

Pivot.
Adjust.

Find new ways to do your work.

WI Cancer Collaborative Conference
Oct. 20, 2021

Kirsten Norslien, Program Director,
Gilda's Club Madison



An Affiliate of the
CANCER SUPPORT COMMUNITY

PRESENTER DISCLOSURE

Presenter Disclosure

Faculty: Kirsten Norslien

I, Kirsten Norslien have no financial relationships or
affiliations to disclose



On-Site Programming



Interactive sessions led by health professionals focused on healthy lifestyles, educational programming, support for patients and loved ones impacted by cancer.

Our goal was to continue as much of the program as we could virtually.

Kid Support

A photograph of six children of diverse ethnicities running together on a grassy field under a clear blue sky. They are all wearing casual summer clothing like t-shirts and shorts. A large red circle is overlaid on the left side of the image, containing the following text.

A structured support and educational curriculum for children ages 4-12 facing cancer or who have a parent or other close relative with cancer.

Survivorship Program



Post-treatment survivorship program that includes group support, exercise tailored to abilities, training in relaxation and stress management, tips for nutritious eating, additional resources.

Patient Advocate

- Insurance coverage
- Medical billing issues
- Disability
- ADA and employer accommodations
- Clinical trial navigation
- Information and referrals to local, regional and national resources for anyone dealing with cancer



Treatment Decision Making



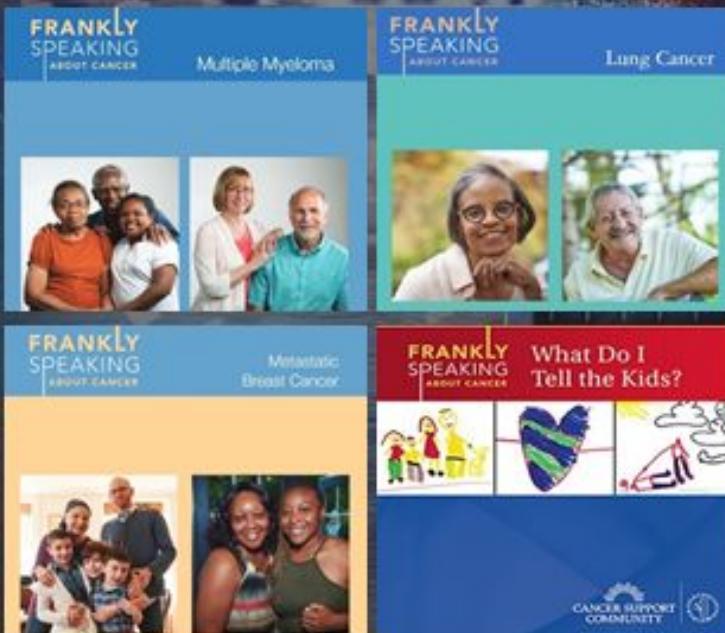
A guided discussion
with a trained
specialist that engages
a patient in a targeted
intervention to align
treatment options with
the patient's goals.

CancerSupportSource®-Distress Screening



A brief in-take
that will help open
the conversation about
each individual's unique
needs and wants to
align resources with the
specific circumstances.

Education Resources



Access to award-winning educational material covering a broad range of cancer topics - such as caregiving, clinical trials, how to talk to your kids, and more.

Personalized Digital Community

A photograph of a man and a woman sitting on a couch, looking at a white tablet device together. They are both smiling. The man is wearing glasses and a yellow t-shirt, and the woman has curly hair and is wearing a white t-shirt.

A digital service called MyLifeLine that makes it possible to **keep friends and family updated on treatments and enlist the help of these individuals** in things such as rides to appointments, babysitting, or any other way they can help in challenging circumstances.

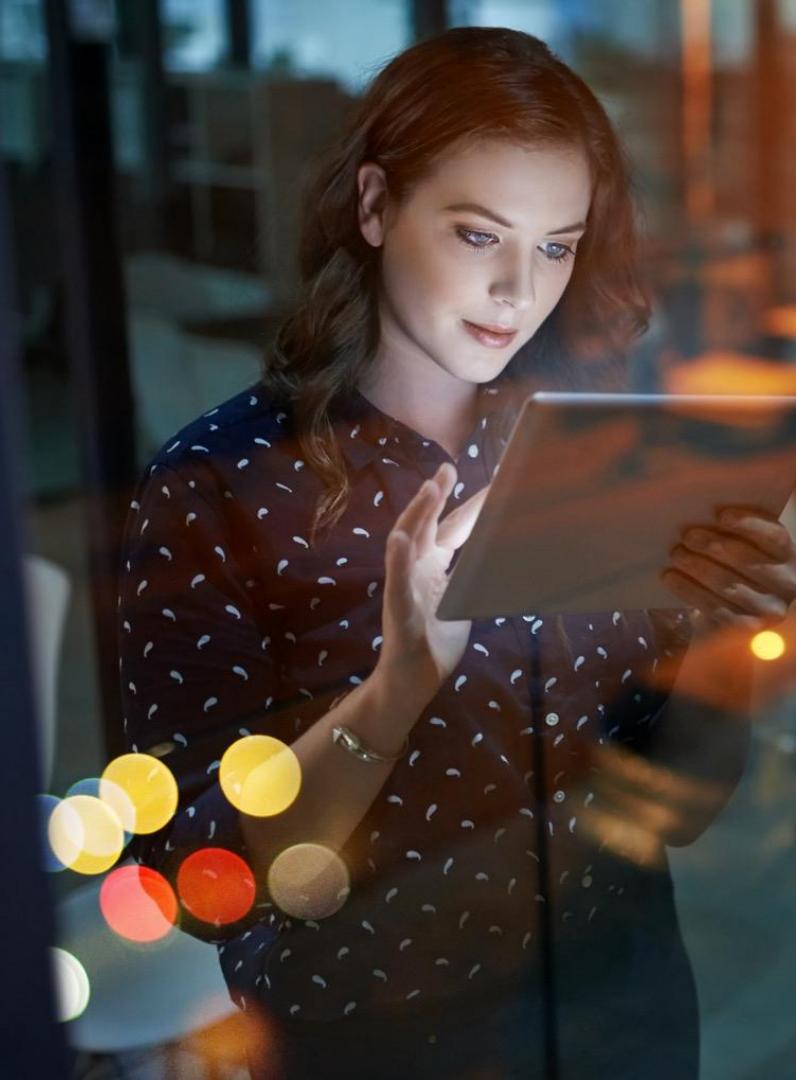
Cancer Experience Research

A composite image featuring a woman in a white lab coat and glasses holding a pen, positioned in front of a dark, glowing digital interface with various charts and data points.

