

# Welcome to Healthy Together Cancer Community Stakeholder Retreat!



University of Cincinnati • UC Health • Cincinnati Children's

**OVERVIEW OF**

# **University of Cincinnati Cancer Center**

**Syed A. Ahmad, MD**

Co-Director, University of Cincinnati Cancer Center



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# Benefits of NCI Designation for our Community

Obtaining NCI designation will validate our scientific enterprise and provide additional funding to expand our groundbreaking research that will help reduce the burden of cancer in our community through our discoveries.

## What is the Value of NCI Designation?

- **Impact** – Reduces cancer risk, incidence and mortality in the region
- **Quality** – Facilitates recruitment of top physicians and scientists
- **Funding** – Secures funding that is only available to NCI-designated Centers
- **Partnerships** – Expand industry and community partnerships



# University of Cincinnati Cancer Center



# About the University of Cincinnati Cancer Center

The Cancer Center unifies cancer research under one umbrella to focus our collective effort toward making transformative scientific discoveries that will lead to better health outcomes for all.



**Cancer Research**



**Education & Training**

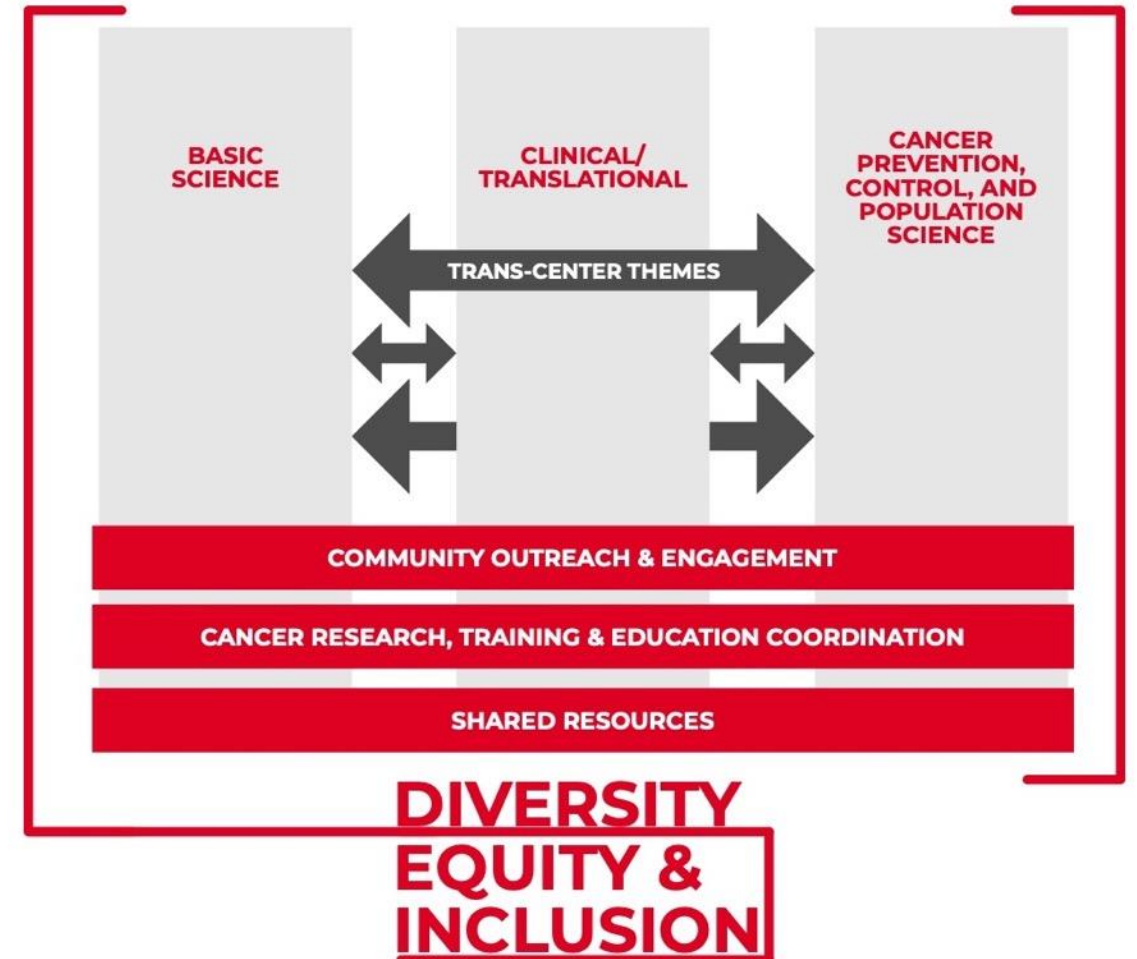
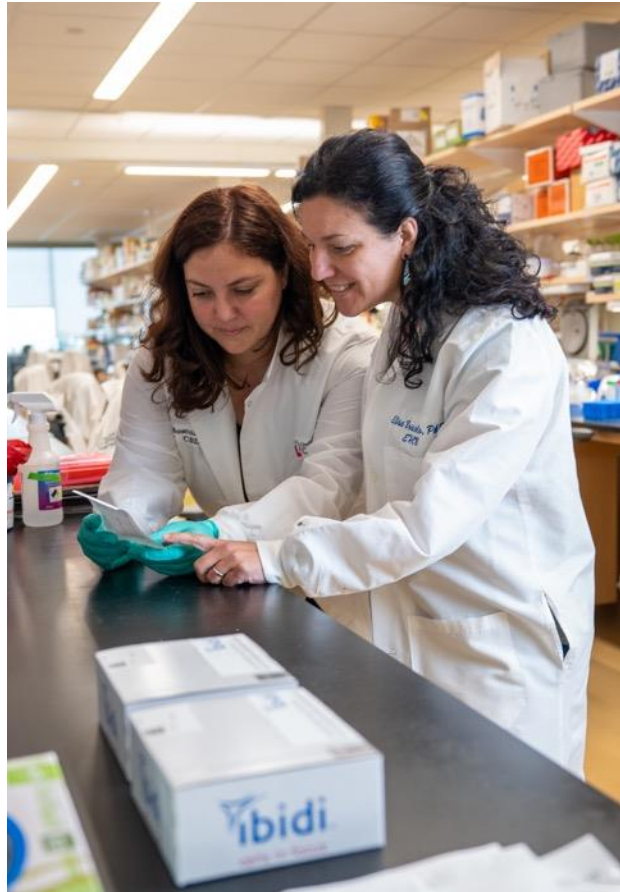


**Cancer Care**



**Community Outreach  
& Engagement**

# Cancer Research



# Cancer Care



## Clinical Partners





# Education & Training





# Community Outreach & Engagement

Research conducted at a Cancer Center needs to align with the community's unique health needs. Through Community Outreach & Engagement, Cancer Centers are tasked with connecting community insights to research and sharing evidence-based findings with the community. This is facilitated through a Community Advisory Board (CAB), which acts as a bridge between the Cancer Center and the community it serves.



# Catchment Area



**2.6M** CATCHMENT AREA  
POPULATION

The Cancer Center serves a catchment area consisting of seven counties in Southwest Ohio and three in Northern Kentucky.

