



2018 Annual Report

Dear Friends of Caring Ambassadors,

Caring Ambassadors Program takes on bold challenges to advocate for underserved issues in the communities we serve.

When I was diagnosed with hepatitis C 20 years ago, we focused on improving current treatments and educating patients on how to improve their odds of achieving a cure with interferon. We advocated for adoption of enhanced screening and testing protocols at the state and national levels. Now that we have a cure for all that is effective and well tolerated, we are focusing on making sure everyone has access to it and that we are on the road to elimination.

In those same 2 decades, great strides have been made in lung cancer treatments and the early detection of lung cancer, but a tremendous amount of work remains. Far too many people are still diagnosed with advanced stage lung cancer, past the point of being curable – or even treatable. We continue to work with the greater lung cancer community to advance screening efforts and promote lung cancer awareness. Survivorship is our goal.

Now moving forward, we see the challenge patients face when confronted with chronic health conditions and a healthcare system that is complicated and focuses largely on addressing illness, rather than promoting wellness. This year we developed *My Choices: A Planner for Healing*. It is a tool for healing when faced with a chronic health condition. Combining elements of a guidebook, health care planner, journal, and activity book, *My Choices* helps users recognize and act upon what they can control throughout their healthcare journey to tip the scales towards health and healing, no matter the health challenges they face.

We continue to measure our results based on the differences we make in individual lives, the ongoing impact of the ideas we plant over time, and the programs we build to make the world a better place.

We are honored that you support us in our mission.

Best Regards,

Randy Dietrich
Board Chair

1997

Caring Ambassadors Lung Cancer Program is founded.



2001

Caring Ambassadors Program establishes its own 501 (c) 3 status and quickly becomes one of the largest lung cancer and hepatitis advocacy organizations in the country.

2013

Jill Wolf joins as the Hepatitis C Program Director and brings her wealth of knowledge on addiction and behavioral health to the program.

2020 and beyond

Caring Ambassadors Program looks forward to continuing its mission into the next decade. We are devoted to empowering people to be advocates for their own health.



1990

2020

1999

Caring Ambassadors Hepatitis C Program is founded.



2000

2008

Cindy Langhorne joins as the Lung Cancer Program Director and has 20 years experience in

2010

2017

Meg Ziemann joins as the Caring Ambassadors Program Manager, expanding our mission to address living well with a challenging health condition.



THE PROBLEM:

60%

of the U.S. population has at least one chronic disease.



“Maintaining or enhancing quality of life for individuals living with chronic illness has not been given the attention it needs...”

- Institute of Medicine



A New Symbol

We’ve redesigned our symbol, the Integrative Health Ribbon, giving it a fresh look and highlighting eight areas of healthcare that contribute to well-being and healing. You’ll see this logo throughout our website, tools, and publications.

An Updated Website

We have updated, and will continue to update, the Caring Ambassadors website with a new look, expanded content, and healthcare management tools. The site provides valuable information, tools, and resources for anyone impacted by a chronic health condition, including the newly diagnosed who may be asking themselves, What now?



Have you signed up for our Integrative Health & Medicine Weekly News?



MY CHOICES

A Planner for Healing

We are excited about the continued development of My Choices: A Planner for Healing. This tool serves to guide anyone facing long-term illness in the process of recognizing and acting upon the healthcare options available to them.

An initial version of the planner was completed in early 2018 and evaluated through market testing and focus groups.

Based on this evaluation, we’re now working with a graphic designer on a new and improved version to roll out to the public. Expected completion is Spring 2019: Stay tuned!

To be notified when My Choices is available for download and print order, email mychoices@caringambassadors.org

THE IMPACT

What Users Say:

“It made you think. Before I got the book, I was just doing the same things that I do. After going through the book...it gave you alternatives. It gave you suggestions you never would have thought of.”

“I didn’t have the understanding that it (long-term illness) was this comprehensive thing. It’s not just going to the doctor and getting a pill and getting better. There’s stuff you have to do.”

“Puts your mind in a straight line.”



Accomplishments & Activities:

Empowerment through Story Telling: The Caring Ambassadors celebrates the unique story within each of us with a goal to empower individuals impacted by hepatitis C to share their story to increase awareness and decrease stigma of HCV. Our collaborative story-collection project, in partnership with StoryCorps, has recorded more than 40 stories from people living with HCV – some are survivors of liver cancer, some use drugs, some are family members, and some people are living with HIV. Our innovative approach to telling the HCV story led us to our partnership with the Young Chicago Authors (YCA), a nonprofit that works towards cultivating young voices through writing, publication, and performance education. In collaboration with YCA, we leveraged a partnership with young artists and YCA apprentices, Luis and Kara (named 2018-2019 Chicago Youth Poet Laureate) to create fresh HCV messages through spoken word.



