

**Pivot.
Adjust.**

Find new ways to do your work.

WI Cancer Collaborative Conference
Oct. 20, 2021

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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 group of six diverse children, three boys and three girls, are running happily across a green grassy field. They are wearing colorful t-shirts and shorts. The background shows a clear blue sky and some trees in the distance. The children are smiling and appear to be in good spirits.

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.

A photograph of two women in a professional setting. The woman on the left is wearing glasses and a striped blazer, smiling. The woman on the right is wearing a blue headscarf and a brown blazer, looking towards the first woman. In the background, a whiteboard shows a pie chart with '75%' written on it.

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 photograph showing a male doctor in a white lab coat and glasses sitting at a wooden table. He is holding a small, yellow and white medical device. A woman in a light blue shirt and a man in a purple shirt are sitting across from him, looking at the device. The woman is holding a blue pen and a clipboard. The background is a plain, light-colored wall.

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 man and a woman are sitting on a light-colored sofa in a modern, well-lit living room. The man, on the left, is wearing glasses and a mustard-colored sweater. The woman, on the right, has curly hair and is wearing a white top. They are both smiling and looking at a tablet computer held by the man. In the background, there is a potted plant and a wooden shelf.

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 woman with dark hair pulled back, wearing black-rimmed glasses and a white lab coat, is looking down at a tablet computer she is holding. The background is a blurred city skyline at night, with lights from buildings visible. The overall tone is professional and focused.

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

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)



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.



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



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



What had to shift?