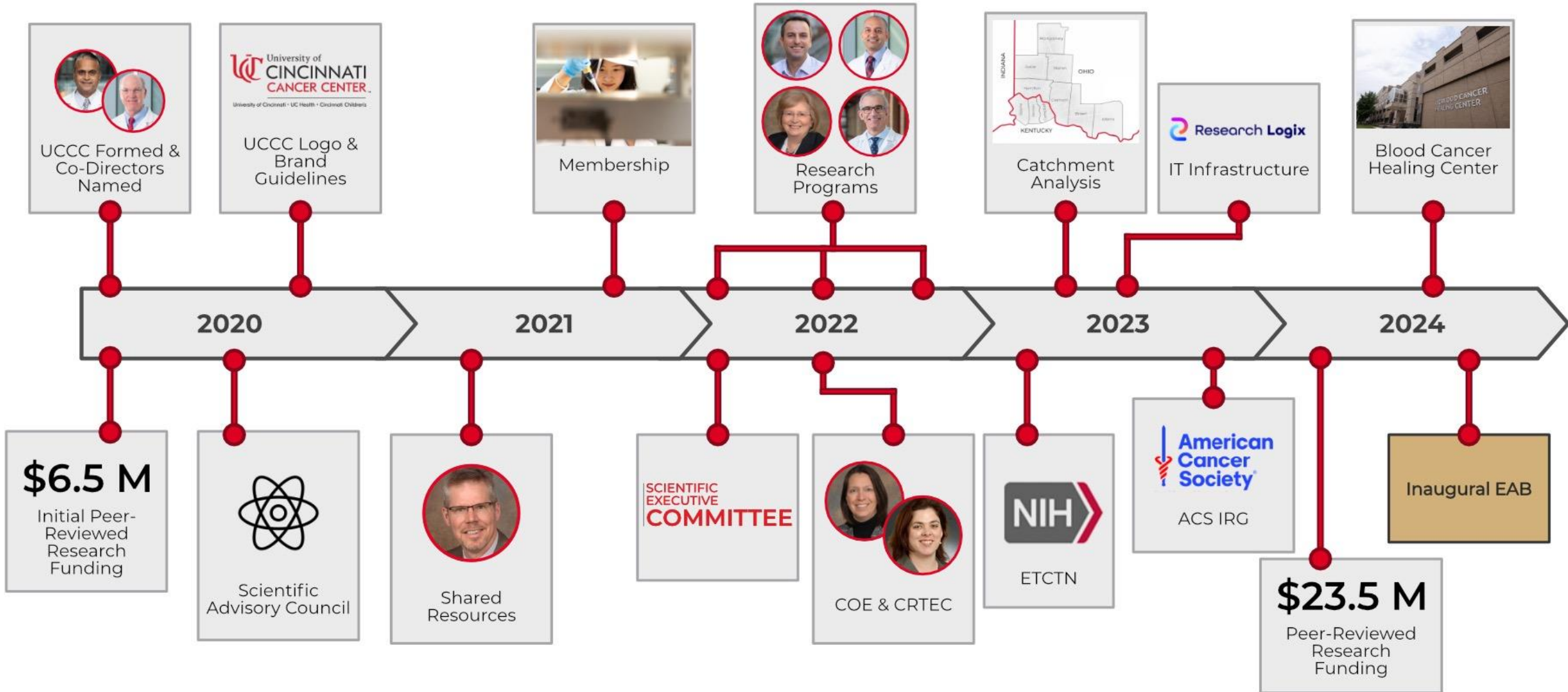
## Priority Disease Areas

- ✓ Lung Cancer
- ✓ Prostate Cancer
- ✓ Breast Cancer
- ✓ Colorectal Cancer
- ✓ Blood Cancer
- ✓ Head & Neck Cancer

## Priority Modifiable Risk Factors

- ✓ Cancer Screening Rates
- ✓ Tobacco Use  
(Smoking/Vaping/Chewing)
- ✓ Obesity & Physical Inactivity
- ✓ Mental Health among Survivors

