Roundtable in the summer of 2017 and has since engaged 54 diverse and interdisciplinary providers in addressing the infectious disease consequences of the opioid epidemic. The Syndemic Roundtable was developed in response to the minimal opportunities that exist to convene diverse groups of people to address a common cause, develop a message, and exercise their right to speak with lawmakers in responsive and innovative ways. Herein lies the value of a syndemic approach and the power of bringing people together who otherwise may not be seated around the same table.

The first Syndemic Roundtable, held in December 2017, was motivated by the book *Dreamland*, by Sam Quinones, which provided us with a clearer understanding of the tangled and intricately woven components of addiction, infectious diseases, health care and policy in America. Aims of the first Roundtable were 1) to convene complimentary key players in the addiction, public health, and viral hepatitis fields to discuss findings in *Dreamland*, and 2) to craft meaningful and compelling messages around the syndemic for media, policy makers and communities.

The momentum built from the first Roundtable informed the development of the second Roundtable. Leveraging the political will and social climate created by the opioid crisis, the second Roundtable (the topic of this report) aimed to address the syndemic through the lens of policy making and advocacy. The objectives of this Roundtable focused on advocacy, skill and knowledge-building among the participants and raising awareness of the syndemic among federal policy makers. The three-day event produced numerous collaborations and partnerships, action items, and new or renewed commitments to combat the infectious disease consequences of the opioid epidemic from a syndemic approach. Most importantly, the second Syndemic Roundtable produced advocates, by giving a voice and a platform to key players in a Syndemic that

has plagued both a generation and a country. Takeaway messages from this event were numerous, and included:

- Individual story development, and most importantly, story sharing, is a crucial component of effective advocacy. For it is through this sharing that attitudes change, dynamics shift, and relationships form.
- Our government's siloed and individualized departmental approach to public health issues will likely not change, and even though many governmental departments (HHS, CDC, VA, DOJ) have individual plans to address the opioid epidemic, our approach needs to be interdisciplinary, inclusive, informed and synergistically interacting through, not within, departments.
- Healthcare data exists, and while much of it siloed in health departments, diagnostic companies, or the government, it is vital to de-monopolize access to accurate healthcare data for true responsive and effective syndemic programming.

Through a syndemic approach, we can quell the unintended and synergistically interacting consequences of the opioid epidemic and provide platforms for interdisciplinary collaboration amongst diverse stakeholders.

Introduction

The Caring Ambassadors Hepatitis C Program convened their second Syndemic Roundtable meeting in Washington, DC from May 16 -19, 2018. The meeting was held in response to suggestions made during the first Syndemic Roundtable meeting, held in December 2017 (access 1st meeting report <u>HERE</u>), to focus on educating key policy makers. The meeting and accommodations were held at The Darcy Hotel. Forty cross-cutting and interdisciplinary participants took part in the 2.5-day meeting.

Meeting Objectives

The objectives of the second Syndemic Roundtable were to:

1. Use the first roundtable meeting in December 2017 as a platform for the second roundtable meeting to reconvene approximately 30 vital key

players in the addiction, public health, and viral hepatitis fields to engage elected Federal officials in Washington, DC.

- Educate elected officials on HCV's impact and toll, the HCV/opioid syndemic, and how addressing HCV through policy can help combat the opioid epidemic.
- 3. Identify key policies and legislation that have the greatest potential to effectively combat the opioid epidemic and resulting HCV/opioid syndemic

Attendees

Name/City, State of Residence	Position/Company		
Christopher Abert, Bloomington, IN	Founder & Director, Indiana Recovery Alliance		
Sara Alese, Knoxville, TN	HCV Prevention Coordinator, Project ACT		
Brian Barsotti, Grayslake, IL	Teacher and Founder, United Students, LLC		
Dan Bigg, Chicago, IL	Director, Chicago Recovery Alliance		
Tina Broder, Oakland, CA	Interim Executive Director, NVHR		
Jim Carey, Washington, DC	US Policy Lead, Merck		
Lindy Clapp, Corryton, TN	Team Lead, Ridgeview Behavioral Health		
Corinna Dan, Washington, DC	Viral Hepatitis Policy Advisor, Health and Human		
Aires Durchis, Dancha Canta	Services		
Aimee Dunkle, Rancho Santa Margarita, CA	Founder and Director, Solace Foundation		
Garrett Eberhardt, Washington, DC	Manager of Policy & Legislative Affairs, NASTAD		
Donna Ferrell, Lexington, KY	Patient Advocate		
Kaylee Ferrell, Lexington KY	Patient Advocate		
Simone Greene, Alexandria, VA	Policy Associate, Addiction Policy Forum		
Marwan Haddad, New Haven, CT	Medical Director, Community Health Center		
Frank Hood, Silver Springs, MD	HCV Policy Associate, AIDS Institute		
Cindy Langhorne, Lakewood, WA	Lung Cancer Program Director, Caring Ambassadors		
	Program		
Jude Leahy, Portland, OR	Adult Viral Hepatitis Coordinator, Oregon Health		
	Authority		
Melody Libby, North Chicago, IL	Manager, AbbVie		
Robin Lord Smith, Severn, MD	Vice President, Hepatitis C Association		
Robert Lubran, Bethesda, MD	Board of Directors, Stop Stigma Now		

