

WILMOT CANCER INSTITUTE
COMMUNITY OUTREACH & ENGAGEMENT

5th Annual Community Cancer Action Council Retreat

**CCAC in
A.C.T.I.O.N.**

Accessing Clinical Trials
In Our Neighborhoods

Friday, October 11, 2024



2023



UR
MEDICINE

WILMOT
CANCER INSTITUTE

WELCOME

MESSAGE FROM DR. FRIEDBERG

Director of the Wilmot Cancer Institute

Wilmot's mission to provide top-tier treatment and care for cancer patients is deeply rooted in the strength of our community. The invaluable insights from our CCAC members bridge Wilmot with over 3 million people across 27 counties in Central and Western New York, directly influencing how we conduct research and care for patients.



*Jonathan Friedberg,
MD, MMSc*

It is crucial for us to address the disparities in cancer incidence within our region, and our CCAC is making that possible. Your voices are vital in shaping our vision and have guided Wilmot's refreshed Strategic Plan, ensuring we tackle these challenges.

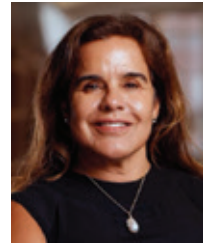
This retreat serves as a key opportunity for bi-directional engagement, aligning our scientific endeavors with community needs. I meet monthly with the CCAC leadership team, and our collaboration is pivotal in steering Wilmot's future. Today is about hearing from all of you.

A special thanks to Dr. Paula Cupertino, Kristina Hawes and the entire COE team for ensuring that the community's input continues to influence our research. Together, as we look towards 2025, we remain united in our mission to eliminate the burdens from cancer in our region. Your engagement not only impacts our work but transforms lives. Thank you for being an essential part of our journey!

MESSAGE FROM COE LEADERSHIP TEAM

Associate Director of Community Outreach and Engagement

It's a beautiful coincidence that our Annual CCAC Retreat coincides with the fall season. Just as the landscape displays vibrant colors, our diversity at CCAC shines through. The unique talents and passions we bring together cultivate a fertile ground for future success.



*Paula Cupertino,
PhD*

Our retreat's symbol—a tree with leaves representing multi-colored cancer ribbons—reflects our commitment to celebrating diversity and renewing our focus on eliminating cancer disparities in our 27-county area. Like fall, this is our time to transform, build resilience, strengthen partnerships, and prepare for the future.

Addressing cancer health disparities is crucial in our work, including community education, preventive measures, and research. To enhance our impact, we must innovate, forge new partnerships, and adapt with the seasons.

This year, we are excited to host a multicultural celebration to honor the diversity of our communities and our shared mission. Together, we can reduce the cancer burden in the Greater Rochester area. Our collaborative efforts are long-term and centered on IMPortant ACTIONS (IMPACT). The Wilmot COE team, alongside CCAC, appreciates your dedication to lessening cancer's impact.

It's truly an honor to partner with you and witness the strengthening of our roots over the past five years.

Our Community Outreach and Engagement Team

Paula Cupertino, PhD, Associate Director
Francisco Cartujano, MD, Assistant Director
Charles Kamen, PhD, Assistant Director
Emily Hayes, MPA Program Manager
Kristina Hawes, MS Community Engagement Manager
Sarah Merritt, MS Regional Outreach Manager
Zhanna Kulshanova, MPA, Outreach Coordinator
Ella Adams, Community Liaison
Melinda Robinson, COE Community Liaison at Bassett Medical Center

Joyce Lucas, COE Community Liaison at Action for a Better Community
Ibero American Action League Community Ambassadors: Lucia Colindres, Joyce Rodriguez, Maria Dominguez, Joaquin Mouliert Bruno
Common Ground Health: Joyce Alexander, John Rutledge, Laniece Simmons, David Starks, Audrey Alexaner, Catherine Galvin, Clara Harrell, Darnell Alexander, Letty Padilla, Roberta Carter