# Progress To-Date





# Leaders and Scientific Organizational Structure



**Co-Director**  
Syed Ahmad, MD



**Co-Director**  
William Barrett, MD



**AD for Basic Science**  
Daniel Starczynowski, PhD



**AD for Clinical Research**  
Davendra Sohal, MD, MPH



**AD for Population Science Research**  
Susan Pinney, PhD



**AD for Translational Research**  
Pier Paolo Scaglioni, MD



**AD for COE**  
Melinda Butsch Kovacic, MPH, PhD



**AD for CRTEC**  
Susan Waltz, PhD



**AD for Shared Resources**  
Ken Greis, PhD



**AD for Administration**  
Tammy Mentzel, MPH

# Scientific Accomplishments

**186**

**Members**

**33**

**Departments  
& Divisions**

**3**

**Research  
Programs**

**2**

**Shared  
Resources**

**383**

**Publications (2023)**  
*24.8% with Impact Factor  $\geq 10$*

**23.5M**

**Peer-Reviewed Research  
Funding (Direct)**

**29.6M**

**Total Research  
Funding (Direct)**

**482**

**Interventional Trial  
Accrual (2023)**

**206**

**Therapeutic Trial  
Accrual (2023)**



# We Can't Tackle Cancer Alone



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OVERVIEW OF

# Community Outreach and Engagement

*Cancer Center Priorities*

**Melinda Butsch Kovacic, MPH, PhD**

Associate Director, Community Outreach and Engagement

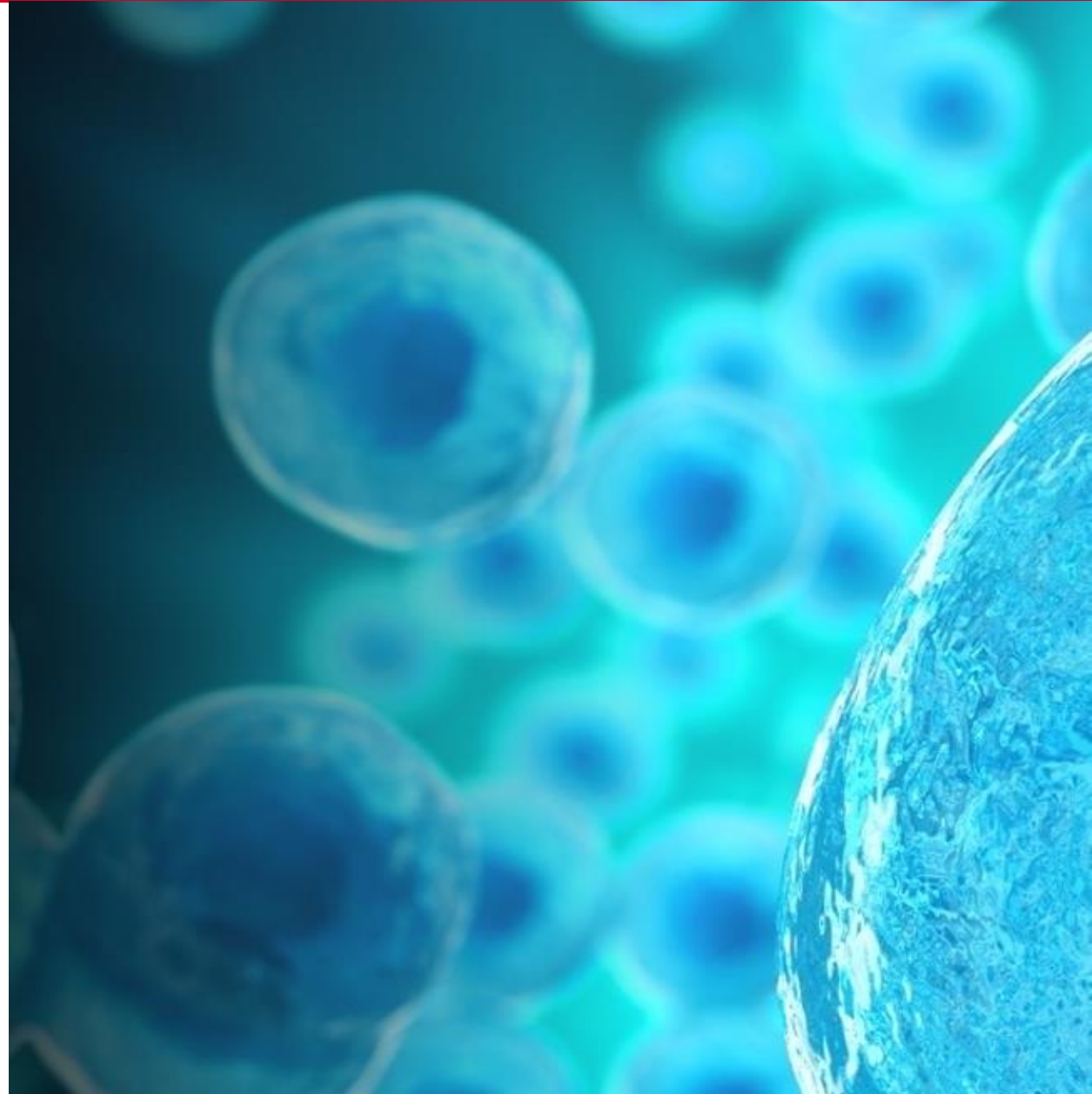


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# What is Cancer?

Abnormal, uncontrolled cell growth.





# What is Cancer?

Most people don't know what cancer is or what factors increase and reduce their risk of a diagnosis.

Many fear it's a death sentence.





# The Importance of Tailored Education, Timely Screening, & Primary Care



### Colorectal Cancer

University of Cincinnati  
CANCER CENTER

#### WHAT YOU NEED TO KNOW ABOUT COLORECTAL CANCERS

##### OVERVIEW OF COLON

myclevelandclinic.org/health/diseases/25565-colorectal-cancer

##### SYMPTOMS CAN INCLUDE

- ⓧ A change in bowel habits
- ⓧ Rectal bleeding with bright red blood
- ⓧ Blood in the stool, which might make the stool look dark brown or black
- ⓧ Cramping or abdominal (belly) pain
- ⓧ Weakness and fatigue
- ⓧ Unintended weight loss
- ⓧ Colon polyps sometimes do not cause symptoms

##### RISK FACTORS

- Obesity
- Smoking/ tobacco use
- Alcohol use

Continued...

- Age - Risk increases as you age
- Race - American Indian have highest rates, followed by African American
- Gender - More common in men than women (1 in 23 men, 1 in 25 women)
- Type 2 diabetes
- Personal history of inflammatory bowel disease or colorectal polyps
- Family history of colorectal cancer
- Survivors: radiation to the abdomen or pelvic area (to treat prior cancer)

##### COLORECTAL SCREENINGS

Types of screenings available:

- Colonoscopy**  
Need retesting every 10 years
- At-Home Tests (Cologuard & FIT)**  
Need retesting every 3 years
- Stool-based Tests**  
Testing typically needed every year

SCAN QR CODE FOR COLORECTAL SCREENINGS

ufc.org/cancercenter/colorectal-cancer

Call 513-585-UCCC to schedule with the Cancer Screening Team

SCAN ME

### Cancer de Seno

University of Cincinnati  
CANCER CENTER

#### Lo que necesitas saber sobre el cáncer de seno

##### DESCRIPCIÓN GENERAL DE LOS SENOS

myclevelandclinic.org/health/diseases/25565-cancer-de-seno

##### FACTORES DE RIESGO

- Edad (El riesgo aumenta con la edad)
- Raza y Etnia (Las mujeres afroamericanas tienen la tasa de mortalidad más alta)
- Obesidad
- Abuso de alcohol
- Genética heredada
- Enfermedad del hígado
- Historia familiar
- Género (Las mujeres tienen un mayor riesgo)

##### LOS SÍNTOMAS PUEDEN INCLUIR

- Un nuevo bulto o masa: *Es importante tener cualquier masa nueva, bulto o cito cambio en el seno verificado por un profesional de la salud con experiencia*
- Hinchazón del seno completo o parte del seno (incluso si no se siente un bulto)
- Hoyuelos en la piel (a veces pareciéndose a piel de naranja)
- Dolor en los senos o pezones
- Retracción del pezón (girando hacia adentro)
- El pezón o la piel del seno enrojecida, seca, descamada, o engrosada
- Secreción del pezón (que no sea leche materna)
- Cambios intencionales inflamados debajo del brazo o cerca de la clavícula (A veces, esto puede ser un signo de que el cáncer de seno se ha propagado incluso áreas de que el tumor original en la mama sea lo suficientemente grande como para palpable)

##### DATOS Y CIFRAS

- El cáncer de seno es el más común entre las mujeres en los Estados Unidos
- Entre 8 posibilidades de que una mujer desarrolle cáncer de seno a lo largo de su vida
- La edad media de diagnóstico es 62 años, poco común en mujeres menores de 45 años
- Los hombres también corren riesgo
- Segunda causa principal de muerte por cáncer en mujeres, después del pulmón
- Las mujeres afroamericanas tienen la tasa de mortalidad más alta

**4 MILLONES +** Sobrevivientes del cáncer de seno en los Estados Unidos

Muchas veces el cáncer de seno es tratable. (La detección temprana es clave)

##### RECOMENDACIONES PARA EXÁMENES DE SENO

Para riesgo promedio	40-44 años	45-54 años	55+
Prueba de detección anual para mujeres de 45 o 54+			
Las mujeres con alto riesgo deben hacer una resonancia magnética (MRI) de mama y mamografía cada año a partir de los 30 años			

ESCANEAR EL CÓDIGO QR PARA SERVICIOS DE MAMOGRAFÍA

Llama al 513-585-UCCC para agendar una cita o visite el sitio web para ver el horario de la caminata de mamografía

ESCANÉAME



# Aims of the Office of Community Outreach and Engagement (COE)

## Aim 1

### INCLUDE:

Understand & monitor our diverse catchment area's needs & assets so our priorities align