Ronni Marks, New York City, NY	Executive Director, Hepatitis C Mentor and Support		
	Group		
Amanda Marsh, Indianapolis, IN	Patient Advocate, Magnetic Instrumentation		
Carissa McGee, Albuquerque, NM	Training Support Analyst, Project ECHO		
Rachel McLean, Oakland, CA	Chief, Office of Viral Hepatitis Prevention, California		
	Department of Health		
Amber McSpadden, Alexandria, VA	Patient Advocate		
Dan Meloy, Cincinnati, OH	Public Safety Leadership Consultant, CorData		
	Community		
Chris Mohrman, Melbourne Beach,	Policy Analyst, Alliance for Patient Access		
FL			
Kate Moraras, Arlington, VA	Senior Program Director, Hepatitis B Foundation		
Will Mueller, Hamilton, OH	Assistant Fire Chief, Colerain Township		
Rick Pesano, San Juan Capistrano,	Vice President, Quest Diagnostics		
СА			
Lorren Sandt, Beavercreek, OR	Executive Director, Caring Ambassadors Program		
Jason Sterne, Seattle, WA	Chief Operating Officer, Hepatitis Education Project		
Scott Stokes, Clintonville, WI	Section Chief, Wisconsin Department of Health		
Luke Tomsha, LaSalle, IL	Founder, Perfectly Flawed Foundation		
Carolyn Wester, Brentwood, TN	Medical Director, Tennessee Department of Health		
Dante Williams, Chicago, IL	HCV Program Coordinator, Caring Ambassadors		
	Program		
Jill Wolf, Chicago, IL	HCV Program Director, Caring Ambassadors Program		
Sara Zamor, Waukegan, IL	Associate Director of Prevention, Lake County Health		
	Department		
Meg Ziemann, Alexandria, VA	My Journey, My Choices Program Director, Caring		
	Ambassadors		

Event Strategy

Vital to the success of this meeting was the intentional group composition that reflected syndemic stakeholders. We targeted people from the identified stakeholder list developed during the first meeting and included: primary care providers, pharmacists, addiction specialists including MAT providers, pain specialists, patients, the general public, advocates, people who use drugs or are in recovery, law enforcement and those engaged with prisons. About 40 participants attended this meeting and among the group there was wide representation of ages, disciplines and baseline knowledge regarding the

intersection of HCV, opioids, policy and syndemics. We capitalized on a lesson learned from the first roundtable meeting and integrated a pre-conference training component. This provided participants with an opportunity to develop a solid baseline knowledge in preparation for the meeting. The pre-training consisted of four different webinars, each lasting about 30 minutes, and included information on HCV and syndemics, state and federal policy, and the current legislative landscape related to the opioid epidemic and its infectious disease consequences. (Access pre-training webinars <u>HERE</u>)

Similar to the intentional composition of the group was the intention placed on the structure of the event and the speakers and topics that were included. In establishing an agenda, our aims were to: 1) build upon participants' knowledge gained through the pre-meeting webinars, 2) provide opportunities to engage with different departments and partners representing both state and federal government, and 3) prepare participants for visits with their elected officials to discuss the syndemic through the provision of information, tools, and role-playing activities.

