

A person with dark hair, seen from the side and back, is wearing a light blue denim jacket and working on a silver laptop. The laptop screen displays a grid of images. To the right of the laptop, a smartphone lies on the dark desk. A large, semi-transparent purple triangle covers the bottom-left portion of the image, serving as a background for the text.


# Lacuna Loft

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2020-2021 Annual Report



Lacuna Loft is a 501(c)(3) nonprofit that encourages, empowers, and connects young adult cancer patients, survivors, and caregivers around the world, 24/7. Lacuna Loft provides online wellness support programs and resources, lifestyle encouragement, and a supportive peer community that young adults need to overcome their challenging health and life circumstances, and thrive.



Lacuna Loft's vision is to become the leader in wellness support programs and resources for young adult cancer patients, survivors, and caregivers, enabling them to have the age-appropriate support they deserve through a medium that fits their lifestyle.

# Why Young Adults

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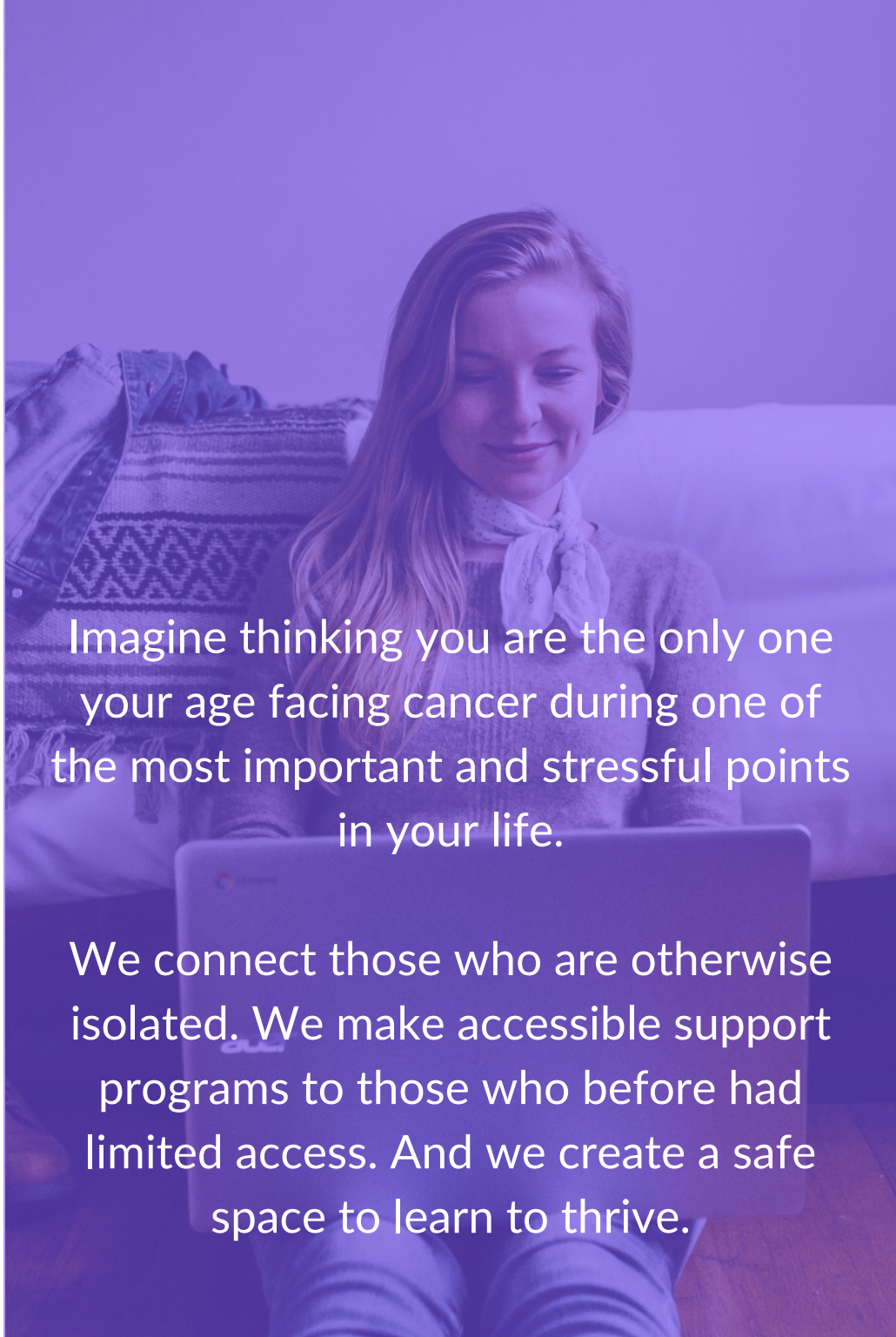
Each year, 90,000 young adults (ages 18-39) hear the words, “you have cancer” and their future changes in an instant.