THE COMMUNITY CANCER ACTION COUNCIL (CCAC)

<p>19 representatives from 13 different organizations came together to determine how to work collaboratively to lessen the impact of cancer in our region.</p>	<p>The CCAC was officially created with a mission 'to work with communities today to lessen the impact of cancer tomorrow!' Community priorities were established.</p>	<p>The CCAC hosted its first in-person retreat and saw over 70 attendees (with COVID testing)!</p>	<p>CCAC input informed the establishment of Community Advisory Boards (CABs) to provide community voice to research projects with specific population focus.</p>	<p>CCAC continued to strengthen and expand community partnerships to further the mission into underrepresented communities, while also playing a key role in Wilmot's 2023–2028 Strategic Plan development.</p>
2019	2020	2021	2022	2023

CCAC is a community-led group that acts as the primary community advisory board for Wilmot and is the cornerstone of community engagement efforts undertaken throughout Wilmot. The CCAC is highly integrated into all of COE's aims and Wilmot's activities, identifying high-priority research, outreach, and education initiatives; leading health improvement projects; organizing an annual retreat and Community Conversations on Cancer to engage and educate community partners and Wilmot members; and incorporating in Wilmot's strategic planning implementation and leadership committees.

The CCAC:

- sets goals responsive to community need and focused on promoting diversity and equity;
- is highly integrated into all of COE's aims and Wilmot's activities;
- identifies high-priority research, outreach, and education initiatives;
- leads health improvement projects;
- organizes an annual retreat and Community Conversations on cancer to engage and educate community partners and Wilmot members; and
- is incorporated in Wilmot's strategic planning implementation and leadership committees.



We are proud of the diverse populations represented in CCAC across the 27 county catchment area.

Would you like to join us? Contact Kristina Hawes at kristina_hawes@urmc.rochester.edu to become a member.

Community Driven Cancer Research (CDCR)

FOCUS: To foster equitable participation in cancer research and to diversify the cancer research workforce

Working Group Co-leads

Elisa DeJesus, 2022 – Present
Don Armstrong, 2023 – Present

Our Voice Your Science Research Project

Survivors and caregivers worked together with Wilmot staff to create an RFA, calling for applications to fund research directly relevant to needs of our community. They reviewed all applicants and funded two projects: 'Impact of a Whole Food, Plant-based Diet on Breast Cancer' and 'Expanding Reach in our Catchment Area with Self-administered Remote Blood Collection: a Feasibility Study with Preliminary Validation.'

Youth Pipeline

In partnership with Black Men Achieve and Encompass, CDCR created an interactive presentation on cancer research careers. The group presented to over 30 high school students from underrepresented backgrounds, sparking interest, and providing direction on how to become involved.

Clinical Trials Video

Using information obtained from focus groups and interviews, CDCR worked with Dr. Paul Barr and WCI Marketing to film a video showcasing a clinical trials participant and his provider. The video focused on addressing myths in clinical trials and was made accessible with ASL interpretation, and closed captioning in both English and Spanish. This informational video has reached over 72,000 people through social media.



Watch part 1 of Ira's story here



Cancer Prevention and Risk Reduction

FOCUS: To educate communities about ways to reduce personal risks for cancer and to increase cancer screening rates.

Working Group Co-leads

Kathleen Maignan, 2023 – Present
Candice Lucas, 2023 – Present

Community Cooking Demo

Hosted at Cameron Ministries, this working group collaborated with chef Philomena Emeku-Iheukwu to show community members how to make a healthy, nutritious meal with cancer prevention benefits. A Wilmot nutritionist provided information on health benefits. At the end of the demonstration, ingredients were given to all participants.

Faith-Based Community Cancer Symposium

Since 2023, Cancer Symposiums have been held at Mt. Olivet Baptist Church and Greater Harvest Church as a product of collaboration between Wilmot and various faith-based organizations in the city of Rochester. This event educated over 80 individuals! At the event, providers talked about different types of cancer, including: prostate, colorectal, breast, and prostate; screening recommendations, and ongoing research. Yoga and meditation were offered on-site, and community partners provided information on their resources.