Program Agenda & Speakers

Wednesday May 16, 2018

Registration & Welcome Dinner

<u>Thursday May 17, 2018</u>

- Welcome, Introductions and Presentations
 - a. Lorren Sandt and Jill Wolf, Caring Ambassadors Program
 - b. <u>Corinna Dan</u>, Viral Hepatitis Policy Advisor, U.S. Department of Health and Human Services
 - i. Group Discussion: National Viral Hepatitis Action Plan
 - c. <u>Dr. Blythe Ryerson</u>, Associate Director for Science within CDC's Division of Viral Hepatitis, Centers for Disease Control
 - i. Access Dr. Ryerson's slides HERE
 - d. <u>Laura Hanen</u>, Interim Executive Director & Chief of Government Affairs, National Association of County and City Health Officials
 - i. Access Ms. Hanen's slides <u>HERE</u>

- e. <u>Chelsea Kelleher</u>, Senior Policy Analyst, Health Division, National Governors Association
 - i. Access Ms. Kelleher's slides <u>HERE</u>
- > Advocating at the State Level, Story Development & Hill Visit Prep
 - a. Group Discussion
 - b. <u>Carissa McGee</u> Telling your Story
 - i. Access Ms. McGee's slides <u>HERE</u>
 - c. Role Plays and Hill Visit Strategies
 - d. Hill Packet distribution
- > Close Out, Evaluation, Dinner & Evening DC Trolley Tour
- Friday, May 18, 2018
 - Hill Visits
 - a. Access Hill Packet contents HERE
 - Senate Briefing & Luncheon Our Syndemic: The Intersection of Viral Hepatitis & Opioids - A Public Health Crisis Co-Hosted by Senator Merkley

Speakers

- a. <u>Admiral Brett Giroir</u>, Assistant Secretary of Health, Health and Human Services
 - i. Access Dr. Giroir's slides HERE
- b. <u>Dr. Jonathan Mermin</u>, MD, MPH, Director, National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP), Centers for Disease Control
 - i. Access Dr. Mermin's slides HERE
- c. <u>Dr. Carolyn Wester</u>, Medical Director, Section HIV/STD/Viral Hepatitis, Tennessee Department of Health, Nashville TN
 - i. Access Dr. Wester's slides <u>HERE</u>
- d. Kristen Ferrell, Youth Patient Advocate, Lexington, KY

Saturday, May 19, 2018 - National Hepatitis C Testing Day

- Hill visit debrief
- > Quest Diagnostics Presentation
 - a. Ashli Douglas, Senior Director, Federal Government Affairs
- > Where do we go from here?
 - a. 1st Post Meeting Report Review
 - b. Group Discussion on Messaging
 - c. Next Steps, Wrap up

Presenter Key Take-Away Points

Corinna Dan Key Take-Away Points

- The opioid epidemic and the national attention it has gained have provided opportunities for federal agencies outside of the CDC and NIH to address HCV within their jurisdiction: Housing and Urban Development, Department of Justice, Bureau of Prisons, and the Veterans Administration. While many government employees and lawmakers do not have a good understanding of the HCV epidemic and its syndemic relationship to opioids, most realize the need to address HCV among highrisk groups.
- The Medicaid Affinity group is a volunteer-based programs focusing on 9 states that will explore the use of data, policy tools, and practice suggestions to expand access to HCV care and cure. Much of the focus of the 2020 updated Viral Hepatitis Action Plan will focus on creating more platforms for sharing stories, best practices, anecdotal data, and program successes.
- The group discussed insurance coverage for HCV screening, confirmatory testing, and funding/reimbursement for these tests. Those covered with insurance through the ACA would have their confirmatory test covered, if indicated through a positive antibody test. Work is also being conducted with HRSA to disseminate HCV screening and diagnostic information to health centers. Ms. Dan indicated that she would inform the Assistant Secretary of Health that current HCV testing and secondary prevention initiatives are not sufficient, as evidenced by low diagnostic rates.
- Decisions around appropriations are based upon what congress signs into law, and while there is a lack of funding to HCV, there are some options for flexibility of funds. For example, up to 5% of HIV prevention dollars may be used towards viral hepatitis services. Further, states can justify the need for additional funding for viral hepatitis and opioid use services based on their CDC Vulnerable County rankings, which assess HIV and HCV outbreak risk as a result of opioid use.
- There was discussion around ensuring that we pay closer attention to the inclusion of HBV as part of the larger opioid/HCV discussion. However, to accurately portray the impact of syndemics, distinctions must be made when presenting data. For example, HBV rates dropped in 2016, and

therefore it would be inaccurate to say that there is a huge increase in all types of viral hepatitis (HAV, HBV, HCV), because this is untrue. When appropriate, it may be best to show the data you have for both diseases separately to provide context. When available, virus-specific demographic and geographic level data are helpful to most clearly illustrate the syndemic's impact.

 Those who are experiencing access difficulties, lack of transparency or restrictions for HCV treatment within their state may contact the Office of HIV/AIDS and Infectious Disease Policy, Office of the Assistant Secretary for Health, at the Department of Health and Human Services to facilitate communication with federal partners at CMS who may directly contact state Medicaid programs regarding the restrictions.