A one-of-a-kind registry
and research study
dedicated entirely to
understanding the patient
cancer experience.

"People with serious illnesses have stress in different ways. We need to understand what individuals are going through and focus on the physical, emotional, and spiritual quality of life our patients want."

— Hunter, MD, Medstar Georgetown Washington Hospital Center



What we know...

- 34% of cancer patients at risk for depression
- 43% of cancer patients and
- 50% of caregivers at risk for anxiety ³
- The cost of cancer was approximately 113% higher for depressed cancer patients than non-depressed patients ⁴

IMPACT OF COVID in 2020

37%

Drop in cancer
diagnosis

87%

Drop in
Mammography
screenings

COVID-19

90%

Drop in Colonoscopy
screenings

83%

Drop in Pap Smears ⁶

Fighting cancer in the pandemic means fighting cancer alone

My surgery would have been stressful in any circumstances. It was even harder this year.

Des Moines Register

Thousands of health care workers are furloughed, laid off in US as routine patient visits drop during coronavirus pandemic

Using Real-World Data to Understand the Impact of COVID-19 on Oncology Patient Care

September 18, 2020

Marcus Neubauer, MD , Sarah A. Alwardt, PhD

Impact of COVID-19 Pandemic

67% of patients reported disruptions or delays in care due to the pandemic.

42% of patients had discussed their risk of getting COVID-19 with their doctor

40% had discussed ways to reduce their risk.

37% of patients were seriously or very seriously concerned about not seeing family or friends as much as usual because of the pandemic.

Patient comments

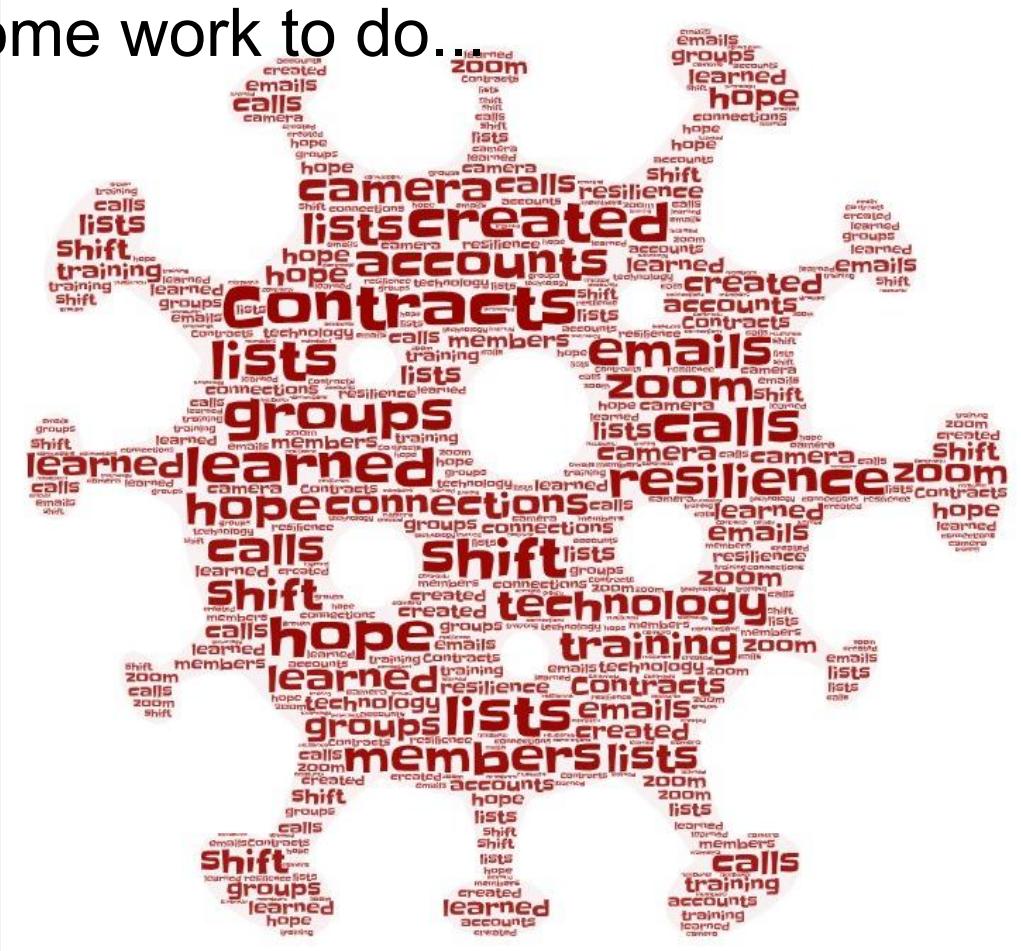
“Your support system is so important, and taking that away ... for me personally, has been the worst part of the whole process. And so, while the people at that Center were absolutely wonderful and caring, you’re still going there alone.”

– Focus group discussion participant

“My husband is not allowed to come into appointments with me and that is very frustrating. I’ve had to do my last rounds of chemo alone. I felt very isolated and alone and depressed. I had the nurses and my oncologist, but your significant other is a huge support system.”

– Focus group discussion participant

We had some work to do.
DreamHUB



What did we need to do?

Prioritize

Get technology set up.

Train staff

Get the word out to members - some without internet.

Breathe

Get creative

Make the next right choices

ZOOM, just in time...



What was transferred to Zoom/ cloud life?

Emails went to members about the process of using Zoom (new for almost all)

Yoga classes were reimagined

Guided Imagery/Relaxation reformatted

Group norms established

Art classes got creative

Technology needed to be distributed to staff for work to get done. Laptops, cameras, headsets, etc

Healing in Nature - AYA Workshop 3/31/21



Gilda's Club Madison

New ways to connect to community

Partnerships with the Goodman Community Center developed

Edgewood College and UW interns worked creatively, collaboratively, and within limits of the pandemic (this continues, and has shifted over time)



CUREative Art

Expressive Art and Writing Contest for Teens Touched by Cancer

Are you a teen (age 13-19) who's been touched by cancer?