Kid's programming

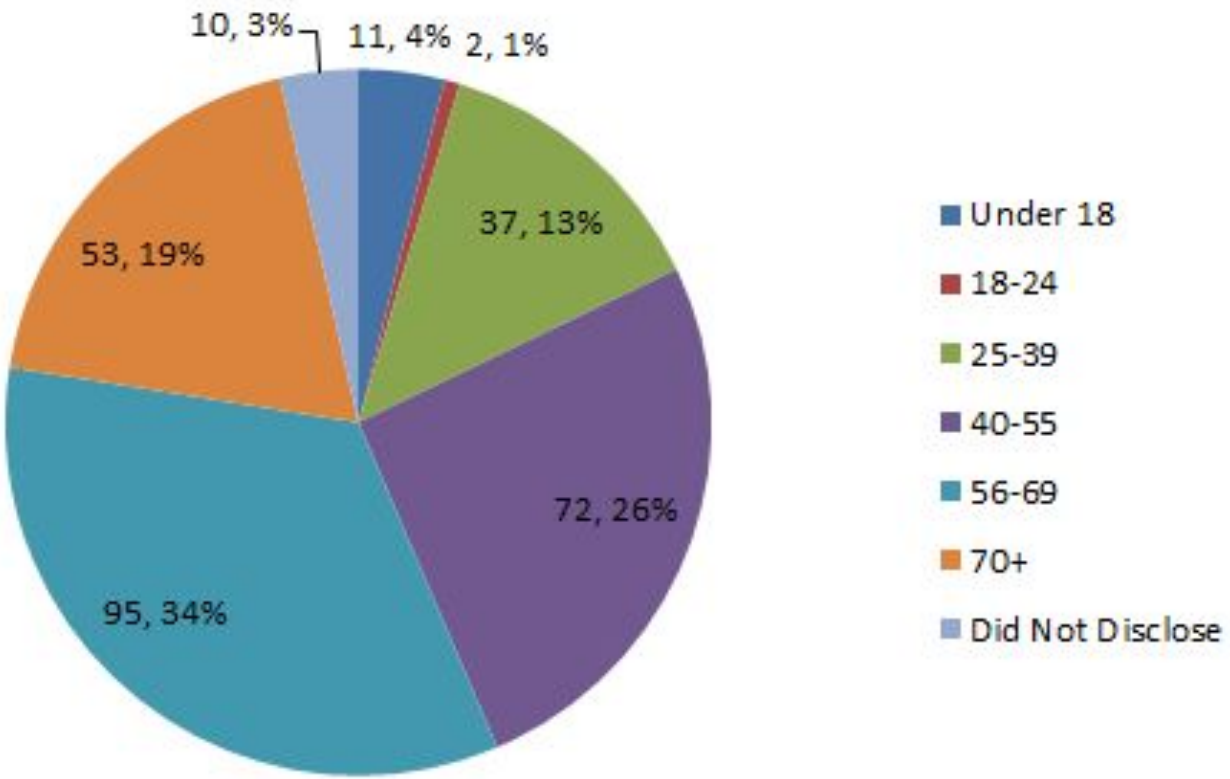
Education

New Member Orientation

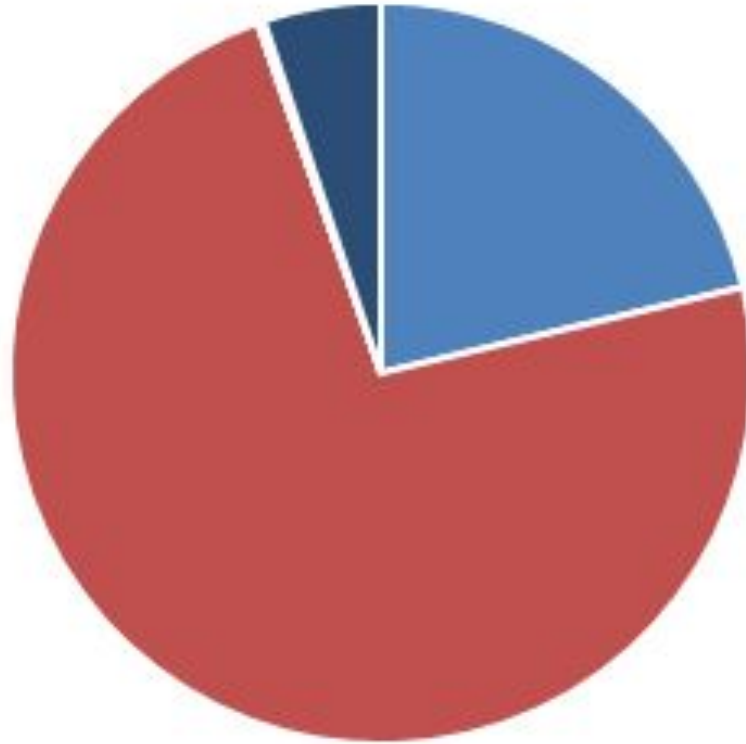


Who showed up?