Blythe Ryerson Key Take-Away Points

- The CDC's opioid response falls under the jurisdiction of 2 offices:
 - Office of Noncommunicable Diseases, Injury & Environmental Health
 - o Office of Infectious Diseases
- Two powerful facts:
 - For the first time since the Flu Pandemic of 1918, we have seen a decrease in life expectancy for three years in a row directly related to increase in overdose
 - There has been a 3.5-fold increase of HCV infection since 2005
- In 2016, there was an increase in HAV and HCV infection among people 18-35 years old. At the same time, there was a decrease in HBV among this group, possibly because this group received the HBV vaccination as children.
- The CDC is focusing on a model HCV elimination program in Hazard, KY
- Determination of Need: This is a process where counties can receive designation as a vulnerable county to increase funding for Health Departments to provide additional services.
- The CDC has identified priority areas in response to the opioid epidemic and infectious disease:
 - Information dissemination: updating and developing guidelines, algorithms, and processes for vaccination and opioid prescribing.

- <u>Building of partnerships</u>: developing partnerships with viral hepatitis communities, corrections and public safety
- <u>Empower Consumers</u>: engage consumers through public education, PSA's and informational tools
- The CDC acknowledges that harm reduction is vital to the prevention of viral hepatitis. A 2015 study identified approximately 270 syringe service programs (SSP) in the United States. Additionally, only about 20% of people aged 18-29 years who are HCV+ live within 10 miles of an SSP.
- There was discussion about perinatal HCV screening because of the increase in HCV among women of childbearing age, and the increase of children born to HCV+ mothers. The CDC has begun the process of developing updated HCV screening guidelines, which is an onerous process like that of the United States Preventive Services Task Force process. Within the guidelines, prenatal screening is expected to be addressed within the context of screening all adults for HCV. This is still under development and research.
- The CDC was asked if there were plans to update the HCV surveillance guidelines, which haven't been updated since 2005. The CDC's current focus is on screening guidelines, but Dr. Ryerson ensured participants that she would deliver the message regarding the need for updated guidelines to the CDC surveillance team. There has been funding to 14 states for enhanced HCV surveillance and some work has been focused on GHOST modeling within laboratories.

Laura Hanen Key Take-Away Points

- NACCHO (the National Association of County and City Health Officials) pays special attention to the needs of local health departments (LHD). The national LHD landscape is illustrated by NACCHO's member profile: 62% of NACCHO members represent small jurisdictions of populations less than 50,000, while just 6% of members represent 51% of the total population served by LHDs nationally, a disparity highlighting the scope and governance of rural vs. urban LHDs.
- LHDs are engaging in various activities to address the opiate crisis: prevention, harm reduction, medication assisted treatment, emergency declarations, and law suits against opioid manufacturers.
- Part of NACCHO's work within syndemics is to help prepare LHDs to set up syringe service programs (SSPs). Inherent in sustaining SSPs is

obtaining community support and maintaining that support over time. Recent shut downs of SSPs demonstrate more than ever the need to maintain community and law enforcement support. NACCHO's additional response to syndemics has included: the development of an Opioid Abuse Working Group; provision of leadership and guidance to LHDs to address infectious disease consequences of the syndemic; increased awareness of the CDC vulnerability assessment; and, the production of opioid-themed newsletters and material.

- The Health Assessment and Health Improvement Plans are tools that identify the most pressing needs in the community and prioritize how to address those needs with the constellation of existing partners. This process is needed for LHD's to become accredited and for LHD's to maintain their tax status.
- NACCHO provides capacity building and technical assistance services to LHDs, especially as it relates to their response to the syndemic. Laura expanded upon federal programs and some recent changes at the congressional level that impacts the trickle-down of funding and service provision.
 - Authorizing language tells agencies what to do with the money, if funding is appropriated. Congress realized that they had little to appropriate to address opioids and expand treatment, so they passed the 21st Century Cures Act. This assembles a wide array of legislation, but most importantly, Congress put a funding vehicle within the authorizing language to provide money for addiction treatment. This provision was used to create SAMHSA's Targeted Capacity Expansion grants, which provide funds within the authorizing language.
 - 317 funding goes to the CDC for use in two ways: the purchasing of vaccines, and the infrastructure to support the vaccines. State immunization programs receive funding from the CDC and they can decide on the priorities within their communities with a focus on immunizations, registries, education on storage and handling of vaccines, scheduling, staffing, etc.