Educating for Impact: The Caring Ambassadors provides education and system-focused capacity building including brochure dissemination and partner collaboration. In 2018, we distributed over 15,000 hepatitis C specific brochures, both general and vulnerable population-specific brochures around the country, and presented at multiple national, regional, and local conferences. We will continue efforts into 2019 and look forward to further building the syndemic coalition and other related partnerships to educate systems and providers on the interrelationship of viral hepatitis and other public health issues.

Advocacy for Elimination: The Caring Ambassadors continues to advocate for increased opportunities to eliminate hepatitis C by engaging with policy makers, elected officials and the community. Our micro-elimination efforts leverage existing programs and partnerships to innovate in the development of responsive and inclusive HCV elimination projects. In 2018, our advocacy focused on states with the tightest restrictions, including both Illinois and Oregon, both of which removed all treatment access restrictions for people living with hepatitis C at the end of 2018. We're on our way to elimination!



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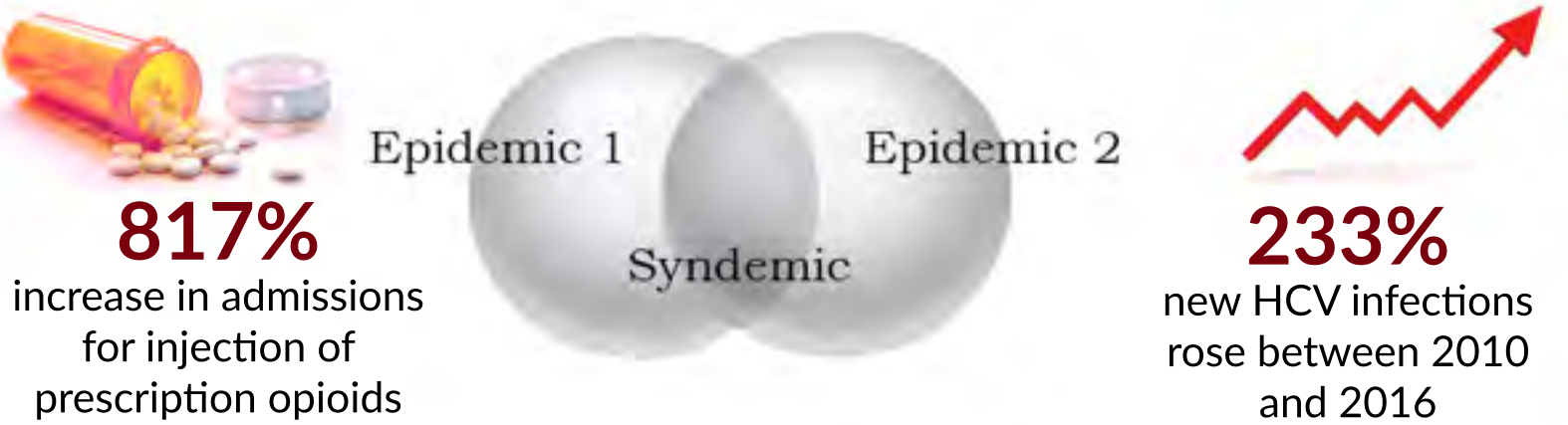
Dear Lorren,
The day I met you in 2014 was a good day. Your knowledge and kindness helped me in 2015 and 2016. Your encouragement helped me in 2017. Your persistence helped me in 2018. And your outrage helped me this year. Got the medicine yesterday. Took the first dose this morning.

Thank you and thank you.

- Barbara

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THE PROBLEM: Opioids & Hepatitis C