3/2020-2/2021 attendance

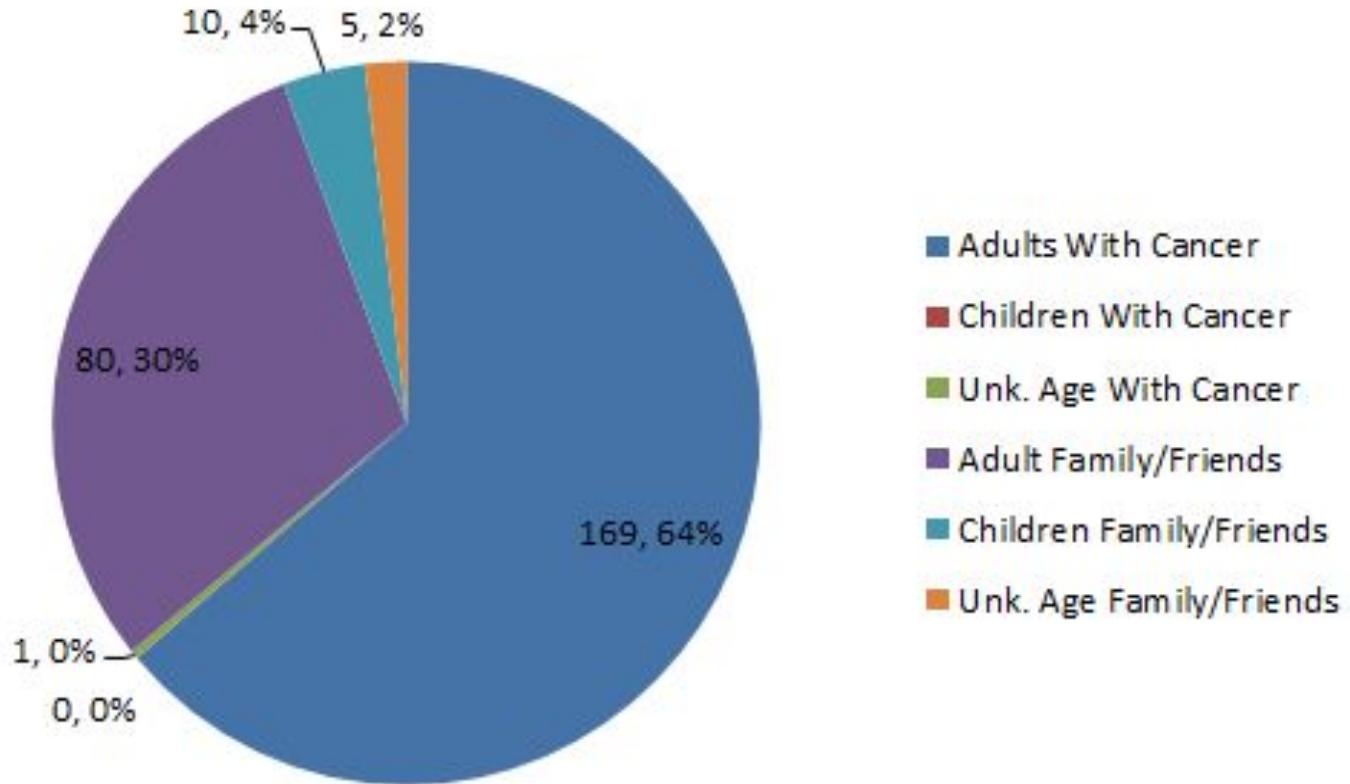


Gender

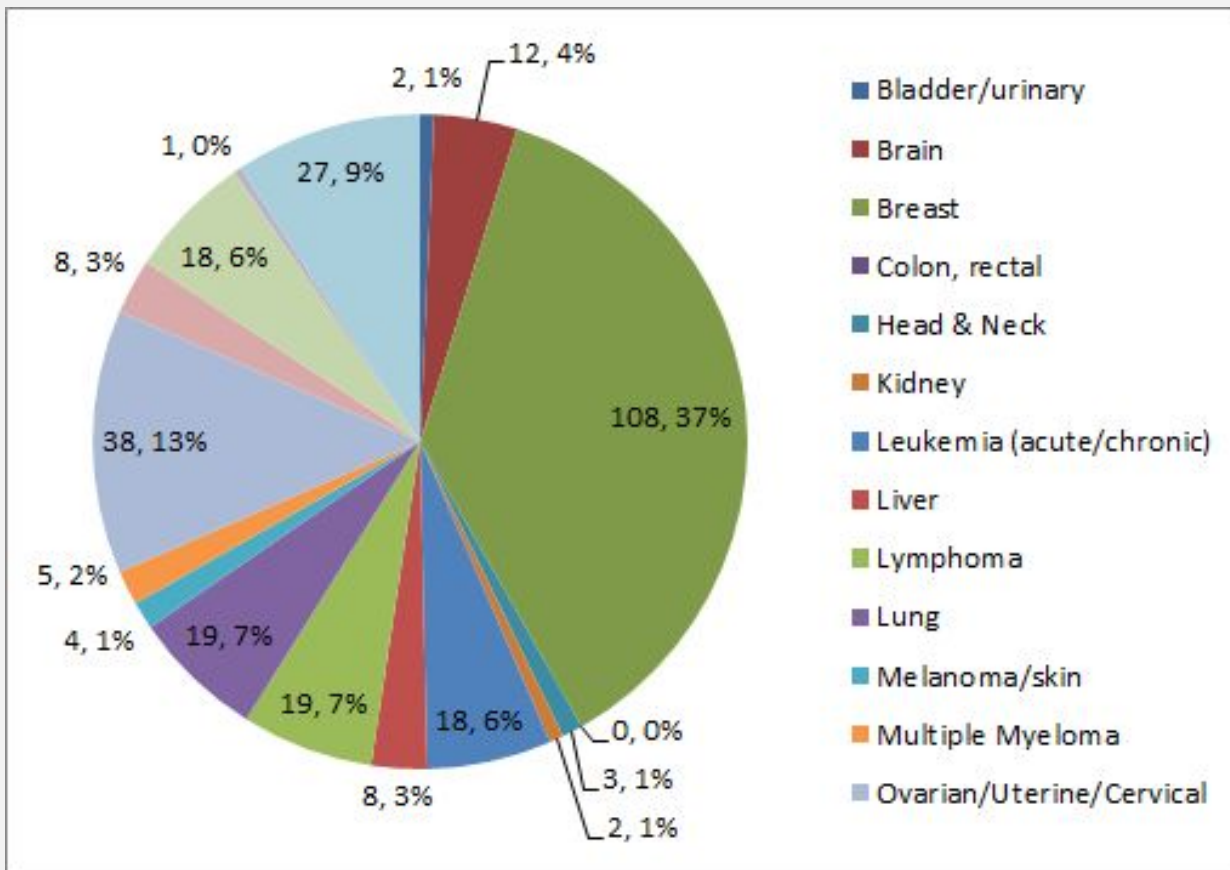


■ Man ■ Woman ■ Transman ■ Transwoman ■ Nonbinary ■ Other ■ Did Not Disclose