Chelsea Kelleher Key Take-Away Points

- The National Governors Association (NGA) is a bipartisan organization that supports all governors' offices and their staff. For the first time in 10 years, 46 governors agreed on a collective action regarding the approach to address opioids. They signed a compact in July of 2016 which focuses on redoubling efforts to:
 - o Decrease inappropriate prescribing
 - o Increase education on opioids and reduce stigma
 - Ensure pathways to treatment and recovery
- In 2016 the NGA developed the Opioid Road Map, available on their website <u>HERE</u>, and to address the crisis they have narrowed the cause of the opioid crisis into three factors:
 - 1. Wide and inappropriate prescribing of opioids, which effectively served the function of priming the pump of dependent opioid users;
 - A lack of access to treatment for people with opioid use disorders (OUD); and
 - 3. A change in the economics and supply of heroin
- The NGA developed Learning Labs with 7 states currently engaged. The goals of the 7 participating states fell into the following themes: Stakeholder engagement, especially law enforcement and LHD; Syringe Service and Harm Reduction Programs; and, Data and Surveillance
- Discussion around the engagement of grassroots and non-traditional groups was identified as a necessary component to the successful integration of state plans. NGA agreed that people in recovery, those with OUDs, and families are uniquely positioned to help lawmakers understand and engage with the front lines, which has been realized in some states through the manifestation of peer model programs in opioid use and addiction treatment.
- Tennessee was highlighted as having made budget and model adjustments to scale up data from a syndemic lens. These model changes, and the data yielded, can make the 'ask' for more surveillance resources justifiable. Vital to the process is the need for governors to receive accurate data from LHDs on the infectious disease consequences of opioid use with accurate information on the true costs of treatment, particularly as it relates to HCV. Many states base their budgets on inaccurate or overestimated dollar amounts, and an overall underappreciation of the extrahepatic impacts a patient experiences even

before the development of advanced liver disease. The NGA has seen that as HCV treatment prices have decreased, there has been a concurrent effort by Medicaid programs to loosen restrictions and provide care.

- A strong point was made about instituting greater oversight and regulations placed on programs that provide addiction treatment services. One participant talked about the inadequate treatment provided which often leaves patients more vulnerable to overdose and death. The NGA supports the development of best practices and a better understanding of people with substance use disorders to inform the regulation of facilities and decrease associated fatalities.
- Rural areas face additional treatment barriers due to: decreased access to proximate providers; varied acceptance of all insurance types; low reimbursement rates to providers, especially from Medicaid; and a lack of support for providers on how to treat patients with complex needs, like OUDs.

Carissa McGee Key Take-Away Points

The Caring Ambassador's met Carissa McGee at the University of New Mexico's (UNM) MetaEcho conference where she provided a powerful and memorable keynote address based on her personal story of perseverance and resilience in the face of isolation, and incarceration. (Access that keynote <u>HERE</u>). Ms. McGee was invited to present on the power of effective storytelling in inciting change and action. The Caring Ambassadors included her presentation in the Roundtable agenda with two aims:

- 1) To motivate and inspire roundtable participants in preparation for their visits with elected officials the following day
- To provide participants with insight on how to craft and relay their own stories and messages in a way which is meaningful, effective, and impactful

Telling Your Story - May 19th, 2018

"You have to be willing to sacrifice EVERYTHING for your message. That includes your income, your security, your pride, your own selfish gains, your time and all of your effort. EVERYTHING. Your message isn't for you; it's for others. You tell your story as a bridge to create the same ideas from your mind to another's. Your integrity should be tied to your message - you do what you do

all the time; it never changes. That's integrity. You share your story with ZERO expectations in return; because if you didn't share your story you'd be killing yourself. The purpose of your message is to share it with the rest of the world and it should be so strong within you that if you kept it in, you'd explode from the pressure. You'd know you found your message because it'd be bubbling over and slipping out all the time. You embody your message in everything you do and sometimes you're just not aware of it. When you recognize it it's undeniable. Because it's seeping out of your entire being, you'll start to take great pride in being used. You'll start to look for opportunities to be used. You'll be begging to be used. Because it is only in being used that your message and story become USEFUL. That's why you have a message; that's the purpose of your story - to be useful for others."