Lung Cancer Screening Telephone Town Hall

A patient navigator from the Lung Cancer Screening Program educated community members through a telephone town hall about the requirements for lung cancer screening and what happens during a screening. This interactive and educational opportunity saw over 750 participants!

Access to Care/Rural Integration

FOCUS: To improve cancer care throughout the region by increasing access to health interventions and research.

Working Group Co-leads

Jason Coleman, 2022 – Present
Michele Foster, 2023 – Present

Community Survey

Access surveyed library patrons and staff throughout the region to identify telehealth capacity and perspectives on telehealth services. 115 people responded and results indicated that there was high interest in developing a community telehealth hub at a local library.

Community Informed Research

Access has partnered with Dr. Maria McGreevey in research! Partnering with community members, focus groups have been created in rural areas to determine the usefulness of a chatbot to determine if hereditary cancer screening is right for individuals.

Telehealth Hub Promotion

Working with libraries in Macedon, Ovid, and Watkins Glen, the group has hosted events to spotlight telehealth options in local locations and to provide information on the uses of telehealth. Working in collaboration with researchers and providers



Cancer Survivorship and Caregiver Resources

FOCUS: To provide the assistance and resources needed to support individuals going through treatment, survivorship, or caregiving.

Working Group Co-leads

Lizanne Zamites, 2021 – Present
Sue Dambrowski, 2023 – present

Survivorship Resource Map

Working with the Wilmot Marketing Team, Survivorship compiled information on the region, created a map and resource listing, and posted the map on the Wilmot website for community members to use. Resources can be searched by county or by category, including: communication and language, financial, end of life care, support groups, and transportation. Organizations can be added to the map, and currently over 100 organizations are listed!

Peer Mentors

Recognizing the need for additional supports at diagnosis for both survivors and caregivers, Survivorship collaborated to create an equitable, appropriate, community friendly program to link current patients/ caregivers with cancer survivors/former caregivers to answer questions, connect to resources, and provide emotional support.

UNDERSTANDING OUR COMMUNITY AND CANCER DISPARITIES IN OUR REGION

Identify:

Key characteristics influencing the cancer burden in the catchment area (CA).

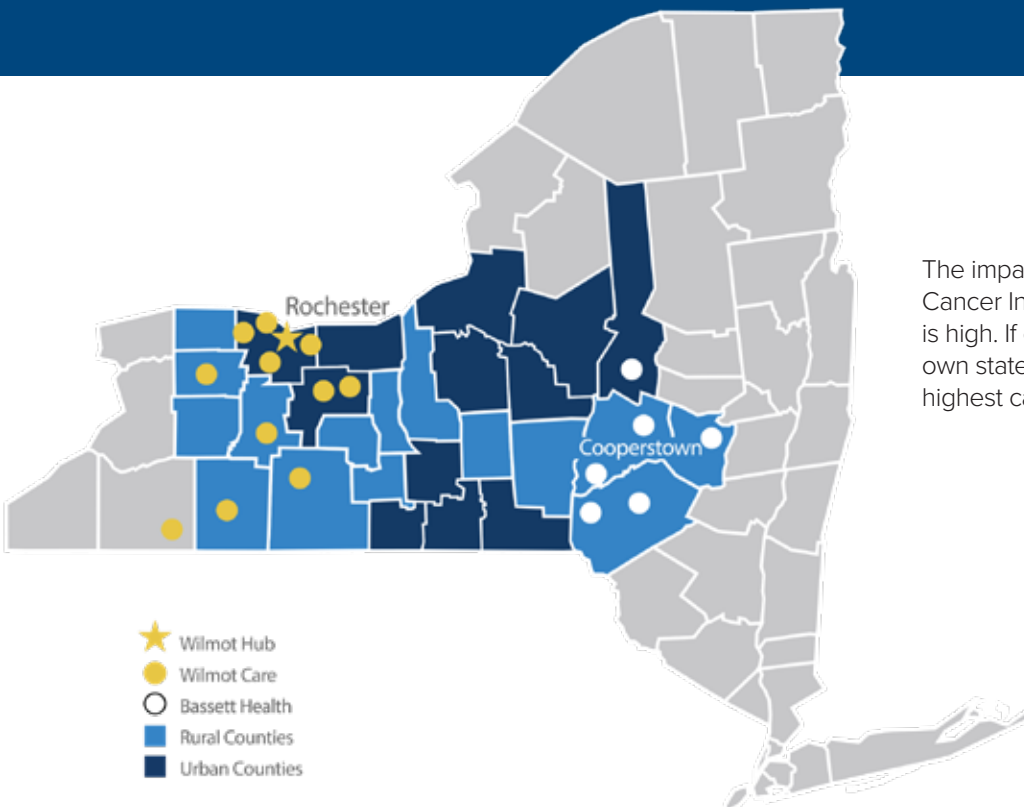
Inform:

The community and Wilmot researchers of cancer-related priorities and community needs through publicly available, geospatial mapping tools and custom reports.

Increase:

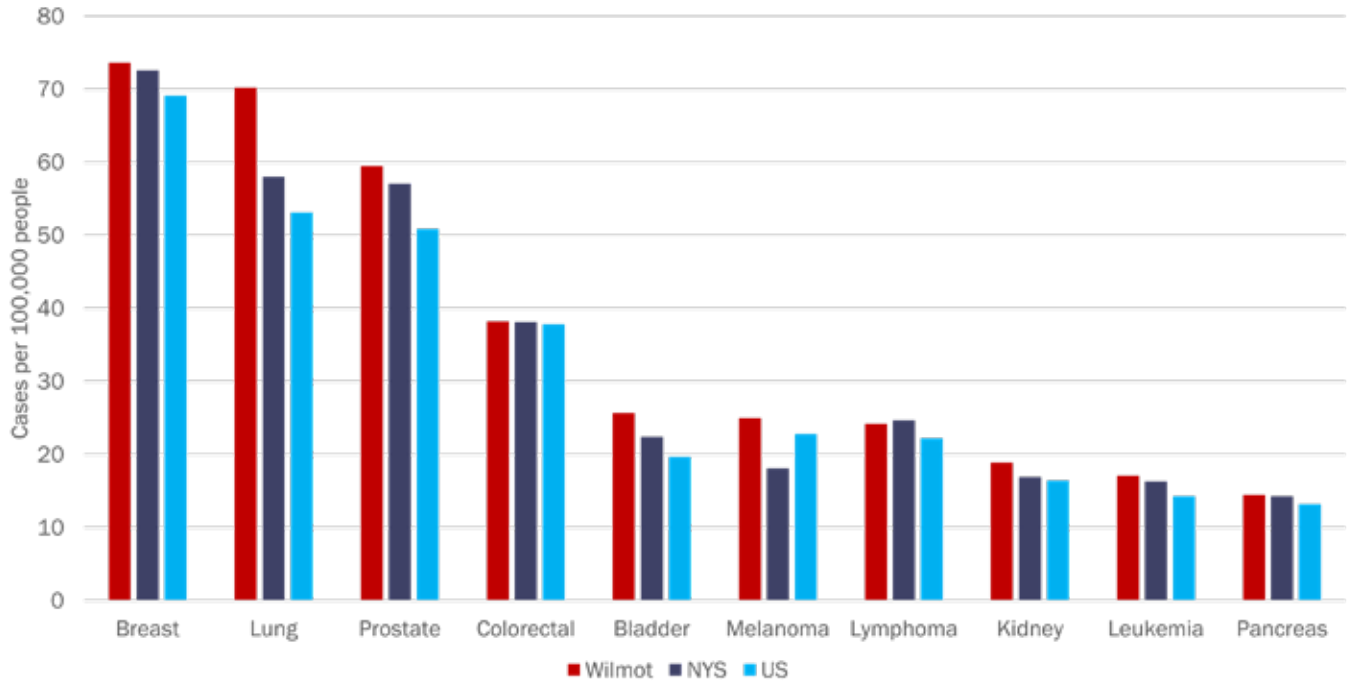
Our research, outreach, and education initiatives that focus on reducing cancer disparities