## Aim 2

### IMPACT:

Mobilize outreach & encourage engagement between our membership & our community



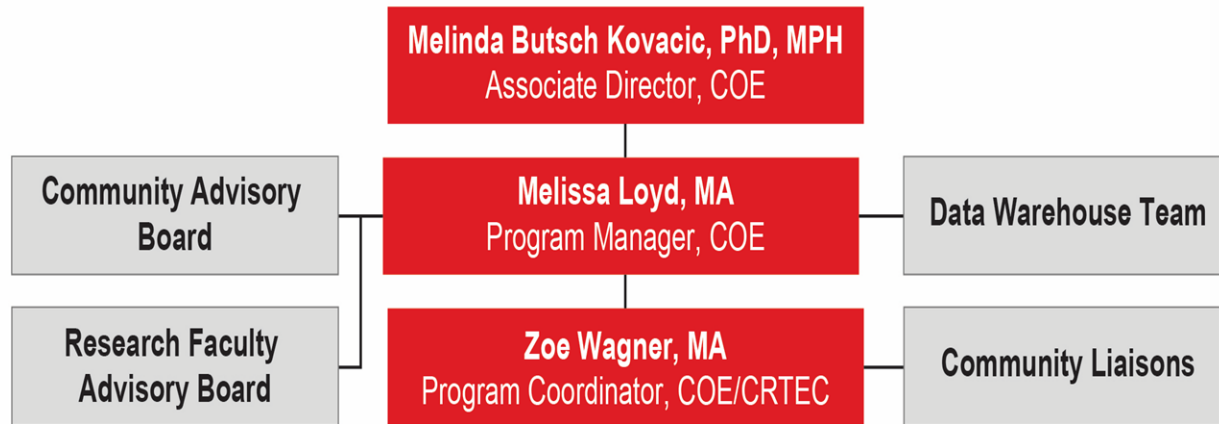
## Aim 3

### INNOVATE:

Catalyze research & policies to diminish disparities, improve survivorship, & defeat cancer



# The Cancer Center's COE Team





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**UNIVERSITY OF CINCINNATI CANCER CENTER**  
 Office of Community Outreach & Engagement

## Community Outreach & Engagement

Community Outreach & Engagement works to establish and strengthen community partnerships throughout the region by connecting community members and community organizations directly to researchers and clinicians at the University of Cincinnati Cancer Center. Leveraging these partnerships, together we hope to better address the cancer-related challenges in our region, and over time, reduce the overall burden of cancer.



Community



Research



Clinical Practices

- ✓ Monitor the cancer burden over time across the region to ensure our research is relevant and impactful
- ✓ Champion education and advocacy programs as well as research initiatives that engage or partner with local communities
- ✓ Promote health equity and eliminate cancer health disparities through meaningful partnerships, community-engaged research, and increasing diversity in clinical trials

### Traditional vs. Community Engaged Research

<p>Community engaged research shifts the focus from a purely academic perspective to one rooted in community impact. The goal is no longer just about advancing knowledge on a theoretical question, but on answering the questions that matter to the community to make our society healthier long-term.</p>	<table border="0"> <tr> <td>Advance Knowledge</td> <td>→</td> <td>Better the Community</td> </tr> <tr> <td>Focus on Theoretical Question</td> <td>→</td> <td>Focus on Community-Identified Problem</td> </tr> <tr> <td>Designed by a Researcher</td> <td>→</td> <td>Designed Collaboratively with Community</td> </tr> <tr> <td>Short Term Relationship</td> <td>→</td> <td>Long-Term, Multifaceted Relationship</td> </tr> <tr> <td>Value Based on Peer Acceptance</td> <td>→</td> <td>Value based on Community Impact</td> </tr> </table>	Advance Knowledge	→	Better the Community	Focus on Theoretical Question	→	Focus on Community-Identified Problem	Designed by a Researcher	→	Designed Collaboratively with Community	Short Term Relationship	→	Long-Term, Multifaceted Relationship	Value Based on Peer Acceptance	→	Value based on Community Impact
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Short Term Relationship	→	Long-Term, Multifaceted Relationship														
Value Based on Peer Acceptance	→	Value based on Community Impact														

### Community Engaged Research Continuum

The diagram shows a horizontal line with arrows at both ends, representing a continuum from "LESS COMMUNITY INVOLVEMENT" to "COMPLETE COMMUNITY INVOLVEMENT". Along the line, there are five points representing different research models:

- INVESTIGATOR-DRIVEN RESEARCH (at the far left, under "LESS COMMUNITY INVOLVEMENT")
- COMMUNITY PLACED RESEARCH (moving right)
- COMMUNITY BASED RESEARCH (in the middle)
- COMMUNITY PARTICIPATORY RESEARCH (moving right)
- COMMUNITY-DRIVEN RESEARCH (at the far right, under "COMPLETE COMMUNITY INVOLVEMENT")



# UC Cancer Center Community Advisory Board



**Artemio Castro**

*Reach Out Lakota*



**Asha Rone**

*Cancer Support Community*



**Casey Faber**

*American Cancer Society*



**Colleen Murray**

*Paddling for Cancer Awareness*



**Courthney Calvin**

*Cincinnati Health Department*



**Herschel Chalk**

*Community Advocate*



**Jada Davis**

*Cancer Justice Network*



**Jill Settlemyre**

*Cancer Family Care*



**Steve Sunderland**

*Coalition for Health Justice*

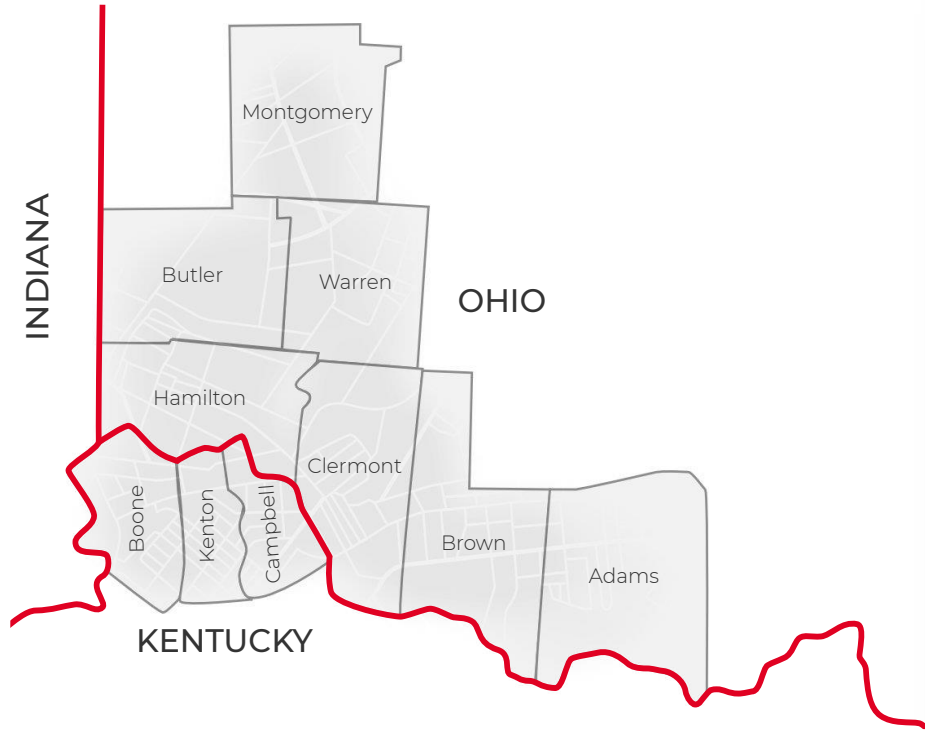
# Cancer Center Community Advisory Board

- ✓ *Identifying* Cancer Center priorities and holding the Cancer Center accountable for making progress in priority areas.
- ✓ *Connecting* community members and community organizations directly to researchers and clinicians to provide opportunities for discussion and enable bidirectional learning.
- ✓ *Strategizing* outreach to ensure education is relevant and screening is accessible.
- ✓ *Reviewing* Cancer Center members' research plans and protocols to ensure they consider patients' perspectives and maximize the research's impact.