Ashli Douglas Key Take-Away Points

- Quest Diagnostics has a strong commitment to addressing infectious diseases in communities and engages in syndemic-related activities through regional partnerships that include a mix of: sales to hospitals and primary care providers; laboratory research for the development and refinement of clinical assays; and, employee education and engagement. Further, Quest has one of the largest databases of de-identified patient data and shares that data with the CDC on a quarterly basis. This data shows the CDC where specific 'hotspots' exits on a state and local level.
- A few participants mentioned how great Quest has been to work with, and how responsive they are in working with community-based organizations to expand services. It was mentioned that they have been especially helpful when working in nontraditional settings, providing low or no-cost diagnostics for the uninsured, and a useful informatics system to obtain results.
- A suggestion was made to use Quest's rich database to identify city, state and regional locations where HCV treatment may be successful. This could be tracked through HCV RNA testing and may demonstrate where people are getting treatment, and the types of healthcare providers that are treating. This data may also provide LDHs with rich information on patients who may need to be engaged through outreach services for follow-up on viral load testing, or other linkage-to-care opportunities.

Hill Visit & Senate Briefing Review

Friday's programming included 59 scheduled Hill visits with Syndemic Roundtable participants' elected officials (or staffers), representing 27 districts and 17 states across the nation. The purpose of the Hill visits was three-fold:

- 1) Allow participants to hone and apply advocacy skills in a real-world advocacy setting with a relevant audience
- 2) Educate on and raise awareness of the infectious disease consequences of the opioid epidemic among elected officials and their staff
- Ask participants' representatives for legislative support for the "Eliminating Opioid Related Infectious Diseases Act of 2018"

Midday, Senator Merkley and the Caring Ambassadors Program co-hosted a Senate Briefing called *Our Syndemic: The Intersection of Viral Hepatitis & Opioids - A Public Health Crisis.* There were over 75 people in attendance at the briefing, which provided attendees an opportunity to hear first-hand accounts from an HCV patient who contracted the virus perinatally and both Federal and State government officials on their response to opioids and infectious diseases in our communities.

The briefing began with presentations from Dr. Giroir, the Assistant Secretary of Health, who highlighted HHS's 5-point strategy to address opioids. They include: 1) Strengthen public health data reporting and collection, 2) Advance the practice of pain management to decrease the inappropriate use of opioids, 3) Improve access to prevention, treatment, and recovery services, 4) Enhance the availability of overdose-reversing medications, 5) Support cutting-edge research that improves our understanding of pain and addiction, leads to new treatments, and identifies effective public health intervention.

Dr. Mermin, Director of CDC's National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention discussed his department's approach to addressing the syndemic in the following broad ways: prevention of harmful opioid use; prevention of viral hepatitis; treatment of substance use disorders; and viral hepatitis treatment.

Dr. Wester, Medical Director of the Tennessee Department of Health's Section of HIV/STD/Viral Hepatitis highlighted her department's approach to addressing

the syndemic impact of perinatal HCV exposures.

Kristen (Kaylee) Ferrell concluded the briefing by sharing her brave and heartfelt story of the impact of syndemics on her life. Kaylee was cured of HCV, which she contracted at birth from her mother who was not tested for HCV during her prenatal care. Her mother recently died of cirrhosis caused by untreated HCV and her father battles with a substance use disorder. Click <u>HERE</u> to learn more about Kaylee's story.

Saturday Review

Participants engaged in group discussion on highlights and thoughts about their Hill visit experience and submitted feedback forms that captured meeting takeaways and collected key contact information. To promote sustained engagement with their elected officials, participants were provided tools and an overview on how to best follow-up with politicians' offices.