People w. Cancer/ Family & Friends



Types of Cancer



Impact of virtual programming

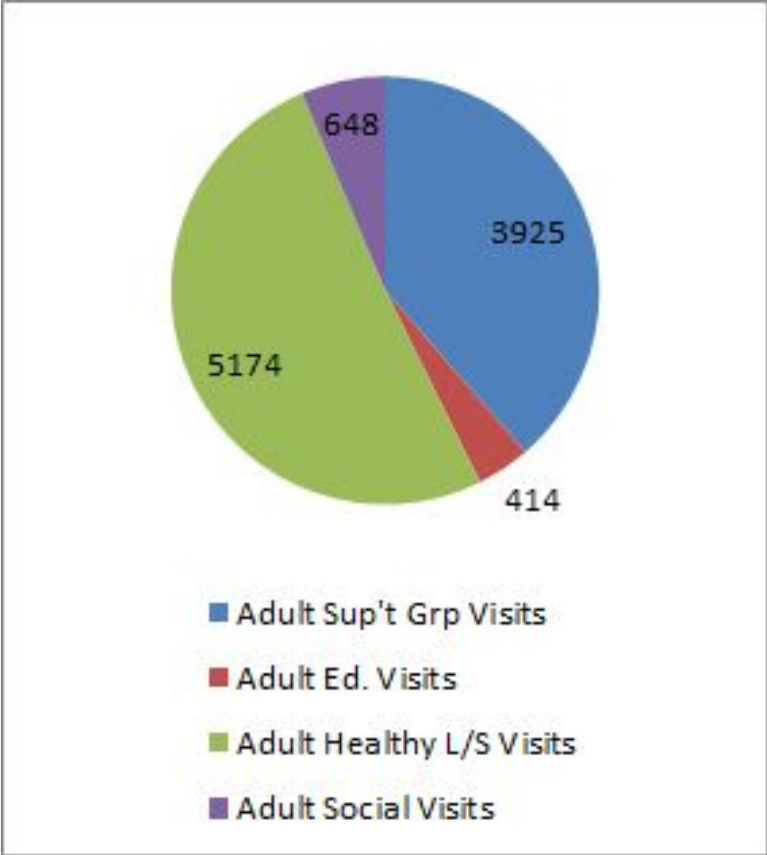
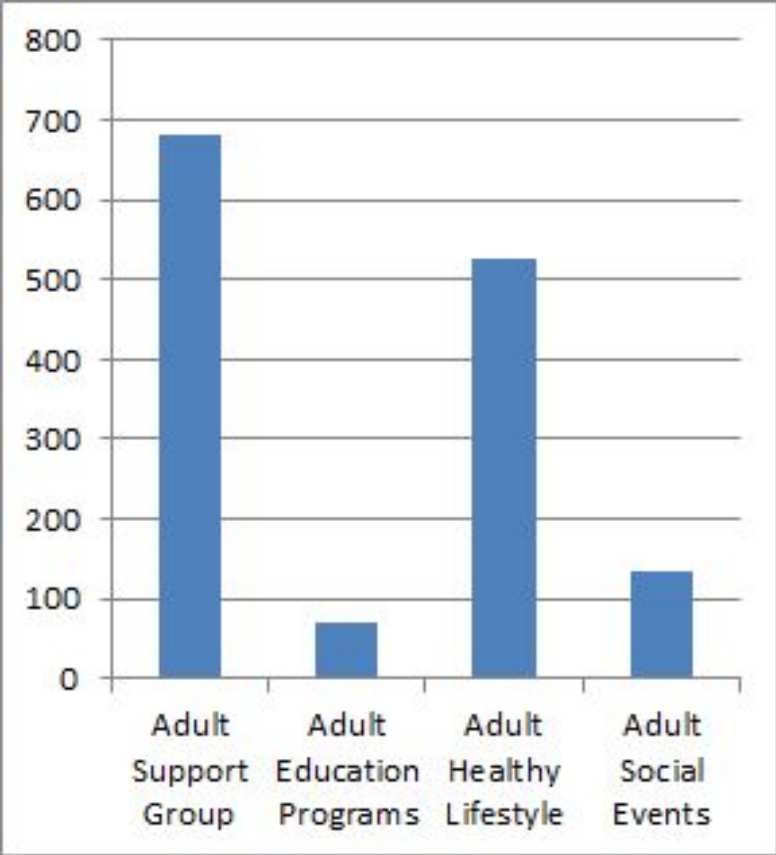