At a time when their peers are moving up the corporate ladder, pursuing advanced degrees, enjoying budding relationships, or planning for new additions to their families, young adults facing cancer spend time away from school, work, and home to endure treatment and recovery.

While the rest of their peers are moving forward, their lives are put on pause. They feel isolated from their peers, face challenges to education and careers, have concerns about relationships and fertility, and are faced with daunting financial burdens.

At Lacuna Loft, we provide those dealing with cancer in their 20s and 30s with the support and tools they need to adapt their once busy young adult lifestyles to fit the complex challenges that arrive after a diagnosis, and into survivorship.

By bringing together wellness and psychosocial support programs and resources that are specifically geared toward this young adult population, Lacuna Loft decreases isolation and improves wellbeing and quality of life.



Imagine thinking you are the only one  
your age facing cancer during one of  
the most important and stressful points  
in your life.

We connect those who are otherwise  
isolated. We make accessible support  
programs to those who before had  
limited access. And we create a safe  
space to learn to thrive.



# Our Staff

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## Mallory Casperson

### Chief Executive Officer & Founder

Mallory is the Founder and CEO of Lacuna Loft. She has an MS degree and half a PhD in Aerospace Engineering from the University of Illinois at Urbana-Champaign. During her Master's and PhD, she worked with the Air Force Research Lab as well as NASA on high-temperature metal fatigue experiments and simulations. Leaving graduate school in August 2013, Mallory worked for a year to launch Lacuna Loft in April 2015. Applying her love for engineering and technology to a nonprofit endeavor, she manages operations, strategy, and development at Lacuna Loft where online support programs and resources are provided to young adult cancer survivors and caregivers in the comfort of their own homes. She is passionate about young adult cancer survivorship and the importance of the patient voice in healthcare. Lacuna Loft is the first nonprofit moving survivorship care for AYA cancer survivors into the realm of digital health, making survivorship care accessible as never before.

## Aerial Donovan

### Chief Program Officer



Aerial Donovan is the Chief Program Officer (CPO) at Lacuna Loft. Her passion is helping the young adult cancer community discover resources and encouraging them to engage with each other. Her knowledge and expertise in community building and organizing and executing digital events has helped Lacuna Loft's programming flourish. Prior to becoming CPO, she was VP of Programs at GRYT Health and volunteered with organizations such as Stupid Cancer, Imerman's Angels, and Lacuna Loft. She continues to lead the Young Adult Cancer Advisory Board at Lacuna Loft.



# A Letter from our CEO

Earlier this year, I continually found myself describing the world as feeling precarious. Well, we're pretty far into this pandemic and I still feel that way. My own cancer treatments this spring left me feeling isolated and disconnected from my peers. Due to restrictions at the cancer center, I went to all of my appointments, tests, and treatments by myself. I found myself feeling alone in a brand new way, even after months of pandemic-imposed isolation at home.

For young adults facing cancer who attend our programs, these barriers of isolation are immediately broken down. Inside Lacuna Loft, we are a united front of inclusivity, acceptance, and community. Experiencing cancer again myself has emphasized the importance of these programs and of finding these cancer peers to my life.

Without these virtual connections, these virtual experiences of creative coping and togetherness, I would have remained lonely, isolated, and anxious. Now, more than ever, our virtual space is providing crucial support to survivors who have nowhere else to go.

Thank you for joining the Lacuna Loft team and for making this a better, more connected world for young adult cancer survivors and caregivers.