Perhaps someone you love has experienced a cancer diagnosis, or you've witnessed how cancer has shaped the life of someone you know? Maybe you are a cancer survivor yourself? Cancer may leave wounds, but the pain can transform into healing.

Express yourself through prose, poetry, art, photography or any creative outlet that tells your story. Let your light shine.



This contest will be part of the
Gilda's Club Art Show

April 19-25

Generously exhibited in Madison by:



Art and writing classes for teens are offered via Zoom in March & April.

Learn More & Enter Today:
gildasclubmadison.org/cureative2021



www.GildasClubMadison.org



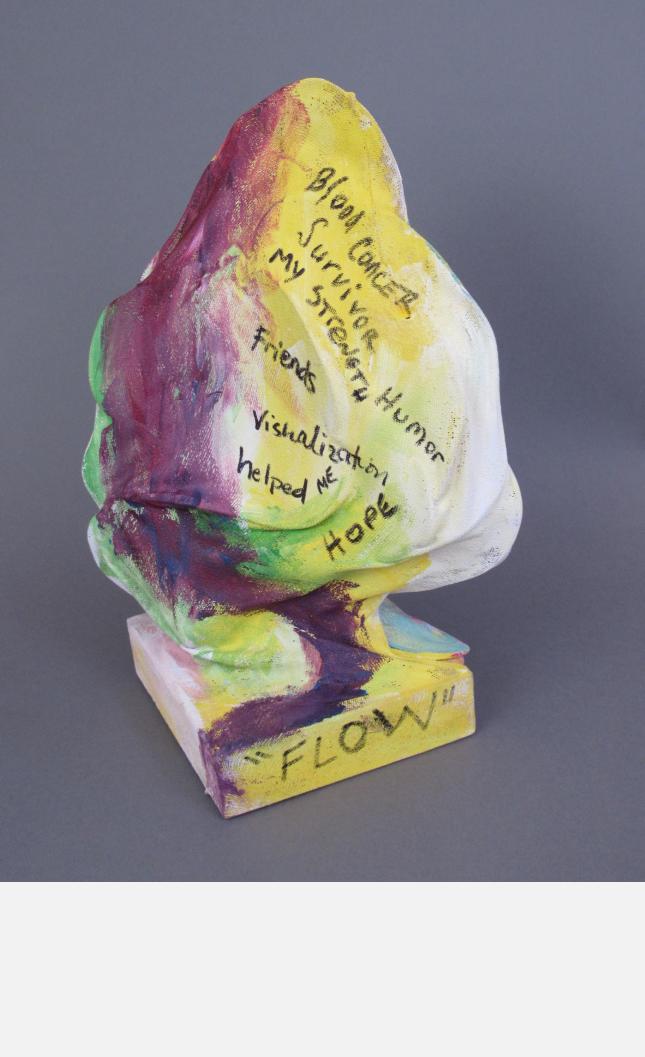
CONTEST PRIZES

- 1 \$300 Gift Card to Amazon
- 2 \$200 Gift Card to Amazon
- 3 \$100 Gift Card to Amazon



"Art is a wound turned into light."
-Georges Braque





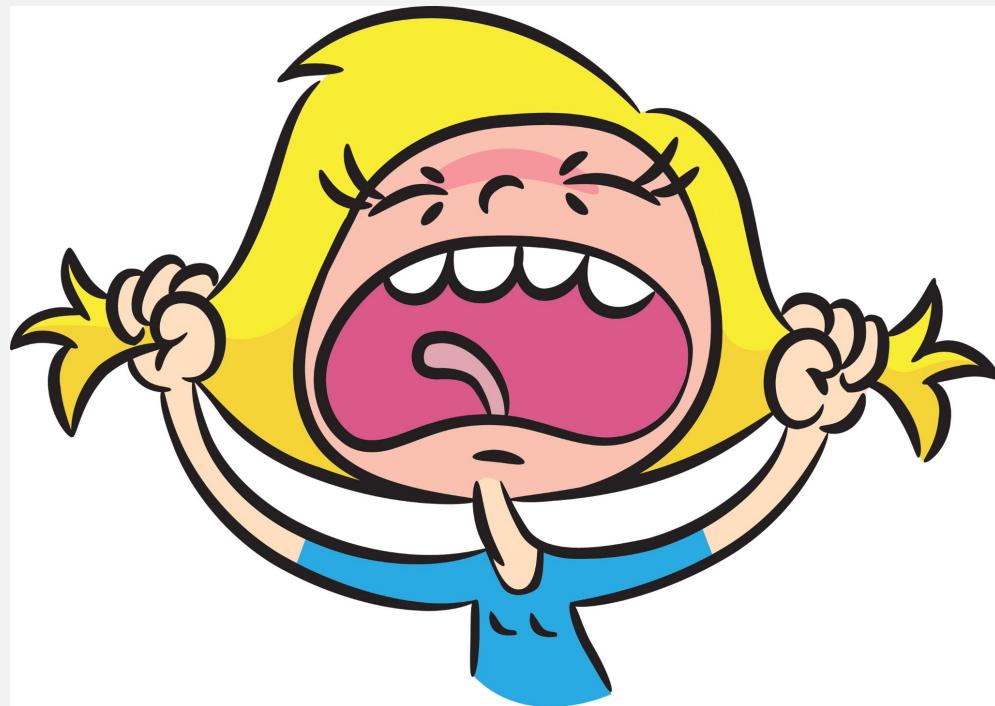


What had to shift?