Having virtual options available indefinitely allows participation of people who don't feel well enough to travel, who can't fit multiple trips to clubhouse in a given week, etc.

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.

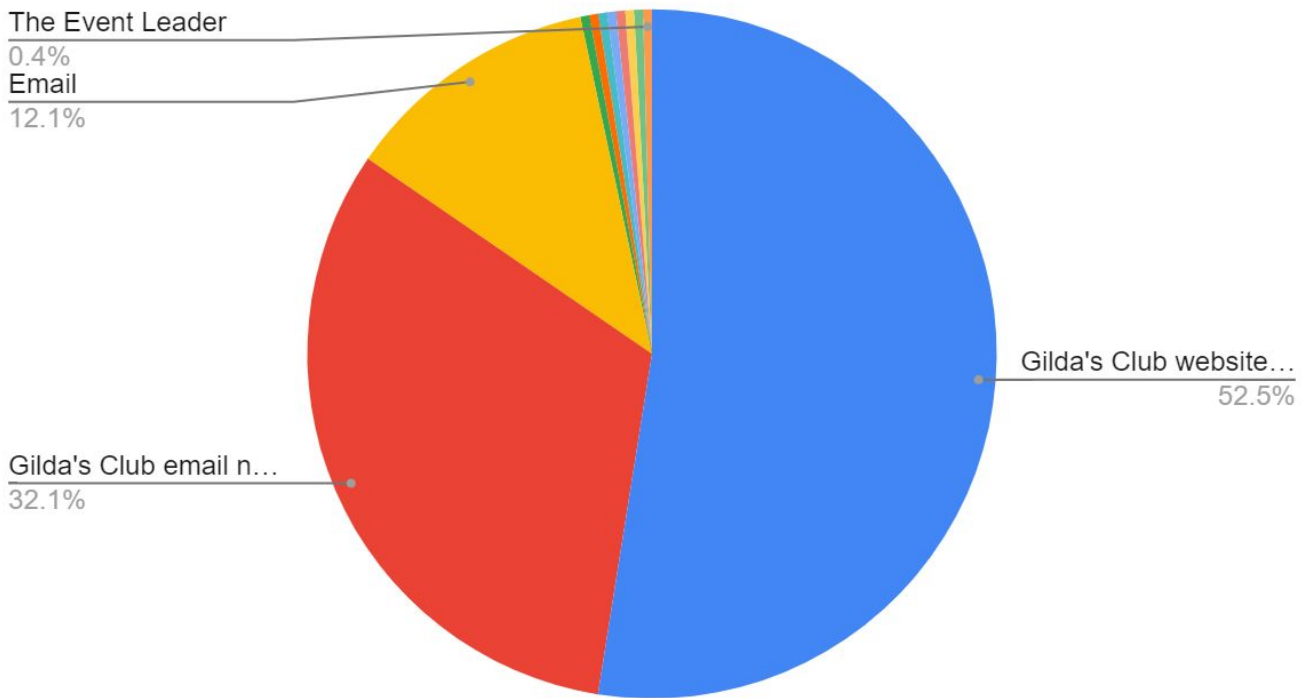
What are people attending?