# Catchment Area Data Dashboard



## University of Cincinnati Cancer Center

### University of Cincinnati Cancer Center Population Based Catchment Data Dashboard

5 Year Age Adjusted Cancer Rate per 100,000 2017-2021

Click on county or counties to update chart and tables to search multiple counties please and hold down and click each county to include. Please click on to clear selections  
Data source: <https://cancerregistryofuc.cancer.gov/>

Map filter  
☒ Incidence  
☐ Mortality

© 2024 Mapbox © OpenStreetMap

5 Year Estimate Catchment County Population Demographics 2017-2021

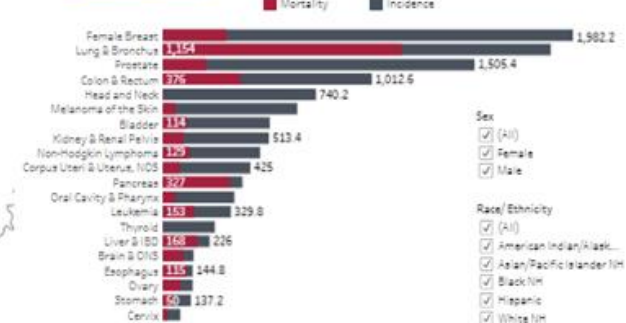
Data Source: [data.census.gov](https://data.census.gov/)

		100.0%	2,673,721
Population	Total		
Race	Asian	2.8%	75,079
	Black	14.1%	375,934
	Other Races	4.1%	110,172
	White	75.4%	2,015,508
Ethnicity	Hispanic	3.6%	96,948
	No Ethnicity Reported	96.4%	2,576,773
Geography	Rural	11.1%	296,406
	Urban	88.9%	2,377,315
Age	Under 18	22.9%	613,393
	25 to 64	60.8%	1,624,737
	Over 64	16.3%	435,591
Education	Below 9th grade	2.4%	64,105
	High School	58.2%	2,357,844
	College	35.4%	945,052
	Advanced Degree	13.7%	366,888
Estimated	Current	100.2%	2,678,469
	Female	51.0%	1,362,416
	Male	49.2%	1,316,053

To request additional data, please fill out the linked form: <https://redcap.link/CatchmentDataRequest>

5 Year Age Adjusted Catchment County Cases of Cancer Incidence / Mortality 2017-2021

Left hand numbers (links) are count of incidence  
Right hand numbers (links) are count of mortality  
Data source: <https://cancerregistryofuc.cancer.gov/>



2021 County Risk Factors

2021 BRFSS

<https://www.doh.mt.gov/brfss>

\*BRFSS 2020 data

Cancer Prevalence	8.2%
*Met Breast Screen %	77.9%
*Met Cervical Screen %	0.0%
*Met Colon Screen %	65.7%
Recent Checkup %	78.7%
*Recent Dentist %	61.4%

2021 County Co-Morbidities

2021 BRFSS

\*BRFSS 2020 data

BMI Obese %	38.5%
Current Smoker %	18.1%
Binge Drinking %	19.2%
BP Medicine %	79.0%
High BP %	35.8%
CHD %	8.0%
Diabetes DX %	13.6%
Had Stroke %	3.9%
Kidney Disease %	0.0%
Asthma %	11.3%
COPD %	9.3%
Depression %	0.0%
Poor Mental Health %	0.0%
*No Teeth %	0.0%
Bad Health %	20.0%
Poor Physical Health %	14.4%
*Sleep Debt %	38.2%

2017-2021 County Economic Indicators

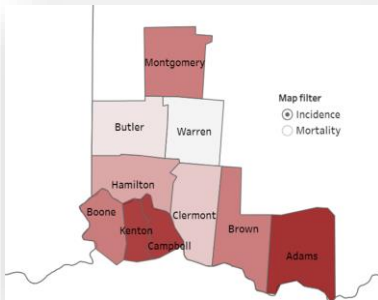
American Community Survey (ACS)

\*Compare Statistics

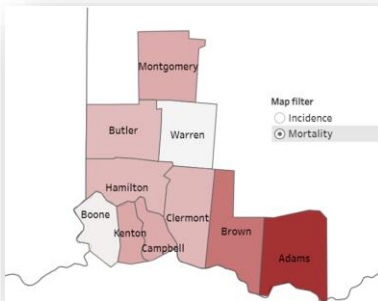
Avg. Household Income	71,838
Avg. Gini Coefficient	0.46
Insurance Coverage %	94.1%
Uninsured %	5.9%
Medicaid Enrollment %	19.2%
Annual Labor Force Participation Rate	64.4%
Annual Unemployment Rate	4.9%
Received Public Assistance %	11.5%
Below Poverty %	8.9%
No Home Broadband %	7.4%
2017-2021 County Housing Overview	
American Community Survey (ACS)	
Median Monthly Mortgage	\$1,302
Median Gross Rent	\$841
Crowded Housing %	1.4%
Lack of Complete Plumbing %	0.3%
Mobile Home %	3.5%
Multi Unit Structure Home %	9.9%
Single Parent Household %	6.6%
Vacancy Rate %	8.5%

# Catchment Area Characteristics

- 10 counties with 2.65 million people
- 90% urban
  - Hamilton and Montgomery counties are mostly urban*
  - Adams and Brown counties are mostly rural*
- 83% of hospital population are included in our catchment



- Brown Co. Incidence is highest – 524/100,000
- Adams & Montgomery Co – 486/100,000
- Hamilton Co. – 471/100,000



- Brown Co. mortality is highest – 245/100,000
- Adams Co– 199/100,000
- Hamilton & Montgomery Co. – 171/100,000 & 165/100,000

5-Year Demographics by Center, State, and US 2017-2021

		UCCC	OH	KY	US
Total Population 2021		2.7M	11.8M	4.5M	332M
Race	White	74%	77%	83%	78%
	Black	14%	12%	8%	11%
	Asian	3%	2%	2%	2%
	Other Races	4%	4%	3%	4%
Ethnicity	Hispanic	4%	4%	4%	5%
Geography	Urban	89%	76%	59%	71%
	Rural	11%	23%	41%	29%
Age	Under 18	22%	22%	22%	22%
	18-64	61%	60%	61%	61%
	Over 64	16%	18%	17%	17%
Education	Below 9th Gr.	2%	3%	4.5%	3.3%
	High School	88%	88%	81.8%	85.6%
	College	35%	30%	26.6%	29.1%
	Adv. Degree	14%	12%	11%	11%
Sex	Female	51%	51%	51%	50%
	Male	49%	49%	49%	50%

Legend: Data sourced from the American Community Survey, US Census Bureau, Population Division; UCCC catchment includes OH counties: Adams, Brown, Butler, Clermont, Hamilton, Montgomery, and Warren, and KY counties: Boone, Campbell, and Kenton

# Cancer in Our Catchment Area

Cases						
Female	Incident Cases	Deaths		Male	Incident Cases	Deaths
Breast	2,268	371		Prostate	1,707	253
Lung	1,122	682		Lung	1,142	748
Colon/rectal	600	222		Colon/rectal	644	238
Uterus	513	96		Skin Melanoma	487	47
Skin Melanoma	348	18		Bladder	460	97
NHL	257	62		Kidney	376	81
Thyroid	234	0		NHL	326	94
Kidney	230	40		Oral Cavity	301	50
Pancreas	212	182		Leukemia	228	108
Ovary	173	110		Pancreas	228	193
Leukemia	172	77		Liver	199	144
Bladder	147	33		Esophagus	140	123
Oral Cavity	122	16		Brain	114	73
Cervix	115	26		Stomach	105	33
Brain	90	52		Thyroid	83	0
Liver	69	61				
Stomach	59	21				
Esophagus	24	20				