Kid's programming

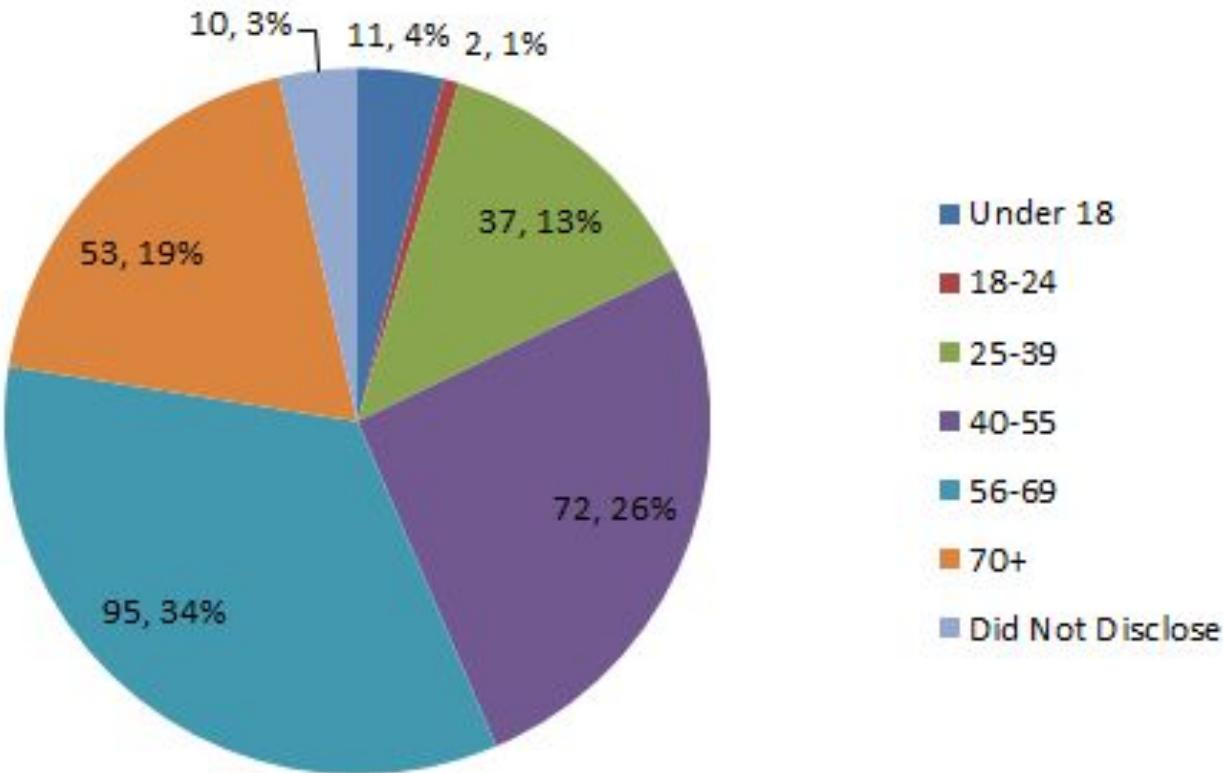
Education

New Member Orientation

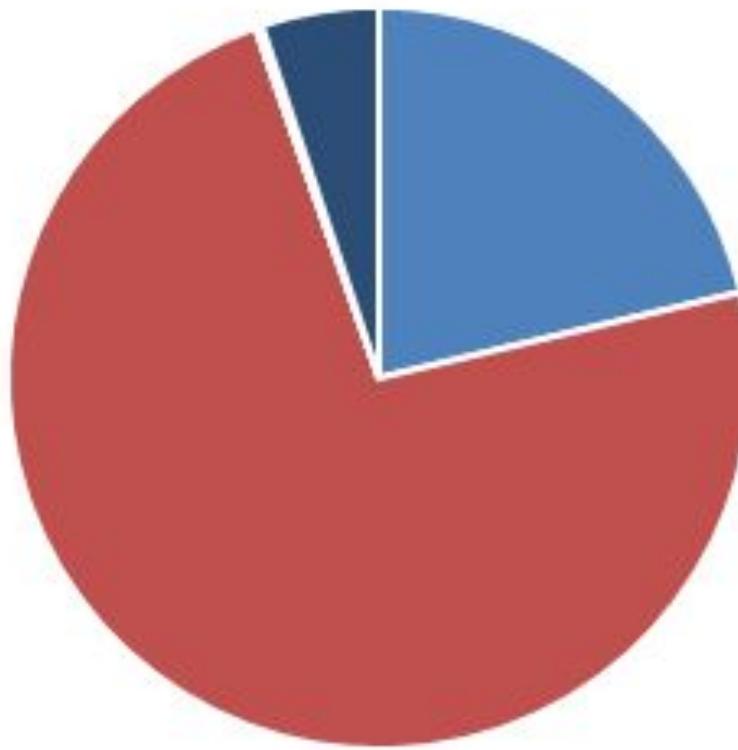


Who showed up?