With gratitude,



Mallory Casperson  
CEO & Founder



# Board of Directors

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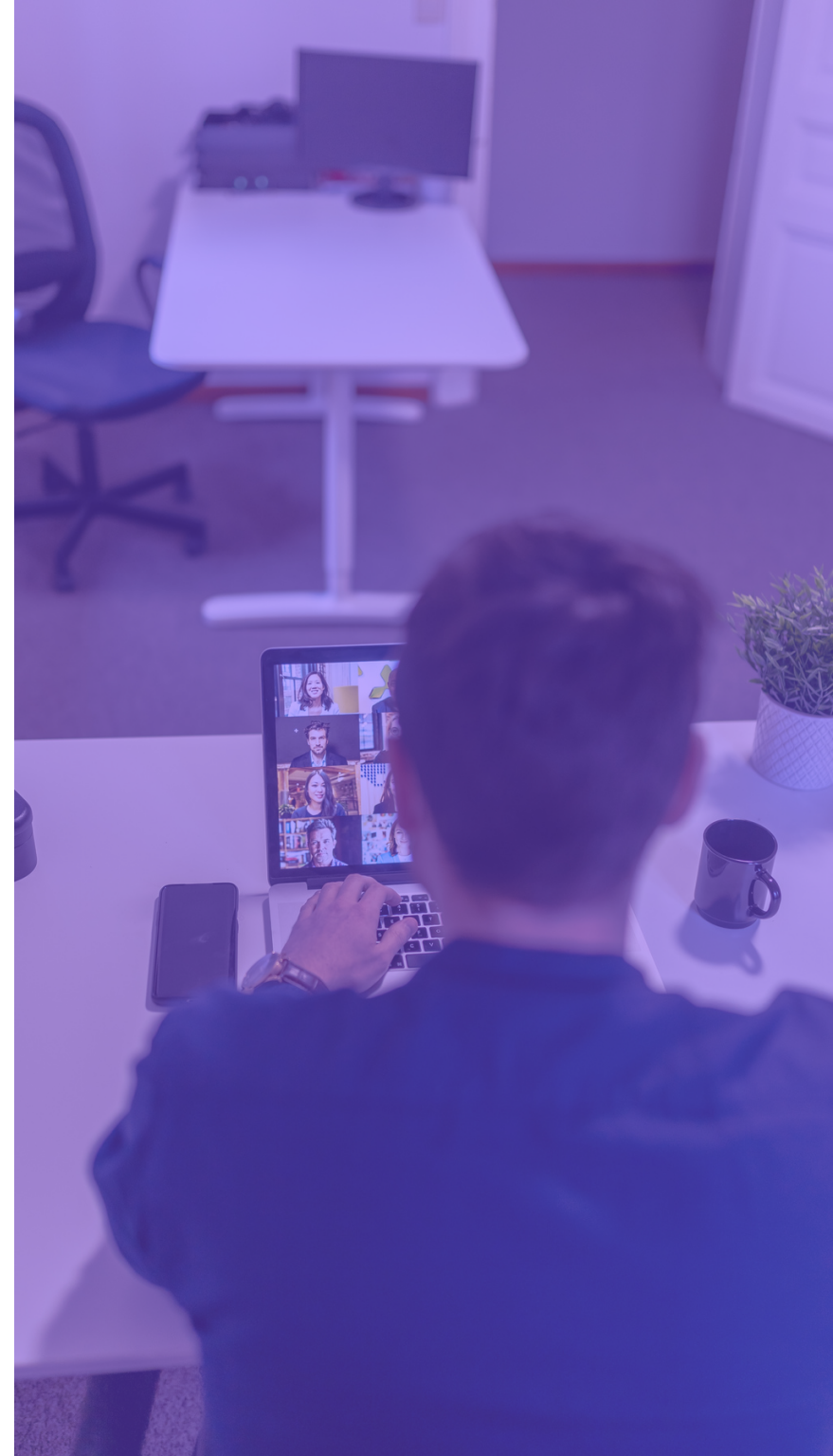
[Patricia McDonald, MBA](#) - Senior Director of Advancement at Southern Illinois University Edwardsville

[Shelly Whitsitt, MBA](#) - Director of Research and Strategy at Fusion Hill

[Kelly Miragliotta](#) - Director of Customer Success at FeeX

[Lauren Creel, MSW, MPH](#) - Program Administrator at City of Hope National Medical Center