# Cancer in Our Catchment Area

Indicator	Race/Ethnicity	UCCC	OH	KY	US
Current smoking	All races/ ethnicities	17.2%	20.8%	23.6%	15.5%
	Non-Hispanic White	16.7%	20.4%	23.0%	16.3%
	Black/African Am.	20.6%	25.2%	25.6%	17.3%
	Hispanic/Latinx	17.3%	19.8%	22.5%	12.3%
Obesity	All Races/ Ethnicities	37.7%	34.8%	36.5%	30.9%
	Non-Hispanic White	36.8%	33.9%	36.3%	29.9%
	Black/African Am.	44.1%	42.4%	42.5%	39.8%
	Hispanic/Latinx	36.6%	39.4%	31.9%	34.1%
Mammogram screening	All Races/ Ethnicities	73.4%	77.9%	75.8%	78.3%
	Non-Hispanic White	73.2%	77.5%	76.5%	78.1%
	Black/African Am.	80.1%	84.7%	82.7%	84.0%
	Hispanic/Latinx	NA*	NA*	NA*	79.4%
Colorectal cancer screening	All Races/ Ethnicities	74.3%	69.5%	65.4%	69.3%
	Non-Hispanic White	75.4%	69.7%	65.7%	71.9%
	Black/African Am.	71.2%	74.1%	62.8%	69.6%
	Hispanic/Latinx	55.7%	58.0%	40.1%	54.8%
Cervical cancer screening	All Races/Ethnicities	82.2%	74.8%	80.5%	80.2%
	Non-Hispanic White	81.8%	73.0%	80.5%	80.6%
	Black/African Am.	83.5%	84.3%	86.6%	84.8%
	Hispanic/Latinx	NA*	NA*	NA*	80.2%

# Our Identified Priorities and Risk Factors

## **Priority Cancers**

- Lung cancer
- Prostate cancer
- Breast cancer
- Colorectal cancer
- Blood cancers
- HPV-associated cancers

## **Risk Factors**

- Tobacco use (smoke/vape/chew)
- Obesity
- Cancer screenings in urban minorities/underserved communities
- Mental health and supportive services for cancer survivors



# Importance and Value of Research



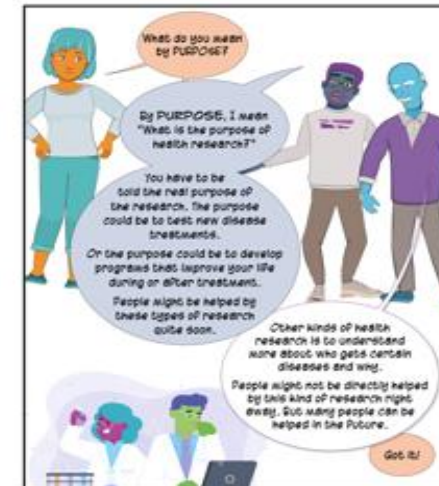
# Helping Communities and Patients to Become Research Ready

"Research Ready"  
co-designed with the West  
End Community Research  
Advisory Board.

"Becoming Research Ready"  
co-designed with six cancer  
survivors to address cancer  
clinical trials.



Panel 1



Panel 2



Panel 3



Panel 4



Panel 5

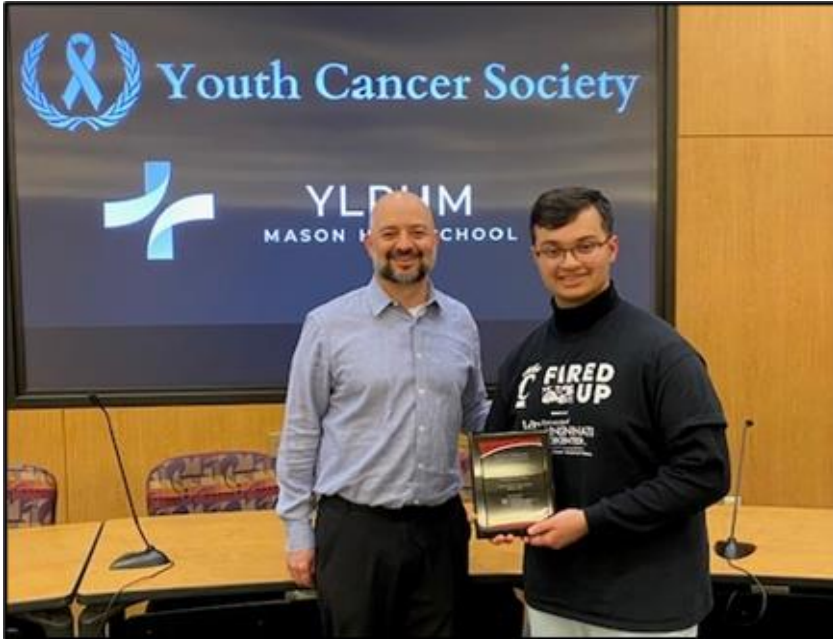


Discussion Guide



# Recognizing Excellence: Our New PRAISE Award Program

*Partnerships. Research. Advocacy. Innovation. Service. Education*



## Award Categories

- Community Partnership and Education
- Advocacy and Service
- Research and Innovation

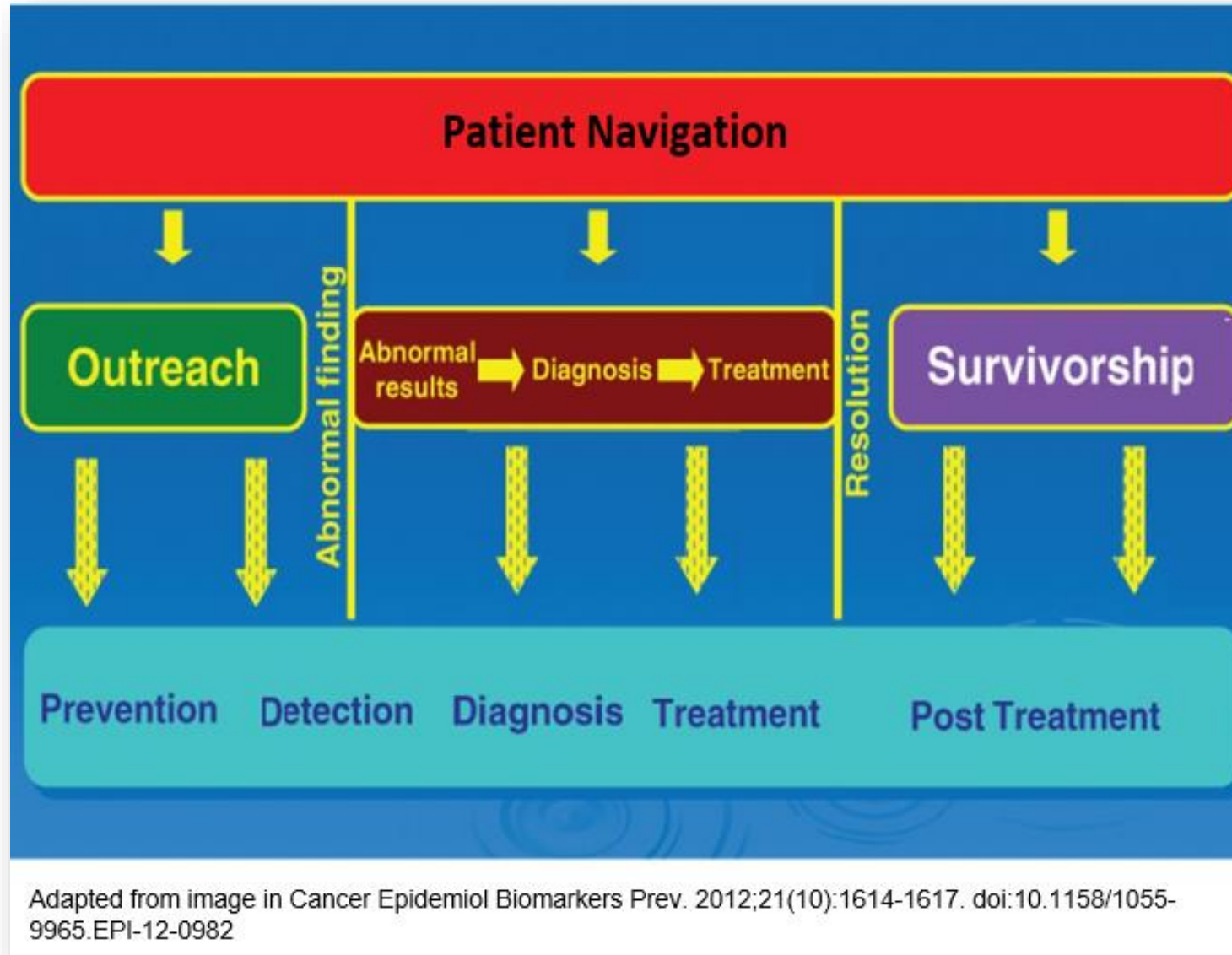
Scan to Nominate  
Someone!