- **3.2 Million People**
- **27 counties in Western and Central New York**
- **31% Rural**
- **18% over 65 years old**
- Largest per capita Deaf community in US, Sexual and Gender Minority population **1.6x higher than US**
- **97%** of new patients seen at Wilmot live in this CA
- **40%** Black and **20%** Latino in City of Rochester



The impact of cancer across Wilmot Cancer Institute's 27-county CA is high. If our counties were their own state, we would have the 2nd highest cancer rate in the country.

Incidence rates in our CA are higher for 9 of the top 10 cancers.



Risk Factors, Behaviors, and Screening in our Catchment Area

Low HPV vaccination rates

Smoking rates are 16.9%, compared to 11.1% for NYS and 14.2% for the US.

High rates of obesity (33%)

Tools We Use

Cancer Visual Analytic System (CANVAS) is web-based mapping tool designed to combine Wilmot patient data with external data sources. CANVAS offers the ability to compare multiple maps with different data points side by side. CANVAS is available to Wilmot members through Wilmot’s informatics team.

New Cancer InFocus is an publicly-available data mapping tool that allows researchers and community members to explore cancer-relevant data variables (including social determinants of health) through interactive maps and downloaded able datasets.

COE OUTREACH HIGHLIGHTS

Being present in the community is much more than words.

Being present in the community means **action**.

COE works strategically to disseminate evidence-based cancer prevention and control initiatives and inform policy, with the goal of reducing the cancer burden and promoting equity across our catchment area. We hear the testimonies and voices of our community partners, leaders and citizens. We learn about cancer-related health concerns and barriers to accessing quality care from the people experiencing them in real time. This information helps drive Wilmot's priorities, resources, and outreach.

30+ community Partners in Outreach



The Great American Smokeout, 2023.



861

Outreach Events

1,322

Community Health Needs Assessments

Rochester Red Wings Survivor's Night, 2024



PARTNERSHIP HIGHLIGHTS

Based on the community priorities and the cancer burden, our COE team and partners develop culturally and linguistically sensitive education and outreach materials to increase knowledge and access to cancer screenings, tobacco cessation programs, genetic counseling, and other Wilmot initiatives. Our team is also prepared to support recruitment in research studies. Our outreach and education depend on our dedicated staff at community offices and community health workers.



Inflatable Colon.

500+
Enrolled into
Wilmot's Quit
Center



Strollin' for the Colon Race, September, 2024.

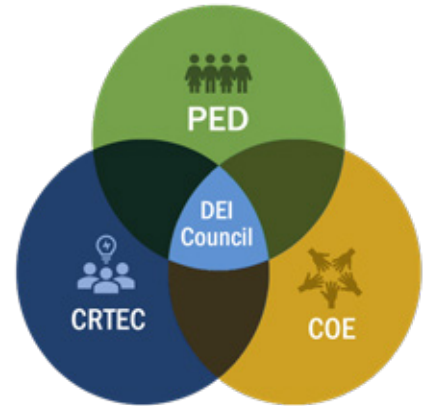


A call to action: women of color event, September, 2024.

25,000+
People
Reached



Associate Directors, Assistant Directors and Program Managers



Cancer Research Training and Education Coordination (CRTEC)

Associate Director: Ruth O'Regan, MD

Assistant Director: Carla Casulo, MD

The CRTEC Office aims to provide the highest quality of cancer research education and training across the learning continuum, from high school students to faculty, strengthening the pipeline of new scientists, clinicians, and educators in the cancer research workforce.