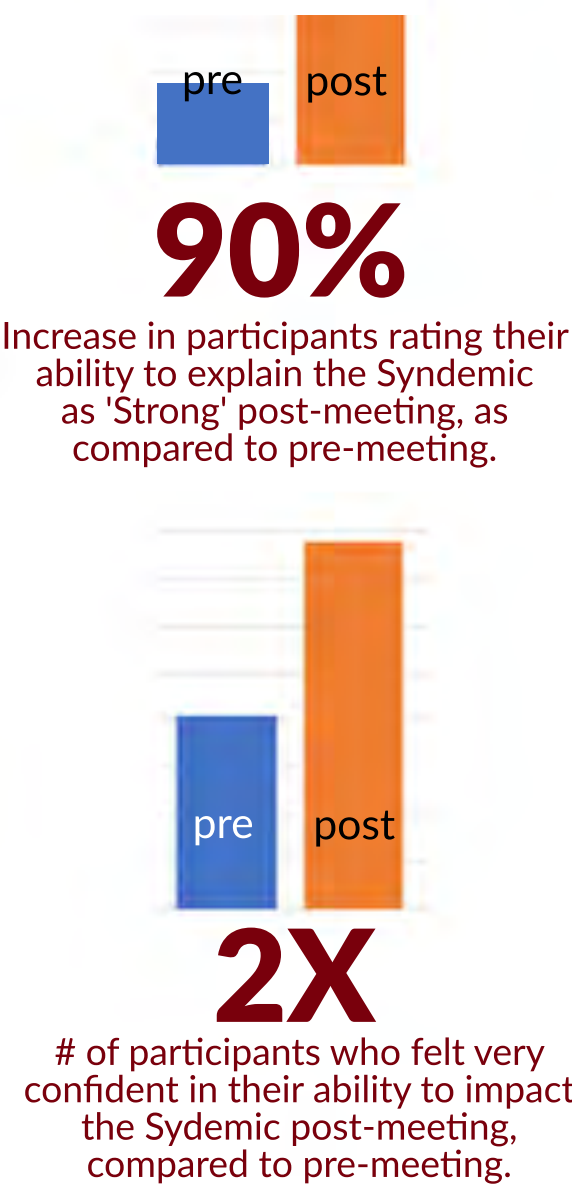


OUR RESPONSE: The Syndemic Roundtable

2 National Meetings **44** Participants **10** Stakeholder Groups



Learn More:
www.hepcchallenge.org/syndemic-roundtable



Collaborating To Address HCV & Opioids

The Syndemic Roundtable: Albeit late, our nation has taken notice and enlisted action to combat the opioid epidemic, yet multiple components have created a larger public health crisis: a “syndemic” in which opioid use and HCV rates have risen concurrently and sharply in the US. In response, we spearheaded the Syndemic Roundtable, convening multidisciplinary professionals and stakeholders to engage in cross-sector agenda setting to respond to the opioid/HCV syndemic. Over the past year, we have organized two meetings of the Roundtable, and we are now taking active steps to formalize the group as the National Syndemic Coalition.

The Syndemic Roundtable aims to contribute to the elimination of HCV by:

- Educating a wide variety of multidisciplinary players on the impact of hepatitis C and its relationship to the opioid epidemic, substance use and infectious diseases.
- Strengthening health and community workers’ ability to effectively advocate for equitable, integrated care for the substance use and HCV communities.
- Promoting the integration of HCV services within existing systems to maximize the impact of HCV prevention, screening, and treatment among the most at-risk population.
- Developing and sharing compelling stories, representing diverse lived experiences, as a tool to destigmatize and demystify HCV and substance use.
- Creating a unified, representative front to advance HCV elimination through a syndemic lens.

THE IMPACT

Educated federal policy makers on the meaning of 'Syndemic' and the HCV consequences of the opioid crisis.

Produced advocates by giving a voice and a platform to key players in a Syndemic that has plagued both a generation and a country.

Facilitated 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.

Founded the National Syndemic Coalition to advance the call to take action on the infectious disease consequences of the opioid epidemic.



Special Thanks To:

MERCK GILEAD
abbvie Quest



Accomplishments & Activities:

Educating for Impact: The Caring Ambassadors Lung Cancer Program’s website is one of our primary tools for community outreach and patient education initiatives. In 2018, we were proud to develop an online resource center for the American Indian/Alaska Native (AI/AN) population, containing culturally-relevant lung cancer resources.

In addition to our online offerings, last year we distributed over 10,000 brochures on important lung cancer topics: *Your Treatment Team and What You Should Know*; *Targeted Therapy for Lung Cancer*; *Immunotherapy for Lung Cancer*; and *Clinical Trials for Lung Cancer*. We also sent out 913 hard copies of *Lung Cancer Choices, 3rd Edition* and 970 copies of *Caregiver Choices* to patients and their loved ones, at no charge.



Advocacy in Action: Advocates are a vital component in the fight against lung cancer. The Caring Ambassadors continues to advocate at both a state and national levels by engaging with policy makers, elected officials and the community. In 2018, the Caring Ambassadors Lung Cancer Program had the opportunity to comment and testify on the Health Evidence Review Commission’s (HERC) coverage guidance for “FDA-Approved Next Generation Sequencing Tests for Tumors of Diverse Histology”. We strongly encouraged HERC to reconsider their recommendation for non-coverage of FDA-Approved NGS tests for Medicaid patients with non-small cell lung cancer (NSCLC). All patients deserve the same access to care! We Won!