[Marc Korobkin, JD](#) - AYA Coordinator and Outreach Assistant at Gilda's Club Madison





# Young Adult Cancer Survivor Advisory Board

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Amy Reichlich, JD - Hearing Officer at Massachusetts  
Bureau of Special Education Appeals

Brandie Langer - Writer at Journey of 1000 Stitches

Bryan Walker - Business Development Manager at  
Maxim Healthcare Group

Christopher Stroh - Situational Analytics Director at  
IHS Markit

Christian Bullock - Director of Digital Strategy at  
GRYT Health

Christina Kosyla - Teacher

Claire Greco, MSW - Therapist at George Junior  
Republic

Deltra Kroemer - Patient Advocate

Diana Cejas, MD - Assistant Professor of Pediatric  
Neurology

Erin Leibowitz - Patient Advocate

Kelly Miragliotta - Customer Success Director at FeeX

Kyle Smith - Filmmaker, Artist, Founder of Check  
Fifteen

Marnie Norris - Data Governance Business Analyst at  
Oregon Health & Science University

Mary Clare Bietila - Patient Advocate at BMT InfoNet

Nick Ross - Filmmaker, Producer, Storyteller

Stephen Heavside - Patient Advocate

Whitney Conkright - Patient Advocate

Yolanda Murphy - Research Specialist and Clinical  
Trial Ambassador at the University of Pittsburgh and  
Hillman Cancer Center

# Scientific and Medical Advisory Board

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**Marcie Ellis** - Program Coordinator, Cancer Peer Navigator Program at UC Davis Medical Center

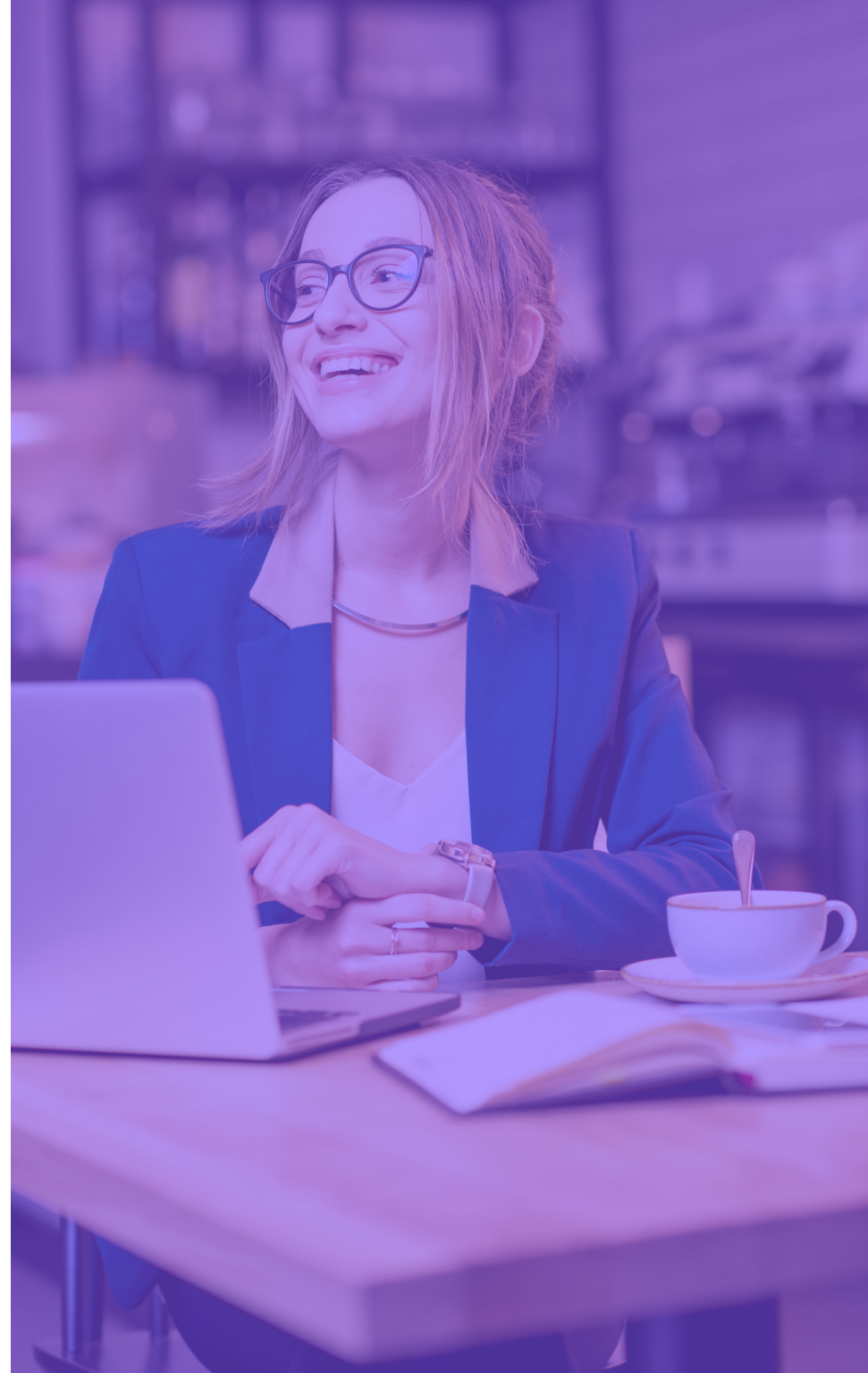
**Cassandra Falby, MS, LMFT** - Program Director at Women's Cancer Resource Center