3/2020-2/2021 attendance

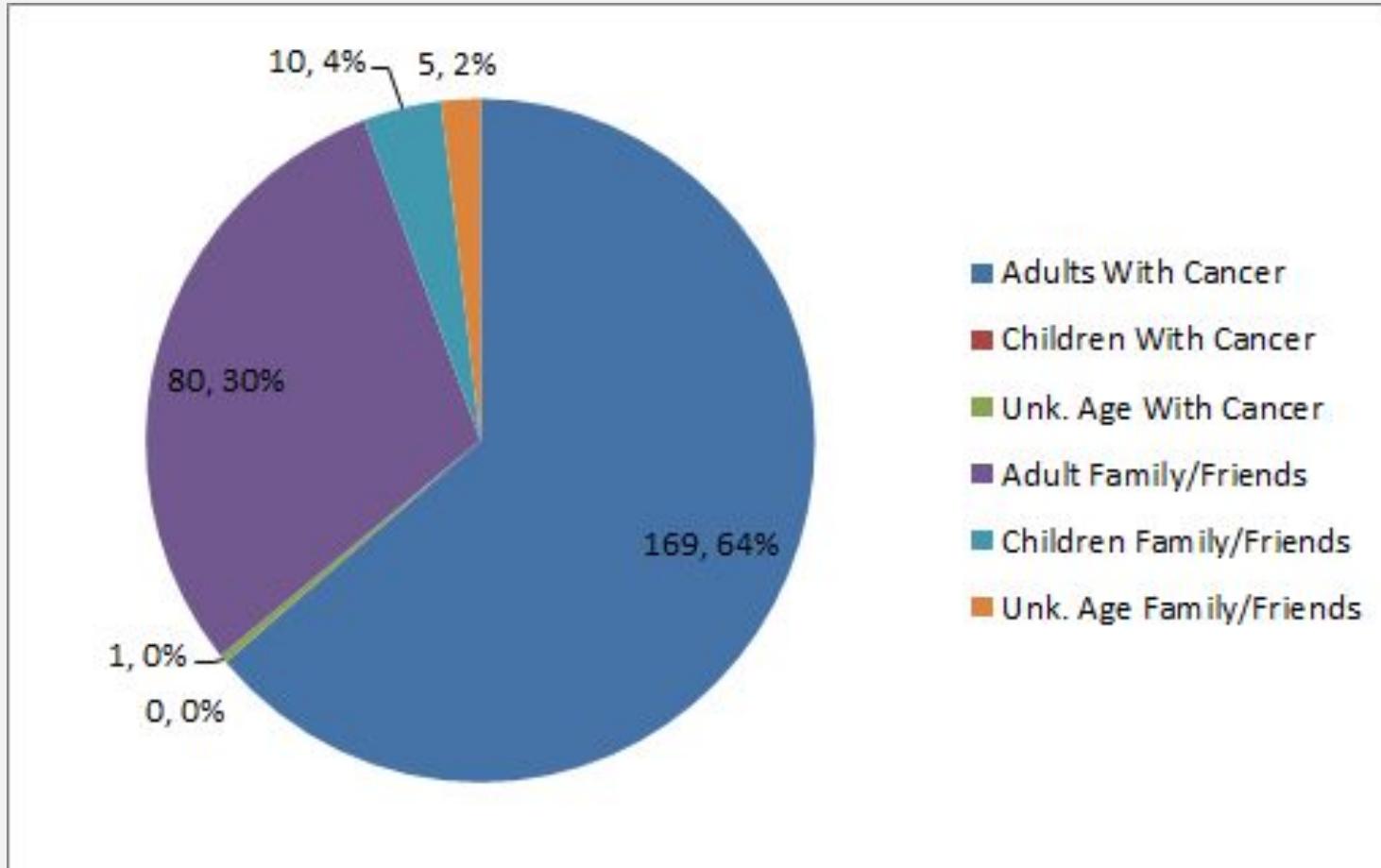


Gender

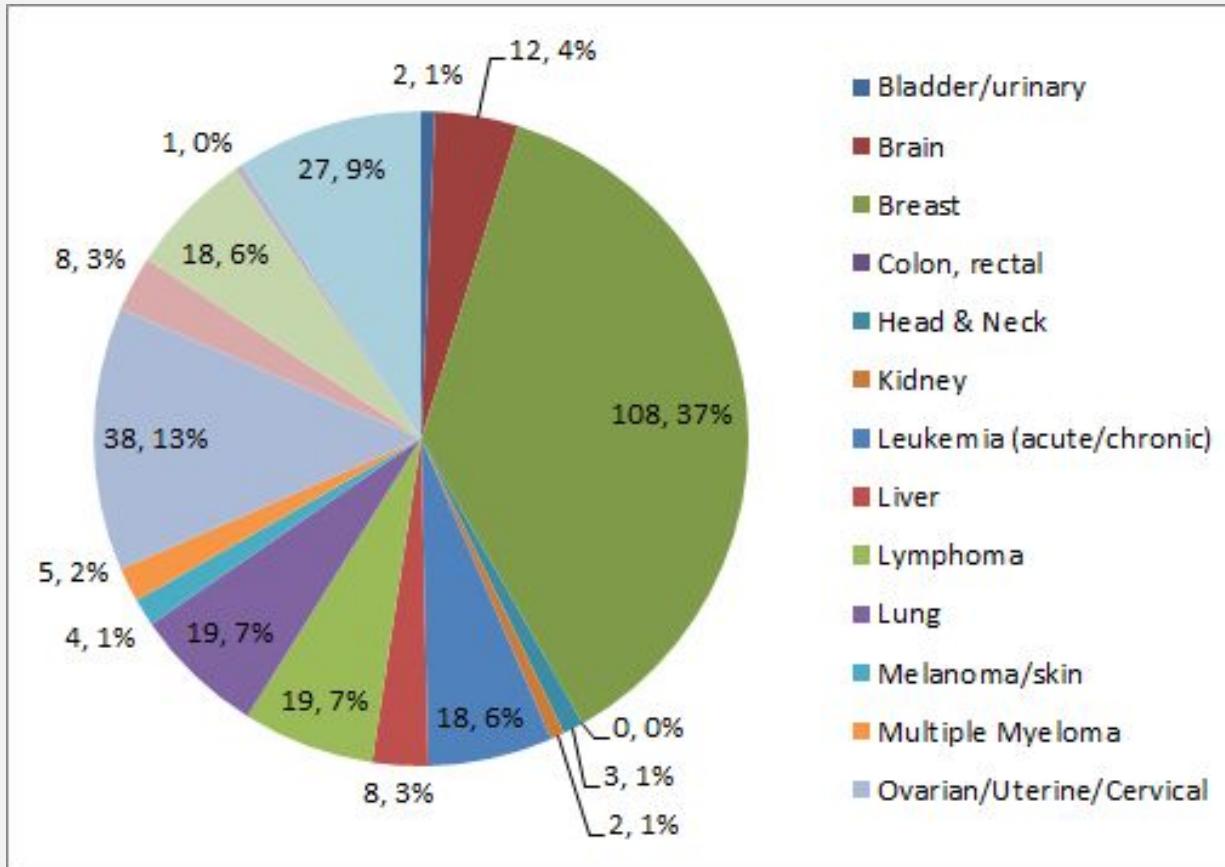


- Man
- Woman
- Transman
- Transwoman
- Nonbinary
- Other
- Did Not Disclose

People w. Cancer/ Family & Friends



Types of Cancer



Impact of virtual programming

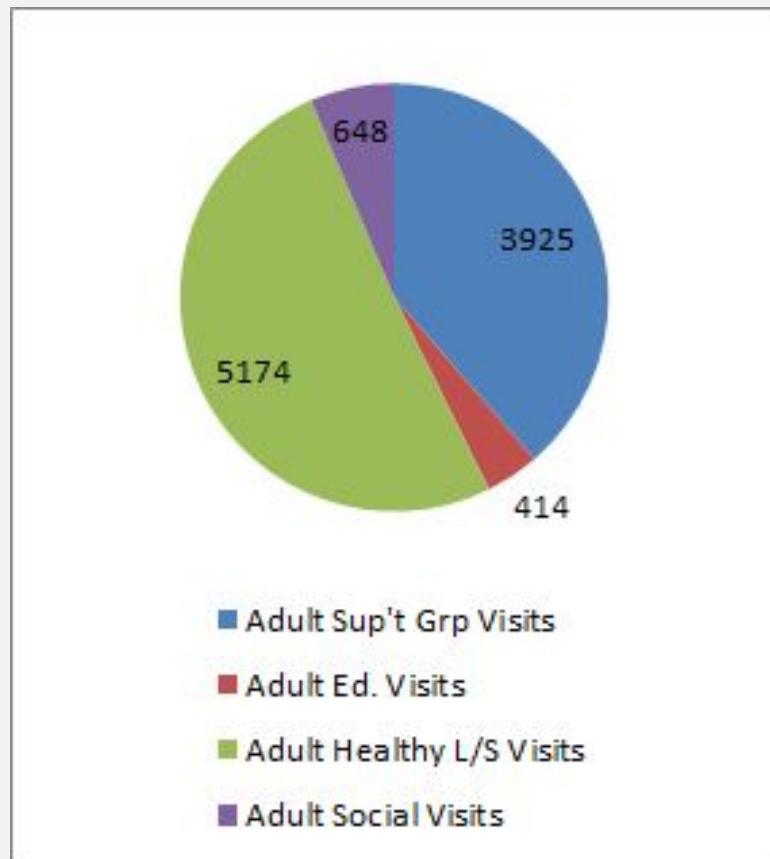
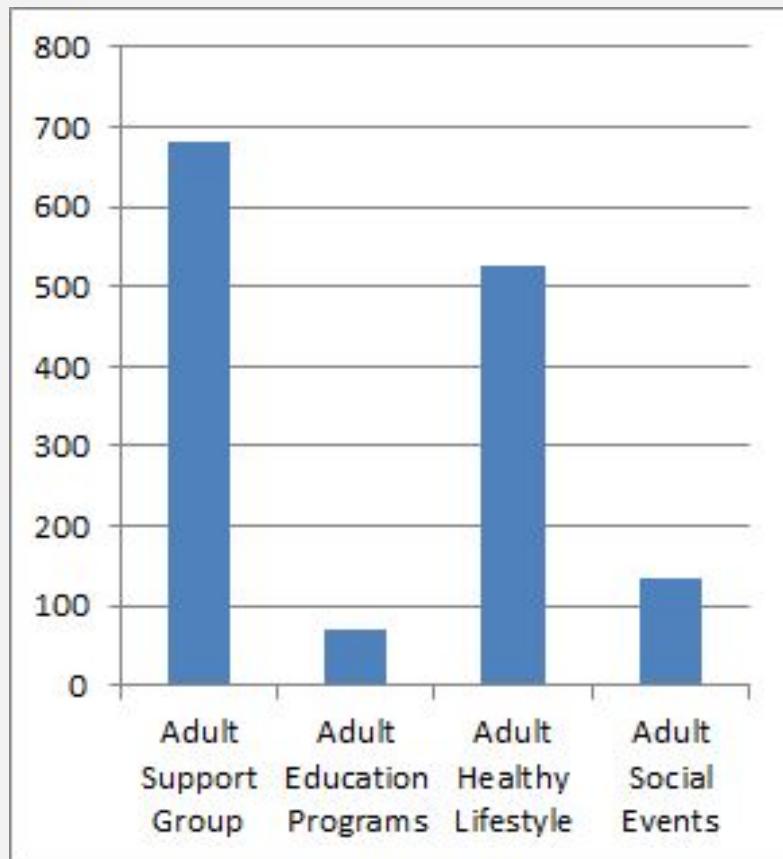


Having virtual options available indefinitely allows participation of people who don't feel well enough to travel, who can't fit multiple trips to clubhouse in a given week, etc.

Also, gives us access to many more classes/social events/lectures, etc. You can have anyone throughout the country do events!

I think virtual could be around for the future.

What are people attending?