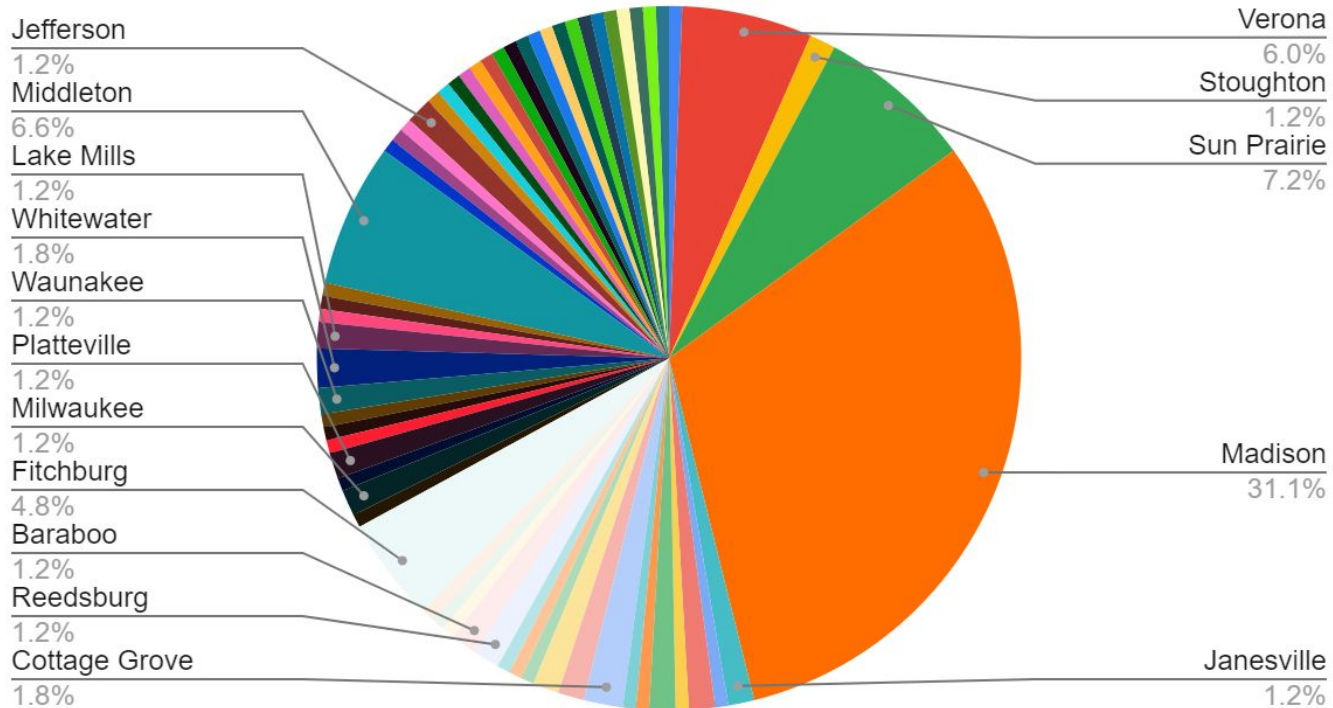
Getting the word out.

Count of How did you hear about this activity?



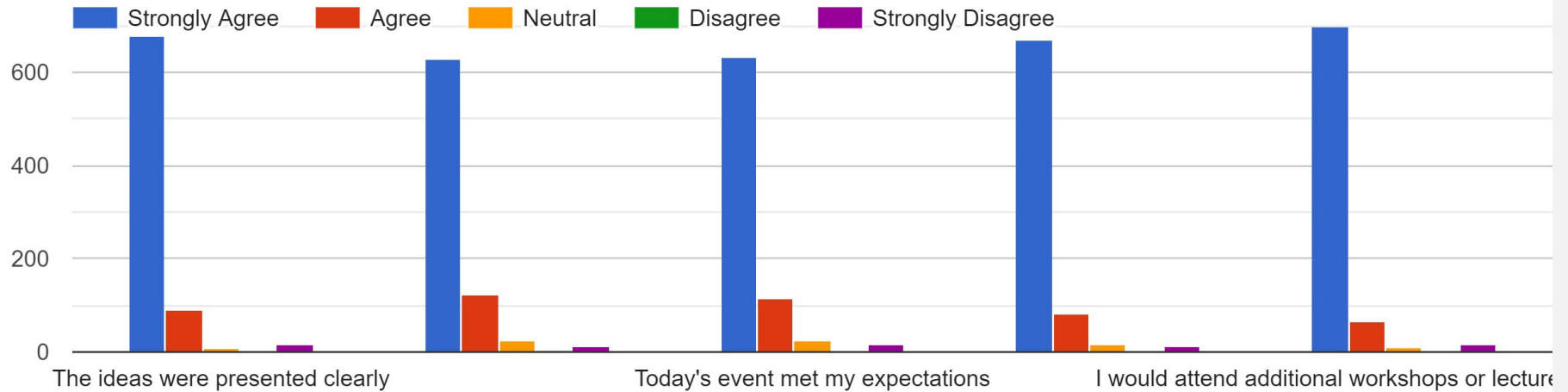
Where are member coming from? (2021)