**Karla Hitchcock** - Oncology Services Consultant at SSM Health St. Louis

**Cathy Moe, EdD** - University of Illinois-Chicago College of Nursing

**Diane Radford, MD** - Associate Professor of Surgery at Cleveland Clinic Lerner College

**Kelly Tschannen** - Nurse Manager at Siteman Cancer Center





# Our Impact



**51,700**

unique visitors to our website



**115**

posts published to our Young Adult Voices Blog



**70**

books sent through our YA Cancer Book Club



**94**

programs held



**2,256 / 50 / 12**

program participants from all 50 states and 12 countries



**93%**

felt less isolated after participating in one of our programs



**92%**

felt more connected to other young adult cancer survivors after participating in one of our programs



# 2020-2021 Programs

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30 Minute Tune Up  
Art Workshops  
Awkward Auntie  
Epic Cooking Class  
Gabfest  
Grief to Gratitude  
How to Turn Your Story Into Advocacy  
It's a Wonderful Life  
Journaling Prompts  
Lost and Found  
Meditation Group  
Mind, Body, Soul Series  
Nourish, Nurture, and Renew  
Survivorship Series  
The Bridge  
Twistshop with Twistout Cancer  
Unspoken Ink  
Young Adult Cancer Book Club  
Young Adult Cancer (YAC) Hangouts  
Young Adult Voices Blog



## 30 Minute Tune Up

30 Minute Tune Up is a widely popular weekly journaling drop-in session led by certified journal therapist and social worker Jean Rowe, LCSW, OSW-C. In the chaos of everyday life, ranging from global pandemics and racial tensions to navigating how best to safely connect with one another, young adult cancer patients, survivors, and caregivers are invited to spend 30 minutes each week journaling and connecting with each other via Zoom. At the beginning of each session, Jean presents a brief journaling prompt and then gives time for each person to journal their response. Participants are then given a few minutes for personal reflection, followed by a time of sharing aloud and reflecting on each participant's writing. This past fiscal year, Jean led 45 sessions for 494 participants.

## Awkward Auntie

Dr. Anne Katz, also known as the Awkward Auntie, is a certified sexuality counselor and nurse who has written several books about young adults and cancer, and all the things that happen to your body, relationships, and sex during and after treatment. In this program, she answers anonymously submitted questions that young adult cancer survivors were otherwise too nervous to ask their physician.

## Art Workshops

Lacuna Loft offers monthly art workshops entitled #LetsMakeStuff @LacunaLoft. This program is a participant favorite and this year, Lacuna Loft offered 14 workshops connecting 290 young adult cancer patients, survivors, and caregivers via online video chat. The Creative Art Workshops allow these young adults to connect with other young adults facing cancer while expressing themselves and their journeys creatively. Lacuna Loft offers the supply box for each art workshop, free of charge to the young adults who participate. 93% of participants felt less isolated and 92% felt more connected to other young adult cancer survivors after participating in one of Lacuna Loft's art workshops.