# Importance of Advocacy, Policy, and Equity



# Patient Navigation





# Identifying Strategies and Identifying Partnership Opportunities



# Building Trust



OPEN TO ALL COMMUNITY GROUPS

## Community Outreach Speaker Network

We are looking for community groups eager to host University of Cincinnati Cancer Center health professionals at meetings, health fairs and more!

*Discuss top cancer-related topics important to your community*

*Hear about current and future research opportunities in key areas*

*Receive cancer prevention resources personalized to your needs*



SCAN ME

**It takes a community.**



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# Video





# Increasing Equity in Cancer

Jada Davis and Steve Sunderland



CANCER JUSTICE NETWORK

# Engaging in Advocacy: Where to Begin

Alique Topalian, PhD, MPH  
Research Scientist

Division of Survivorship and Supportive Services  
University of Cincinnati Department of Family and Community  
Medicine

# Why I Advocate





## HELP SAVE A YOUNG GIRL'S LIFE

Alike Topalian, age 4, suffers from Acute Myelogenous Leukemia, a severe form of leukemia which threatens to end her young life unless a suitable donor can be found for a bone marrow transplant.

Alike has undergone intensive chemotherapy and her doctors hope that with a marrow transplant she may survive. Her doctors have not been able to find a match in her family, where her chances were highest, or within the more than 2 million individuals in the Marrow Donor Registry. Her best hopes is to find a donor within the Armenian community, where potential donors are more likely to share her tissue type.

Alike's parents, ANCA Chairman Mourad Topalian and Michele Seyranian Topalian of Cleveland, ask you to help save their child.

Committees are now being organized by the Armenian Relief Society to work with the American Red Cross in arranging one-day blood testing drives in Armenian churches and community centers around the nation. Throughout the Eastern US, we have arranged the following:

**CLEVELAND** - March 1  
7 AM - 2 PM  
St. Gregory of Nareg Church  
675 Richmond Road  
Richmond Heights, OH  
Contact: Rose Perrito 330-273-4567  
Aida Davonian 330-489-8337

**DETROIT** - March 1  
11 AM - 5 PM  
Armenian Community Center  
18230 Ford Rd.  
Dearborn, MI  
Contact: Shakh Basmajian

**CHICAGO** - March 1  
10:30 AM to 1:30 PM  
Hudisvian Hall  
Contact: Anahid Sarratian 847-470-0349

**WASHINGTON, DC** - March 1  
12:30-2:30 PM  
Sorp Khatch Armenian Church  
4508 Flint Dr.  
Bethesda, MD  
Contact: Vrejohi Armenian 202-822-6265  
or 703-634-3606

**NEW JERSEY** - March 15  
1 PM - 5 PM  
Hovnanian School  
River Rd.  
New Milford, NJ  
Contact: Anni-Bege Koroghlian 201-599-9812  
Lucy Keomurjian 201-567-3318  
Silva Kouymurdjian 201-945-5016

**PHILADELPHIA** - March 15  
St. Gregory's Church  
Contact: Majda Garabedian 610-825-2895  
Mero Prounjan 215-368-9824

**MERRIMACK VALLEY** - March 21  
10 AM - 2 PM  
St. Gregory Church Hall  
158 Main St.  
No. Andover, MA  
Contact: Violet Dagligian 978-692-3915

**NEW YORK**  
Contact: Gemma Vartanian 718-441-2134  
Goharik Davonian 914-354-5567  
Sandra Shahbazian 718-263-2255

**PROVIDENCE**  
Contact: Joyce Yereimian 401-837-7797

**BOSTON**  
Contact: Grace Kulegian 617-923-9133  
Heather Krafian 617-648-8164

**FLORIDA**  
Contact: Siran Der Bedrossian 954-565-0482

**GRANITE CITY, IL**  
Contact: Janet Harolan 618-692-0478

**RACINE, WI**  
Contact: Vartuhi Abojan 414-639-8771

**FAIRFIELD, CT**  
Contact: Violet Gedikian 203-877-6330

**HARTFORD, CT**  
Contact: Sona Garabedian 860-763-2671

### HOW OUR COMMUNITY CAN HELP:

Take a blood test to see if you can help Alike or another leukemia patient. Community members between the ages of 18 and 60, in good general health and with no history of cancer, diabetes, heart disease or heart attack are urged to participate in the Blood Test Drive to become a potential bone marrow donor. For more information about the Drive or to sign up to participate, please contact your local representative listed above.

Help defray blood-testing costs by making a donation to the Alike Topalian Fund. Laboratory costs for testing for a potential bone marrow match are \$43/person. To help defray the costs for those who cannot afford the procedure, the Topalian family has made arrangements with the National Marrow Donor Foundation to set up a fund to cover blood analysis costs. Contributions may be written and mailed to: The Aliques Topalian Fund, c/o Pat Cirillo, 3641 Southerland Rd., Shaker Heights, OH 44122.



# LOCAL

## SUNDAY



**Pets find a safe haven**  
A Wilson laundromat and health club takes on another job — caring for lost or unwanted pets — Page 3B

## A cry for help

Armenian community tries to save a dying girl

By Bill Michelmore

Niagara Sunday  
NIAGARA FALLS — Little Alike Topalian is dying.

The Armenian community of Niagara Falls came out in force Saturday to try and save the 4-year-old, who has a severe form of leukemia.

Unless a suitable donor can be found for a bone marrow transplant, she will die, said Alice Arutunjan, chairwoman of the blood drive committee.