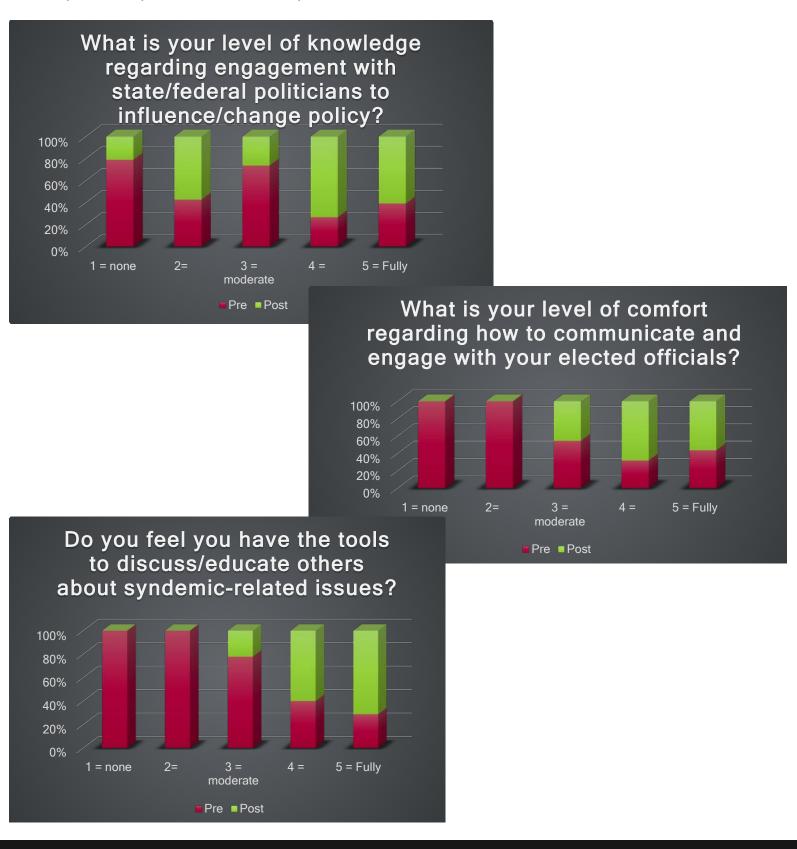
As part of Saturday's programming, participants reviewed messages that were developed during the 1st Syndemic Roundtable and provided feedback on semantics and opportunities for further development and dissemination of those messages. There was also discussion around expanding the reach of the Syndemic Roundtable to make it a national movement, and leverage the stories and resources in different regions of the country.

At the close of Saturday's program, participants were asked to say one word that reflects on where they are left at the conclusion of the meeting. The following words are direct quotes from participants who were present at the close of the conference.

Empowered	Норе	Reinvigorated	Accomplished	Encouraged
Learning from	Inspired	Challenged	Determined	Ideas
Experience	-			
Busy	Strengthened	Ensemble	Tapestry	Reconnected
Sobering	Intention	Humble	Effective	Moved
Love	Encouraged	Grateful	Invigorated	Supported

Program Evaluation

<u>Quantitative Outcomes</u> - Using an Audience Response System, we collected pre- and post-data from our partners. Here are the results:



<u>Qualitative Outcomes</u> - On the final day of the Roundtable, participants were asked to complete a post-event evaluation with the aims of: 1) assessing the impact of and reactions to individual event components, 2) gathering feedback on how the event could have been improved, and 3) obtaining input on proposed next steps for the Syndemic Roundtable. Overall, participant feedback was overwhelmingly positive. Constructive feedback will be taken into consideration by the Caring Ambassadors for future planning purposes and included:

- Foster more participant connections and dialogue throughout the event: Several participants emphasized a desire for more time built into the Roundtable agenda for open dialogue, networking, and individual story telling.
- Modify the agenda: Several participants described feeling overwhelmed or drained by the first day of the roundtable, citing the back-to-back nature of the day's presentations (which totaled ~3 hours).
- Webinar time commitment: Although the pre-Roundtable webinars were valued and well-received by most, some cited the time commitment (about 2 hours) and concentrated timeline (spanning only two weeks) as being burdensome.

Participant Comments:

- "Yet again, Caring Ambassadors has put together a meeting that can serve as a model of how best to run a meeting. It was engaging, informative, diverse, and impactful."
- "When I think I can't hear another amazing story, my world gets rocked!...This is an amazing group of individuals that I am both blessed and honored to be a part of. So appreciative!"
- "Very motivating, empowering, and educational event. Excited to see how far we can go."

Key Recommendations & Lessons Learned

In order to up-train participants during the pre-training webinars, we used a teleeducation platform which proved to be a great use of time, resources and energy. The majority of participants engaged in the webinars and commented on the usefulness of the information provided. It also served as an opportunity to

communicate the process of the conference and how the information presented in webinar trainings would be used during the 2.5-day meeting. We recommend the use of pre-training webinars for meetings that bring together a diverse group of participants with varying levels of subject matter knowledge.

To ensure diverse representation from key stakeholder groups at roundtable discussions, we suggest employing an application process to aid in participant recruitment. While we did not utilize an application process for this meeting, we are considering doing so for subsequent meetings to attempt to leverage the most diverse and representative group possible, and ensure participant buy-in. Lastly, we recommend instituting strict deadlines for travel confirmations to aid in a smooth and logistical accommodations process, including preparation of participant materials, and budgeting.