Diversity, Equity and Inclusion (DEI)

Associate Director: Patricia Rivera, MD

Assistant Director: Allison Magnuson, MD

The DEI Office launched in August 2022 and is committed to creating leadership and career advancement opportunities for underrepresented members who will be future leaders.

Collaboration Spotlight

Engagement of the Deaf and Hard of Hearing Community

COE and CCAC have identified enhancing engagement of the Deaf community as an urgent priority.

Needs Assessment of the Deaf Community in Rochester

- Collaboration between COE and Innivee Strategies to survey 118 Deaf and HoH individuals, providing valuable insight into this community's current needs.

Recruitment of Deaf Health Professionals

- In response to community recommendations, the DEI office is implementing specific strategies to support hiring more Deaf faculty and staff.

Wilmot Future Deaf Scientists Internship Program

- Collaboration between CRTEC and the Rochester School for the Deaf (RSD). Now in its 4th year, this innovative summer internship program sees Deaf high school students spending four weeks at Wilmot, gaining insights into careers in translational cancer research and clinical care.

- Wilmot received additional funding from the National Cancer Institute in 2024 to expand the summer internship to a complete two-year academic program and to include four additional sites across the U.S.

Cultural Competence Training for Mentors of Deaf Trainees

Develop Cultural Competence Training for Mentors of Deaf Trainees.



ENGAGING THE COMMUNITY IN RESEARCH

Cancer Prevention and Control (CPC)

Supriya Mohile, MD, MS & Karen Mustian, PhD, MPH
Researchers in Cancer Prevention and Control (CPC) work alongside patients, survivors, and caregivers to develop effective interventions for reducing cancer risk as well as develop supportive care therapies that reduce lingering effects of cancer and its treatments. Current focuses include behavior change through interventions (e.g. tobacco control, screening, and exercise), aging, and diversity.



CPC Liaison Highlight: *Dr. Scott McIntosh studies technology-assisted and self-help interventions for risk behavior change. He has worked with other CPC members and Wilmot's COE team to evaluate and share community-engaged interventions for tobacco cessation in communities with high smoking rates. Additionally, he is working closely with CCAC members to elevate research on emerging community priorities, such as helping people quit vaping.*

Cancer Microenvironment (CM)

Laura Calvi, MD & Minsoo Kim, PhD
Researchers in Cancer Microenvironment aim on improving cancer treatment methods through utilizing their research on cell manipulation. Current focuses include developing methods of disrupting cancer-cell promoting micro-environments, reprogramming immunosuppressive responses, and mitigating tissue injury due to cancer treatment.

CM Liaison Highlight: *Dr. Benjamin Frisch's research is focused on changes of the bone marrow microenvironment caused by myeloid malignancies, with the goal of translating this research for clinical use. He has a specific interest in outreach to rural and Mennonite communities, and with his support, CM members have engaged rural and older adult hematologic cancer patients/survivors via a Community Advisory Board convened by Wilmot's COE Office in new research happening in his program.*



Genetics, Epigenetics & Metabolism (GEM)

Paula Vertino, PhD & Darren Carpizo, MD, PhD
Genetics, Epigenetics, and Metabolism (GEM) is a laboratory-based research program that aims to better our understanding of cellular factors that drive cancer development. Current focuses include genetic and epigenetic factors effecting cancer cell plasticity, aging's effect on vulnerabilities to cancer, and exploiting vulnerabilities brought about by oxidative stress and metabolic re-programming.

GEM Liaison Highlight: *Dr. Isaac Harris's research focuses on uncovering the various roles of antioxidants in cancer by using pre-clinical approaches (i.e., using cancer cells in a dish or animal models). In 2023, he was awarded COE Pilot funding to look at the impact of a whole-food, plant-based diet on patients with metastatic breast cancer. He is partnering with the Faith in Community Advisory Board to guide this research, help disseminate study results, and lay the foundation for future clinical trials.*



ENGAGING THE COMMUNITY IN RESEARCH

Integration of Community Voices on Clinical Trial Committees

- Clinical Research Leadership Committee
Community Representative: Jeffrey Freeman
- Protocol Review and Monitoring Committee
Community Representatives: Karen Hermance and Ira Starks

CTO Liaison Highlight: Anna Weiss, MD

Dr. Weiss is the Director of the Breast Cancer Service Line at Wilmot and serves as the COE Clinical Research Liaison to support clinical trial recruitment and retention efforts. She works closely with the COE Office and CCAC members to strategize on ways to enhance research productivity and clinical trial accruals from diverse populations.