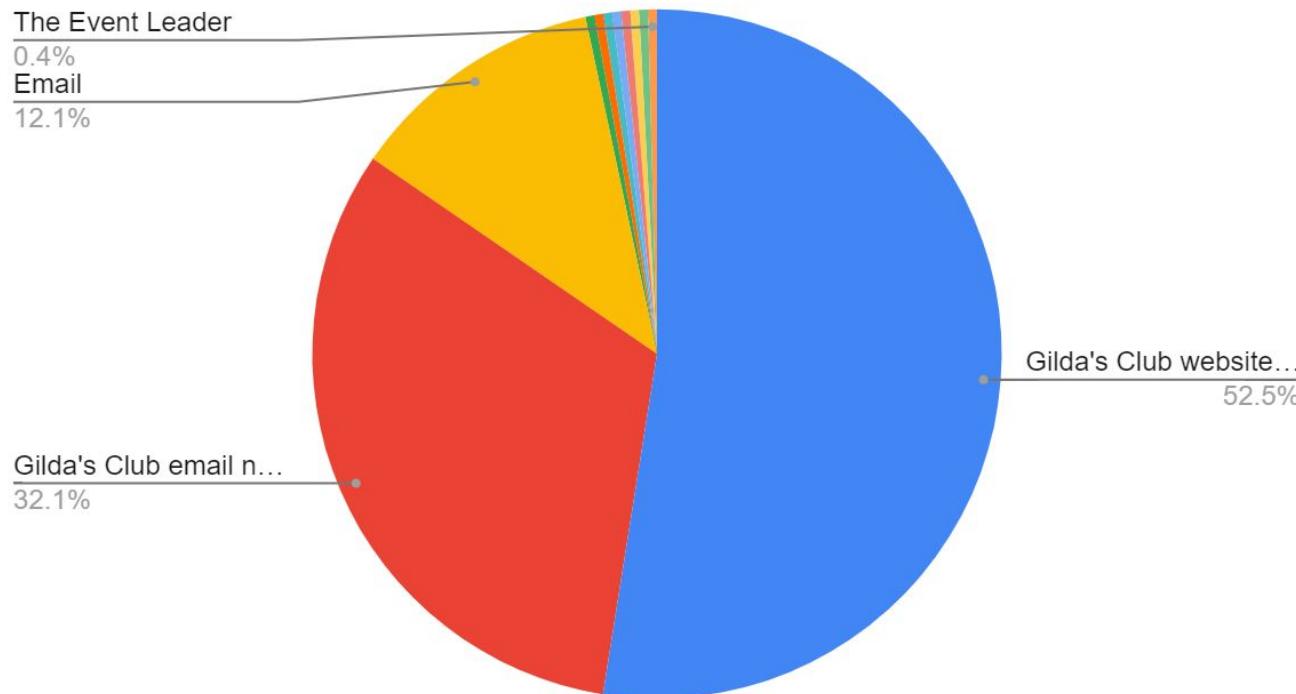


Share

John Willia

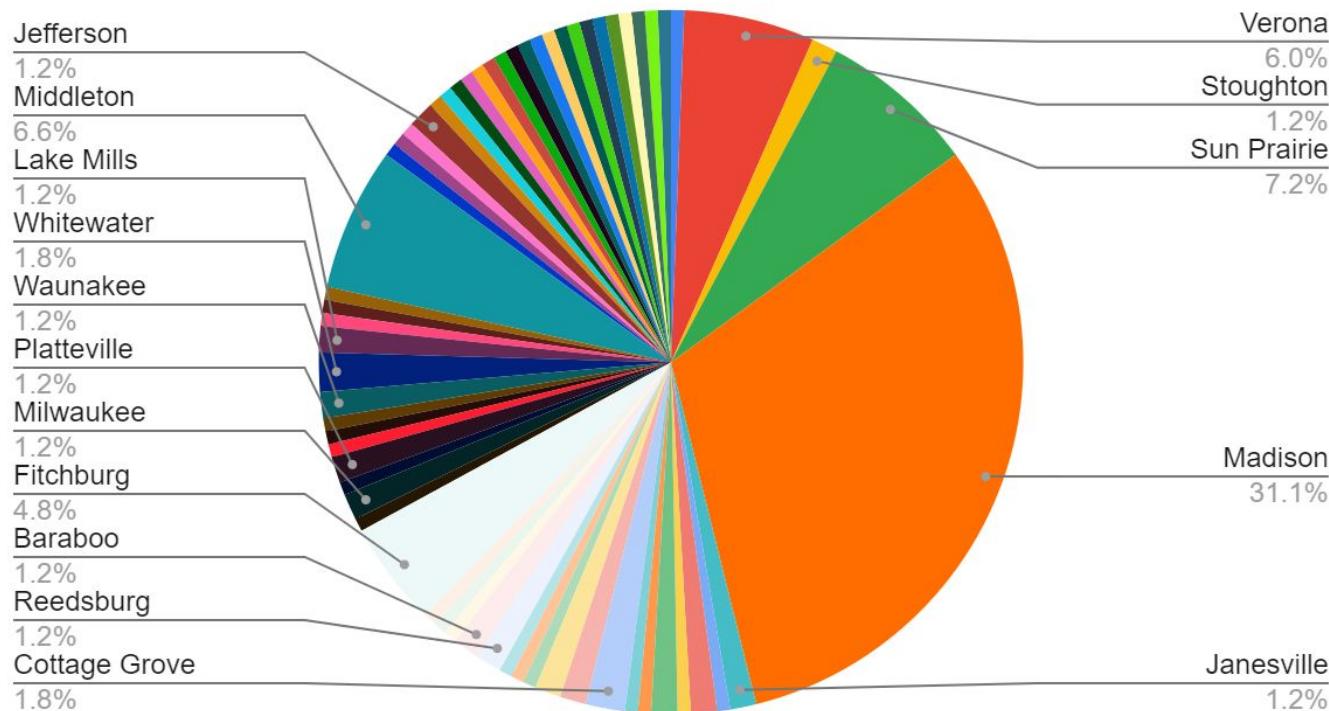
Getting the word out.

Count of How did you hear about this activity?



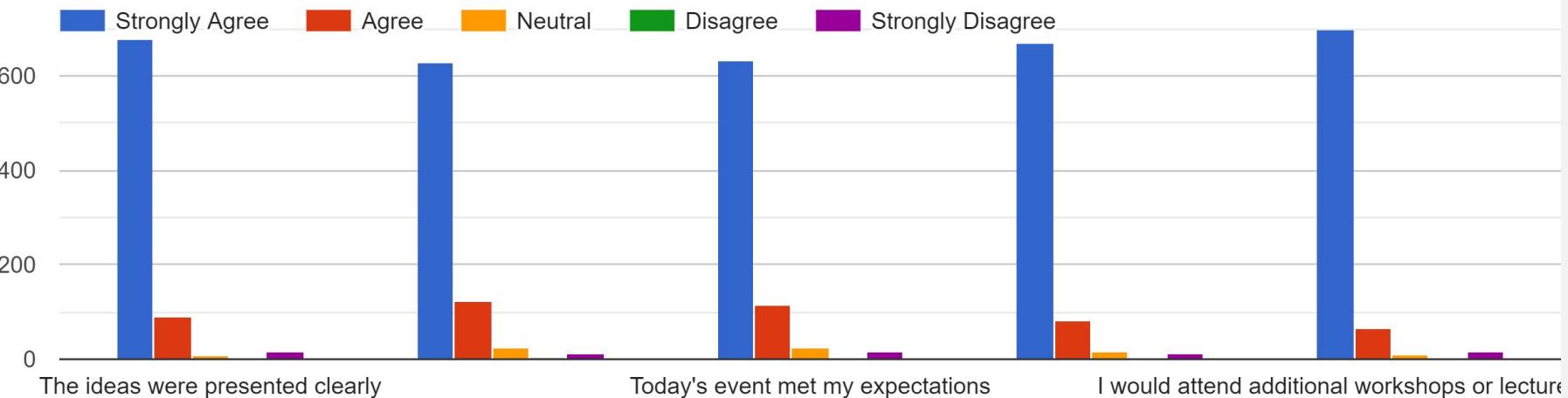
Where are member coming from? (2021)

Count of City



Survey says...

Overall



We keep putting the pieces together



The Challenges

- Those without internet.
 - Equipment issues- no computer, no/slow internet connection,
 - Learning Zoom
 - Space/ privacy requirements
 - Scheduling
-
- Concerns include:
 - Not serving some people
 - How are they doing now?
 - Creating welcoming environment in support groups, virtually
 - Making connections

Benefits

- No travel time
 - No traffic to deal with
 - Can live in far off areas (Platteville, Green Bay, Wausau, Milwaukee all possible)
- Location less important
- Emotional safety of cameras
- Can get to group even if not feeling well
- Connecting with those in more rare situations (young adults, those with less common cancers)
- Partnering with other affiliates across the country



CANCER SUPPORT
COMMUNITY
COMMUNITY IS STRONGER THAN CANCER



GILDA'S
CLUB



CANCER SUPPORT
COMMUNITY
LOS ANGELES



GILDA'S CLUB
MADISON

An Affiliate of the
CANCER SUPPORT COMMUNITY

YOUNG ADULT GAME NIGHT HALLOWEEN EDITION

DRESS UP & WIN PRIZES!