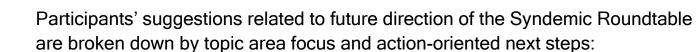
As part of the program we identified a few key recommendations for future planning. First, while it is important to expose participants to various solid and useful presenters, it is just as important to provide multiple platforms and opportunities to facilitate networking and group engagement amongst participants. It is vital to allow for plenty of time for group discussion and processing, especially as it relates to practicing story-telling in preparation for Hill visits. In retrospect, we would consider adding more time between presenters for processing and small group engagement, and possibly fewer speakers to leave space for more role playing. During multiple day meetings, we also recommend providing social opportunities for participants outside of meeting hours. We chose an evening DC trolley tour which proved to be a great success.

Further, while planning for hill visits among a group, we highly recommend the use of a colorful and easily identifiable marker for participants to wear while doing visits. We chose to use sashes with our message displayed on them and distributed one to each participant. Overall, the sashes provoked inquiry and interest on the Hill and in public, as intended. However, we did receive some feedback from participants who were uncomfortable wearing sashes. In the future, we will need to consider how to reconcile Caring Ambassador's belief that presenting a united front - sometimes through outward expression - is imperative to the advocacy process, with our desire to respect the individual preferences of our allies.

Participants identified a multitude of ways they planned to stay engaged with syndemic-related work and apply the lessons, knowledge and skills acquired during the roundtable to their work and mission once they returned home. These included:

- Systems integration work:
 - Acknowledging and implementing harm reduction services as a core component in infectious disease prevention
 - Integrating HCV screening, testing, linkage to care, and treatment into MAT and other addiction treatment programs
 - Working to establish joint HCV/substance use support groups
- Enhanced advocacy efforts
 - Using story telling skills acquired to enhance messaging
 - o Dedication to serve as a local-level champion
 - o Influencing policy makers
- Nurture collaborations, partnerships, and engagement opportunities
 - o Between Roundtable participants
 - o With local health departments
 - o Between elected officials and advocacy organizations
 - With local level stakeholders
- Raise awareness and educate others on the Syndemic, including:
 - Substance use recovery communities and support groups
 - o Students
 - Elected officials
- Improve their own organization's response to the syndemic
 - o Including syndemic language in agency materials
 - Pursuing new/more funding opportunities and RFPs

The continuation of the Syndemic Roundtable and associated advocacy and programmatic work is a priority for the Caring Ambassadors. Participants were asked whether they wished to continue to be involved with the Roundtable, and to provide input on proposed future direction of and next steps for it. Encouragingly, all participants in this convening of the Roundtable expressed a desire for continued involvement with the group and syndemic-related work.



Future Topic Areas (as they relate to the Syndemic):

- 1. Mental health
- 2. Stigma and discrimination
- 3. Harm reduction
- 4. Incarceration and the criminal justice system

Action Items

- Form work groups/committees based on participant area of interest and expertise
- Form a national Syndemic coalition
- Continue to hone participant advocacy skills and strategies
- Engage in strategic planning as it relates to infectious disease, harm reduction, and drug treatment systems integration
- Bolster Syndemic Roundtable recruitment and membership efforts, especially as they relate to the targeted recruitment of subject matter experts and diverse populations
- Pursue relevant conference opportunities for the Syndemic Roundtable

Moments



Participants engage in Roundtable discussions



Participants Sara Zamor and Brian Barsotti prepare to meet with Senator Duckworth







On an evening trolley tour, participants saw the Washington Monument from a few angles. The tour provided an opportunity to see the Dr. Martin Luther King Monument, too.

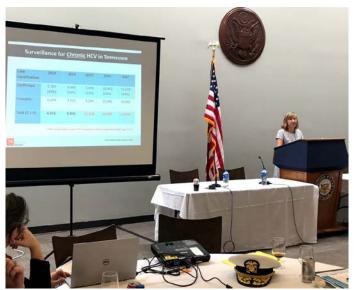


Participant Luke Tomsha meets with his elected official, Congressman Kinzinger





Assistant Secretary of Health, Dr. Giroir presents at the Senate Briefing



Dr. Carolyn Wester, TN Department of Public Health speaks at the briefing



Participant, Dan Bigg asks Dr. Mermin a question at the briefing



Patient Advocate, Kaylee Ferrell shares her story at the briefing



Participants gather following the Senate Briefing

Sponsorship & Acknowledgement

The Caring Ambassadors Program would like to thank our sponsors: Merck, Gilead, Abbvie and Quest. A BIG shout out to our Syndemic Roundtable participants! A big thank you to Virginia at the DC Trolley Company, Federal City Caterers, and The Darcy Hotel and staff for assisting in the planning of what turned out to be a great event!



Thank you to the Darcy Hotel and staff