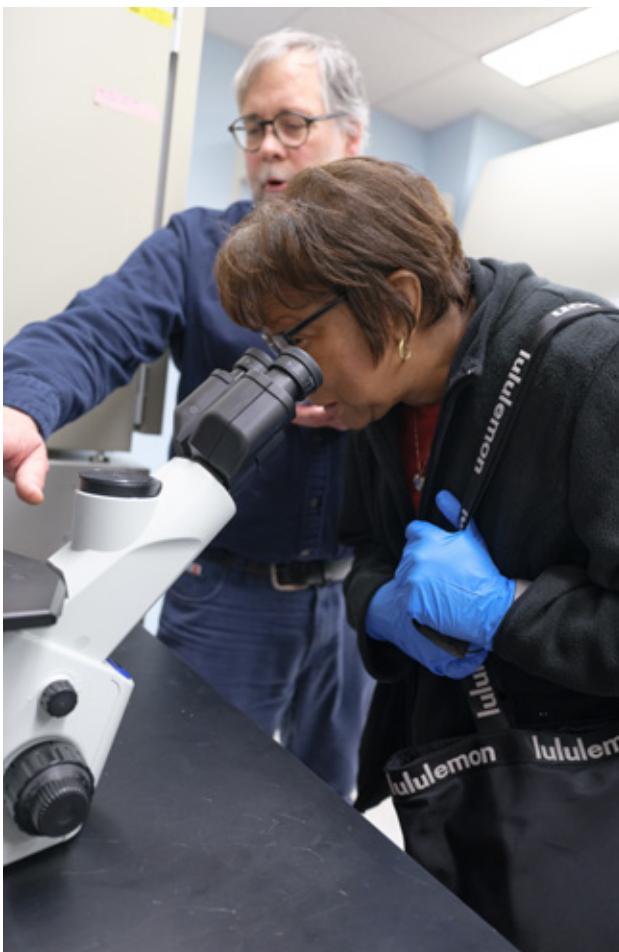
New Community-Informed Research Projects

To ensure Wilmot's research is responsive to community needs, the CCAC and COE work together to convene Community Advisory Boards (CABs). CABs are comprised of small groups of community members that represent the community voice, identify and advocate for community preferences and interests, and provide feedback on all aspects of the research.



Impact on Community-Informed Research

- 97** community members engaged
- 29** investigators presented
- 32** projects reviewed
- 27** publications supported
 - 16** with community members as co-authors



Active CABs in 2024:

Faith in Community Advisory Board

Latinos Contra el Cancer

Latino Youth Kick Vaping

Sexual and Gender Minority (SGM)

SOCARE (Specialized Oncology Care and Research for our Elders)

Adolescents and Young Adults

Acute Myeloid Leukemia

Together Against Pancreatic Cancer

Keynote Speaker

Sharon Belvin

Stage 4 Melanoma Survivor
Personal Trainer
CRI ImmunoAdvocate

In 2004, at the age of 22, Sharon Belvin was diagnosed with stage 4 melanoma. After trying nearly all cancer treatments and experiencing severe side effects, Sharon was almost out of options. After talking with her oncologist, Sharon joined a clinical trial testing a new type of cancer treatment called checkpoint blockade immunotherapy. One year later, after four rounds of treatment, Sharon was cancer free. She now dedicates herself to helping others become as healthy as possible and sharing her story to inspire others in their fight against cancer.