## Epic Cooking Class

A collaboration with nonprofit, Epic Experience, join CEO and Founder Nancy Ferro and CEO and Founder Mallory Casperson as they guide us through the perils of the kitchen! Make one of Nancy's favorite famous recipes within the cancer community! We'll give you an ingredient list ahead of time so you can cook right along with her! Then chat the evening away with the Lacuna Loft + Epic Experience teams as your delicious food cooks along with others facing cancer! This past fiscal year, we had two sessions and were joined by 21 participants.

# Gabfest

Gabfest is a week-long online conference for young adults facing cancer, presented in partnership with Elephants and Tea. Young adult cancer patients and survivors are the experts in their own care, so along with experts in their fields, Gabfest combines and elevates the individual voices of the young adult cancer community. The week includes survivorship crash courses, interactive panels, and informal hangouts. The entire event was offered through zoom, and our top priority was creating space for interaction between the patients/survivors and between the survivors and the experts. Participants were face-to-face with one another in each and every crash course, panel, and hangout. Each day encompassed a different theme: modes and methods of storytelling, self-advocacy and storytelling, mental health and wellness, caregiving, metastatic disease, sexual health and relationships, and young adult cancer and the body. There were 405 unique registrants at this year's inaugural Gabfest conference.

## How To Turn Your Story Into Advocacy

The How to Turn Your Story into Advocacy Workshop brings together young adult cancer survivors and caregivers in a 90-minute online video chat and teaches them how to turn their young adult cancer story into advocacy. Advocacy comes in many different shapes and sizes, and the workshop goes through a process to help them shape their own narrative into the change they wish to see around them. This fiscal year, the workshop was delivered to 17 young adults facing cancer through two online sessions.

## Grief to Gratitude

Grief to Gratitude is a 6-week yoga and mindfulness workshop focusing on processing grief. This program helps participants tune in and connect with their bodies, minds, and souls through yoga, breathwork, meditation, and other contemplative practice. Participants join together as a community to discuss, process, and move through their grief. This year, we held one 6-session program attended by 13 young adult cancer patients, survivors, and caregivers.

## It's A Wonderful Life

This 6-week holiday journal writing workshop helps young adult survivors design a plan for low stress, create or reconnect with meaningful traditions, and decorate your soul with a little TLC.

The holiday season brings nostalgia (like a favorite song), connection to family and friends, and an undercurrent of expectation. There can be an added layer of managing expectations to be positive and happy – even in the middle of treatment or when everyone appears to look “fine” when, inside, they are not. Finding peace between the wrapping paper and the stuffing is within reach! This program was facilitated by LCSW Jean Rowe, one time last year, was six weeks long, and had 9 participants.



## Journaling Prompts

Participants sign up to receive a journaling prompt sent periodically to their email inbox. The prompt is designed to help focus the chaos happening in their lives and minds to write away some of those cares and anxieties through a structured prompt. This past fiscal year, Lacuna Loft delivered 36 journal prompts to 363 young adult cancer survivors and caregivers via email, with a total of 3,269 email opens.

## Lost and Found

Young adult cancer survivors often worry about returning to the dating world, to their established intimate relationships, and to themselves. Jean Rowe, LCSW, OSW-C, Certified Journal Therapist returns to facilitate this meaningful and powerful program. This workshop has helped past participants dip their toes back into the water of intimacy after diagnosis and treatment. Lacuna Loft and Jean are excited to offer this journal workshop online to young adult cancer survivors (women only) of any diagnosis. Using journal techniques and cultivating an action plan for self-care, in 8 weeks survivors have the opportunity to emerge from the water renewed, informed, and ready to reconnect. For young women cancer survivors who understand what you've gone through while learning how to reconnect, welcoming a compassionate understanding of their body now, and creating ways to open their heart to intimate opportunities after cancer. This was offered one time in the past year, it was an 8 week program and there were 8 participants.

## Meditation Group

A collaboration with Elephants and Tea, the online meditation class brings together young adult cancer survivors and caregivers for an hour of guided yoga nidra meditation classes. The goal of this group is to help these young adults to access their inner calm and activate their ability to heal physically, emotionally, and psychologically. This fiscal year, we held 4, 4-week sessions for 215 program participants.