"I hope your pure Armenian blood will save this little girl's life," she said as people filed into the Armenian Community Center at 322 Ninth Street.

There are about 300 people in the local Armenian community.

Alike's mother, Michele Seyranian Topalian, was born and

raised in Niagara Falls and is a graduate of Niagara University. She currently lives with her husband, Mourad, in Cleveland, where she is a senior vice president for Key Bank.

People came from Hamilton, Ont., and St. Catharines to have their blood tested as potential bone marrow donors, said Mrs. Arutunjan, whose committee compiled addresses of former Niagara Falls residents and mailed out flyers of the event.

Thirty people showed up in the first two hours of the four-hour blood test drive.

"We've had a tremendous response so far," said Linda Kerwin, a registered nurse from Wilson, "It's obvious this is a very close-knit community."

Mrs. Kerwin is the bone

marrow coordinator with the Western New York chapter of the Leukemia Society of America.

Alike's doctors think there is a better chance of getting a match if they zero in on Armenian communities, said the little girl's aunt, Denise Seyranian.

The odds are still not good. In four previous bone marrow drives held across the United States since the beginning of March, 1,000 people were tested, she said.

"The response has always been great," Mrs. Seyranian said, "but no match yet."

Alike is too sick to attend the community drives.

"Alike is very optimistic and bright," said Mrs. Seyranian, "but she has been in the hospital



**DONOR:** Phlebotomist Trish Rozbicki draws blood from Martin Sarkisian Saturday at the Armenian Community Center. Doctors are trying to find a match for a bone marrow transplant for a 4-year-old Cleveland girl who has a severe form of leukemia.

for each of the drives." Money is needed to pay for the blood analysis, which cost \$50 each, said Dorothy Mooradian, vice president of the Armenian Relief Society.

Contributions to the Ali Topalian Fund may be mailed to Dorothy Mooradian, Armenian Relief Society, 548 Meadowbrook Drive, Lewiston, ME 04092.



Alike Topalian, 4, is held by her parents, Michele Seyranian-Topalian and Mourad Topalian at Shaker Heights, who are adding Americans of Armenian ancestry to have their blood tested for the National Bone Marrow Registry, in case their daughter needs a transplant to fight her rare form of leukemia.

## A match that could save a life, more

Parents of 4-year-old leukemia patient are paying for tests to identify potential bone-marrow donors

By MICHAEL SANGIACOMO  
PHOTO BY GREGORY W. WILSON

Four-year-old Alike Topalian does not know how unusual she is, or that steps taken to battle her cancer might someday benefit others of Armenian ancestry.

The child, daughter of Michele Seyranian-Topalian and Mourad Topalian of Shaker Heights, had a rare form of childhood leukemia diagnosed last month. Doctors say she might need a bone marrow transplant if her condition

prohibits bone marrow match.

"Because my husband, me and Alike are of pure Armenian descent, we're told our best chance at finding a match will be in the Armenian community," Michelle Seyranian-Topalian said. "The National Bone Marrow Registry program has few Armenians registered in it, so if we can get Armenian people typed and tested for Alike, they may help the next Armenian child who needs a transplant to find a donor. This is going beyond our family."

Greater Clevelanders of Ar-

Washington, D.C.; Boston and other cities over the month.

The child's family is paying for the cost of the typing, which is \$43 per person. The family has been established at KeyBank to help the family pay for the tests.

The child's physician, Robin Miller of Rainbow Children's Hospital, said







## For SELF

Personal Advocacy,  
Empowerment

## For OTHERS

Patients, Family, Groups &  
Organizations

## For COMMUNITY

State & National interests,  
including research and  
public policy



"My mission as an advocate is for all patients to be able to receive the kind of care and psychosocial support that I did. I was always provided so many resources, symptom management, and support services during and after treatment. This is something that can be harder and harder to find, especially in adult care settings. I believe that these resources and the shared decision-making process I had with my providers are why I have had such positive outcomes, and I believe all patients and families should have access to these kinds of supports."

– Alique Topalian,  
Acute myeloid leukemia survivor

Why is advocacy  
important?





# How can you get involved?



*\*Always be sure to follow your organizations policies for how, and in what capacity, you can engage in advocacy.*



# National Coalition for Cancer Survivorship (NCCS)



- Focused on National Policy initiatives
- Cancer Policy and Advocacy Team
- Survivorship Champions  
<https://canceradvocacy.org/>
- Advocacy manager: Veronika  
[vpanagiotou@canceradvocacy.org](mailto:vpanagiotou@canceradvocacy.org)

# American Cancer Society Cancer Action Network

- Local and National Policy Efforts
- **Ohio grassroots manager:**  
**[sarah.morris@cancer.org](mailto:sarah.morris@cancer.org)**



# Professional Societies

## ASCO:

- Drug shortages,  
funding research,  
insurance coverage



## AACR:

- Cancer Research  
Funding





**Get involved in your professional associations and serve on their boards.**

- Consider contacting your organization's advocacy group or policy board to see how you can support them through letter writing and reaching out to legislators.

**Subscribe to your state's legislative notifications.**

- For example, in your browser, search for "Ohio legislative notifications" to be added to their listservs and to view the list of bills and session times.
- Be willing to attend legislative sessions and personally advocate for policies when invited.

**Identify local candidates and lawmakers and develop relationships with them.**

- Be willing to contact your legislators by phone, email, or mail to discuss issues relevant to cancer, healthcare practice, or your research.





Consider meeting with lobbyists to discuss how you can better encourage policies that will improve the health and well-being of communities.



Write and provide lawmakers and lobbyists with layman's summaries of the published literature and/or your research findings.



Share your laymen's summaries with the public via your social media sites, during talks you give in the community, and within your institution.



Encourage the public and your colleagues to get involved in letter writing to lawmakers to advocate for positive public policies.

# **We want to partner with you!**

Are you doing advocacy in the community? We would love to hear about it and see how we can build collaborations!

# Go forward and find your voice!

- Questions?
- Alique Topalian, PhD, MPH  
[topaliag@ucmail.uc.edu](mailto:topaliag@ucmail.uc.edu)



AYAs are a unique population with needs that are unique based on the time of life their diagnosis takes place, during some of the most critical years of development toward their future goals. I am lucky to have the education and resources to be that voice for others like myself, to raise awareness, and to have the AYA voice be heard both throughout and beyond the oncology community.

– Alique Topalian,  
Acute myeloid leukemia survivor  
Originally diagnosed at age 4



**Adolescent and Young Adult  
Cancer Awareness Week**



# Breakouts

Brainstorm and identify ways to work together to alleviate the cancer burdens in our catchment communities.

1. Three neighborhoods or populations we should target first
2. Three organizations we can partner with.
3. Three strategies we can use.

Breakouts will be both in-person and virtual.

## **#1: Risk Factors**

- Tobacco / Obesity (Rm 255)
- Cancer screenings in urban underserved communities (here)
- Mental health & supportive services for cancer survivors (Rm 220)

## **#2: Priority Cancers**

- Lung cancer (Rm 220)
- Prostate cancer (Rm 466)
- Breast cancer (Rm 210)
- Colorectal cancer (here)
- Blood cancers (Rm 255)
- HPV-related cancers (here)



# Risk Factor Breakout Groups

Virtual breakout links available in the Chat





# Cancer Breakout Groups

Virtual breakout links available in the Chat

# Thank you for joining us!



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Get our Newsletter!