“



“Yes, Cindy – I received Lung Cancer Choices and the other information you sent to me. Thanks, it is very informative and helpful.

I am starting my first round of chemo as I’m typing this. Thanks again for all you help.”

- Teri

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THE PROBLEM:



Lung cancer is the leading cause of cancer death for men and women in American Indians and Alaska Natives

OUR RESPONSE: American Indian Alaska Native Lung Cancer Roundtable



100%
of participants agreed to work collaboratively on a Lung Cancer Awareness Campaign focusing on Native Communities in 2019.

“Thank you for the opportunity to participate in last week’s planning session. I appreciate the time and effort put forth to gather input. Thanks again and look forward to “round two” of this planning group.”

THE IMPACT

As a result of this meeting we will:

- Create basic education and messaging around lung cancer screening in Native communities.
- Respectfully educate tribal leaders about the importance of lung cancer screening at tribal meetings/conferences.

-Develop culturally appropriate screening materials for providers and patients in Native communities in OR, WA, ID, and AK.

-Partner with the Alaska Native Medical Center on developing messaging to bring awareness to screening in Alaska.



Thank You To:



Roundtable participants show what lung cancer advocates look like!
Brainstorming how to build Lung Cancer Awareness in Alaska Natives and American Indians

American Indians and Alaska Natives (AI/AN) are disproportionately burdened by lung cancer, and many barriers pose challenges to screening and treatment in this population. Caring Ambassadors is responding to the need for enhanced efforts to prevent and combat lung cancer in the AI/AN population.

Several action strands were developed as a result of the meeting. Data: Utilization of Lung Cancer Screening; Communications and Marketing; Policy; and Clinical and Community Healthcare Members. This diverse group will be moving forward on these action items to better serve the Native communities they represent.

The goal of the American Indian/Alaska Native Lung Cancer Awareness Roundtable was to convene a diverse group of individuals and organizations, united in their dedication to decrease lung cancer morbidity and mortality in the AI/AN population, and to collaborate on strategies to increase awareness of lung cancer screening and treatment resources within AI/AN communities.



Early detection, by low-dose CT screening, can decrease lung cancer mortality by 14%-20% among high-risk populations.

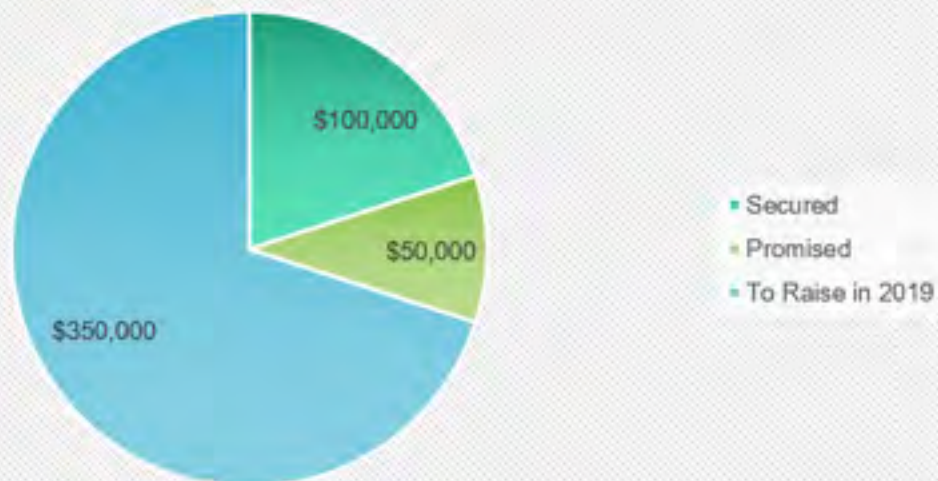


Fundraising

It's time to invest in resources that improve individuals' capacity to live well with chronic health conditions, rather than just manage it. **The Caring Ambassadors Empowerment Campaign** seeks \$500,000 from individuals in general mission support to sustain, sow and grow our programming over the next two years.

This revenue will enable us to continue to create a solid foundation on which to build a program that will challenge norms to change the lives of those facing chronic health conditions.

Empowerment Campaign 2018/2019



2018

Thank you to each and every one of our individual supporters!

Thank you to our Corporate supporters!



2018 Fundraising



Some problems are so difficult they can't be solved in a million years unless someone thinks about them for five minutes
H.L. Mencken