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



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

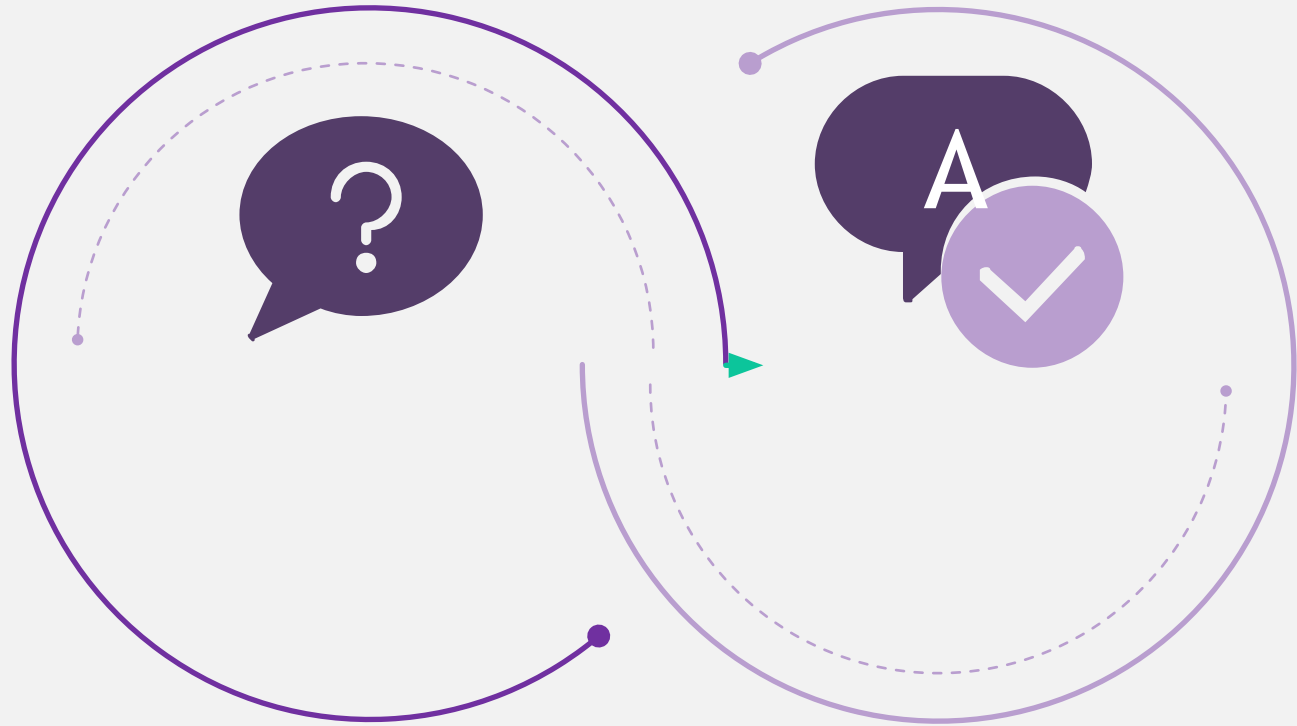


“Life is about not knowing, having to change, taking the moment and making the best of it, without knowing what's going to happen next. Delicious Ambiguity.”

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.igvia.com/insights/the-igvia-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

Cancer Support Source (screening)

Open to Options (treatment decisions)

Patient Advocate

Individual Cancer Counseling

www.MyLifeline.org

Publications

HelpLine 888-793-9355

Cancer Experience Registry

Blog



Call 608-828-8880 for more information



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