Wednesday, October 27
5pm PT | 7pm CT | 8pm ET



Addressing concerns... AKA Big Opportunities

- Sending clear instructions/guidelines
- Being flexible about how people engage, within the boundaries and comfort of participants
- Sending lots of reminders
- Email check-ins
- Being creative about ways to engage - games, art sessions, writing
- YouTube channel -www.YouTube.com/GildasClubMadison
 - tai chi class
 - lectures (including one in Spanish) ** more are in the works!



I looked through my sketchbook of what I have learned and thought "I'm an artist"

Where to next?

- Currently planning virtual programming until at least January 2022
- Virtually 2022 and Beyond
 - At least two weekly support groups (for People with cancer, as well as supporters)
 - Certain monthly groups
 - Some hybrid options - workshops, some healthy living classes
 - Especially short classes, or those early or late in the day.
- We have an opportunity to reimagine our program. What will the future bring?
Living with “Delicious Ambiguity”.
- Members are clamoring to return to the magical vibe of Gilda’s Club and will so, when its safe

A shared journey

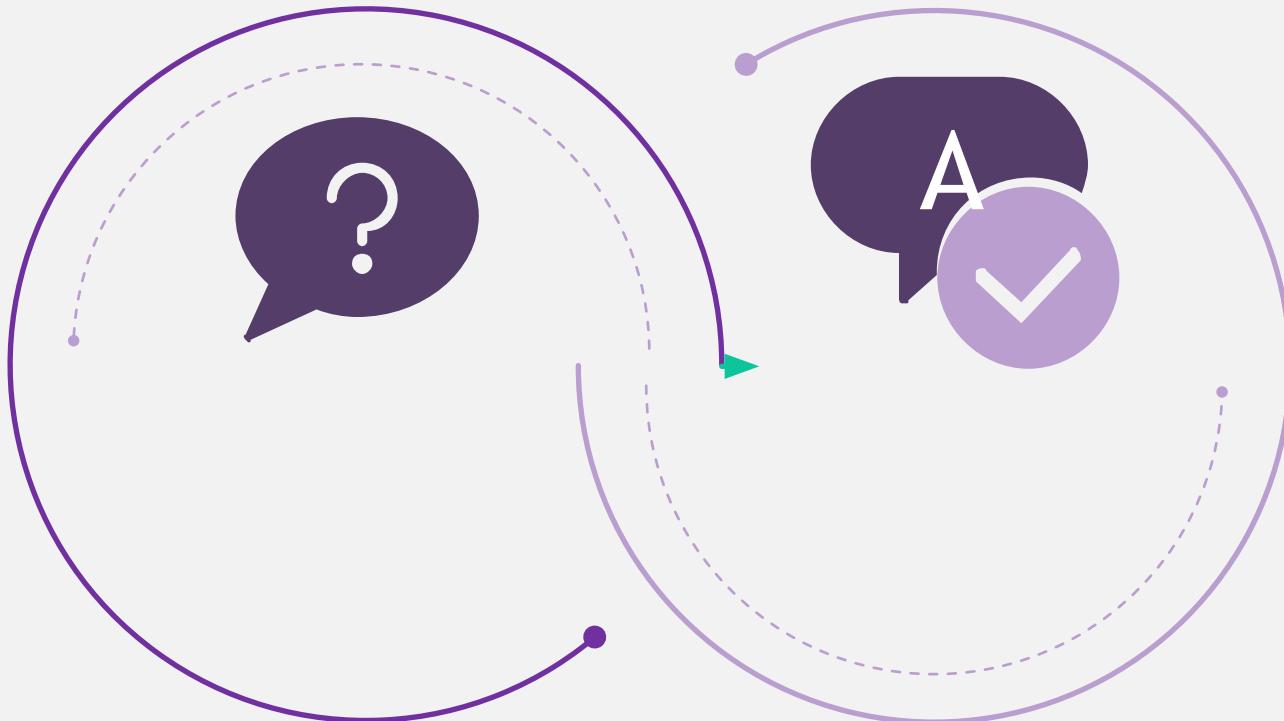


“Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. Delicious Ambiguity.”

Gilda Radner



Q&A



Sources

1. <https://www.cancer.org/research/cancer-facts-statistics/all-cancer-facts-figures/cancer-facts-figures-2019.html>
2. Cancer Treatment & Survivorship Facts & Figures 2019-2021. Atlanta: American Cancer Society; 2019.
3. (2018, Cancer Experience Registry Study, Cancer Support Community Research and Training Institute).
4. (Psychooncology. 2018 Jul;27(7):1735-1741. doi: 10.1002/pon.4716. Epub 2018 Apr 25. Health care costs of depression in patients diagnosed with cancer. Mausbach BT^{1,2}, Yeung P³, Bos T⁴, Irwin SA⁵.)
5. AJMC The Institute for Value Based Medicine. July 11, 2015. Definition of “Value” in Cancer Care Varies. Laura Joszt.
6. <https://thehill.com/opinion/healthcare/503473-the-unintended-impact-of-covid-19-on-cancer>.
<https://www.iqvia.com/insights/the-iqvia-institute/covid-19/shifts-in-healthcare-demand-delivery-and-care-during-the-covid-19-era>
7. National Comprehensive Cancer Network 2020 Annual Conference, Orlando, FL, March 20-22, 2020. Melissa F. Miller, PhD, MPH1 , Melyssa L. Allen, BS 2 , Diane C. Robinson, PhD2 , Nicole Nicksic, PhD, MPH1 , Alexandra K. Zaleta, PhD1 1Cancer Support Community, Research and Training Institute, Philadelphia, PA 2Orlando Health UF Health Cancer Center, Integrative Medicine, Orlando, FL. Results from a Pilot Study Examining the Impact of Distress Screening and Referral on Health Care Cost and Utilization Among Breast Cancer Patients.
8. file:///S:/Program/2021/Impact%20of%20the%20COVID19%20Pandemic-PCORI.pdf

Gilda's Club Madison & Cancer Support Community Resources

A calendar FULL of opportunities - still virtual

www.MyLifeline.org

Cancer Support Source (screening)

Publications

Open to Options (treatment decisions)

HelpLine 888-793-9355

Patient Advocate

Cancer Experience Registry

Individual Cancer Counseling

Blog



Call 608-828-8880 for more information



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