Visiting Professors Panel

Learn from national experts representing the Black, Latino, and Deaf Communities who are presenting best-practices for recruiting under-represented populations to clinical trials!



Marvela Ford, PhD

*Associate Director, Population Science and Community Outreach and Engagement, Hollings Cancer Center
Endowed Chair, Cancer Disparities, Medical University of South Carolina*

An overarching goal of Dr. Ford's research is to identify and address the disparities in cancer outcomes due to race, geography and other contextual and/or socioeconomic factors.



Poorna Kushalnagar, PhD

*Professor and Director of the Center for Deaf Health Equity, Gallaudet University
Chief Research Officer in the Office of Research, Gallaudet University*

Dr. Kushalnagar's work is at the interface of health communication and patient reported quality of life outcomes in deaf and hard-of-hearing people across the lifespan.



Jesse Nodora, DrPH

*Associate Director for Community Outreach and Engagement, Moores Cancer Center, UC San Diego Health
Associate Professor in the Department of Radiation Medicine and Applied Sciences (RMAS), UC San Diego*

Dr. Nodora is committed to improving health outcomes through discovery, implementation, and dissemination of effective health promotion and health service interventions.

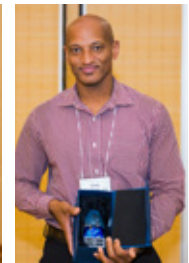
Edgar Santa Cruz Aspire Award

This award is presented to two members of the CCAC who have demonstrated outstanding support of the mission of the CCAC. This year's recipients have not only attended CCAC meetings and activities, they have also aspired to cultivate an inclusive culture to promote equity and increase community engagement in academics/healthcare. Recipients are chosen by their CCAC peers for going above and beyond to make a difference in their community.



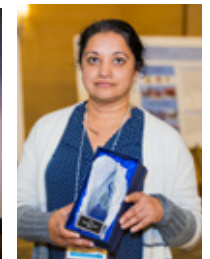
Community Vision Award

This award is presented to two community partners that have worked with the CCAC to further projects and affect change in our region, all with a focus on equity. This year's recipients embrace the mission of CCAC and empower community, giving voice to true community need.



COE Innovator Award

This award is presented to two Wilmot employees that work with COE and CCAC to engage with community, reduce health inequity, and cultivate an inclusive culture. This year's recipients have identified and implemented innovative ways to involve the community in research, to ensure community voice in Wilmot's Strategic Plan, and to be responsive to community need, all to lessen the burden of cancer across our region.



AGENDA

MORNING

8:00 am – 9:00 am Poster Session and light breakfast

9:00 am – 12:15 pm

Land Acknowledgement

Welcome Dr. Friedberg

Keynote Sharon Belvin

Visiting Professors & Q & A

- Poorna Kulshalngar, Gallaudet University
- Dr. Marvella Ford, Medical University of South Carolina
- Dr. Jesse Nodora, UC San Diego Health

Stretch break and photo

Breakout rooms

- Diversity in recruitment, enrollment, and retention in research studies
- Overcoming language barriers in clinical trials
- Social media and marketing clinical trials
- Disseminating research findings to the community
- Overcoming social determinants of health barriers to clinical trials
- Community engagement in basic science research

AFTERNOON

12:15 pm – 1:30 pm Lunch and Poster Session

1:30 pm – 4:00 pm

Awards

CCAC Working Group panel

Stretch break

Community priorities break out session

- DEI at Wilmot
- Increasing cancer screenings in the community
- Youth and the vaping epidemic
- Needs of rural communities
- Doctor/patient relationship and communication
- Community priorities on cancer

4:00 pm – 5:00 pm CCACtail hour

THANK YOU

Special thank you to our CCAC members, community partners, and Wilmot team that have worked tirelessly for the past five-years to enact equitable change in our region. We will continue 'working with communities today to lessen the impact of cancer tomorrow.

*With gratitude,
CCAC co-chairs Karen Hermance and Jeffrey Freeman*

The 5th Annual CCAC Retreat is sponsored by

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