## Mind, Body, Soul Series

In collaboration with the young adult cancer communities of Dear Jack Foundation, Elephants and Tea, and Lacuna Loft young adult survivors were invited to join our month-long, Mind, Body, and Soul wellness series for an opportunity to connect, grow, and stretch! We offered weekly, 90-minute sessions to help enhance the mind, body, and spirit and provide a chance to break down some of the isolation we've all been experiencing over the past few weeks. Whether you join as a seasoned yogi, meditator, doodle genius, or a newbie to the world of mind and body care, come and try something new in a safe, fun, and encouraging environment – your own home! This 4-week series was held once for 39 participants.



# Nourish, Nurture, and Renew

Nourish, Nurture, and Renew: A Roadmap from Burnout to Self-Care is a 6-week workshop designed for social workers and nurses. This workshop is led by social worker Jean Rowe, LCSW, OSW-C, and is presented in partnership with the Leukemia and Lymphoma Society. The workshop is built on evidence-based, peer-reviewed research that indicates that expressive writing has been successful as a therapeutic tool for improved health, wellbeing, and general functioning. This online, interactive workshop offers 12 continuing education credits for participants who attend all 6 sessions. This past fiscal year, Jean held 4 6-week sessions. 49 nurses and social workers completed the workshop and a total of 588 continuing education credits were awarded.

## The Bridge

The Bridge: When Before and After Meet is a journal workshop for Grief, Loss, and Healing. This is a 6-week workshop using journal techniques to recognize, embrace, and cultivate acceptance around the themes of grief, loss, and healing. Of particular focus is the “before” and “after” of a cancer diagnosis and the multilayered impact it brings. Last fiscal year we had one 6 week program which served 10 participants.

## Survivorship Series

One of our newest programs, the Survivorship Series combines some of our most popular programs into a 6-week program. In this program, a cohort of young adult cancer patients and survivors attend a series of programs together, at a cadence of one every two weeks, for a total of six weeks. Cohorts participate in an art workshop, a game night/hangout, and a journaling workshop. The same group of young adults participates the entire time, creating a tight-knit community similar to that which we have seen in other long-term programs at Lacuna Loft. This past fiscal year, we held two 6-week series for a total of 30 participants. One series was open to any young adult cancer patients, survivors, and caregivers, while the other was open only to young adults diagnosed with metastatic cancer. After participating in the series, 100% of participants felt that what they had to say mattered, compared with only 60% before participating in the series. Additionally, only 40% of participants felt isolated after participating in the series, compared with 80% before participating in the series.

## Twistshop With Twistout Cancer

In collaboration with Twistout Cancer, “Virtual Twistshops” are art therapy-focused workshops that promote healing, relaxation, and emotional recovery through art therapy-based interventions. Topics change each time and Lacuna Loft provided the journal prompt for this workshop. This past fiscal year, we had one session and 20 participants.



# Unspoken Ink

Unspoken Ink: Young Adult Cancer Creative Writing Workshop continued as a favorite program this year. Unspoken Ink was delivered via online video chat to 94 young adult cancer survivors through 4, 8-week sessions and 3 one-night Unspoken Ink Express nights. Participants are given a few writing prompts each session and asked to share their writing aloud after each quiet reflection period. Sharing is voluntary, though reading their work aloud helps participants process their journey and connects them more intimately to the other participants in the group. The Amherst Writing and Artists (AWA) Method is used, facilitating a trusting and inclusive environment where the participants can share pieces of their cancer journeys without fear of judgement. 100% of participants said they felt better after sharing their feelings in writing and 100% reported feeling more connected to other young adult cancer survivors after participating in a writing workshop.

## Young Adult Cancer (YAC) Hangouts

Young Adult Cancer (YAC) Hangouts bring together young adult cancer survivors and caregivers twice monthly in an informal, online video hangout. Whether they talk about cancer or anything else under the sun, they meet in an atmosphere with others who understand what it is like to go through young adult cancer. The YAC Hangouts are guided by a Lacuna Loft volunteer but they are not a support group and are not facilitated by a healthcare provider. This past fiscal year, we connected 149 young adults facing cancer through 19 YAC Hangout sessions.

## Young Adult Cancer Book Club

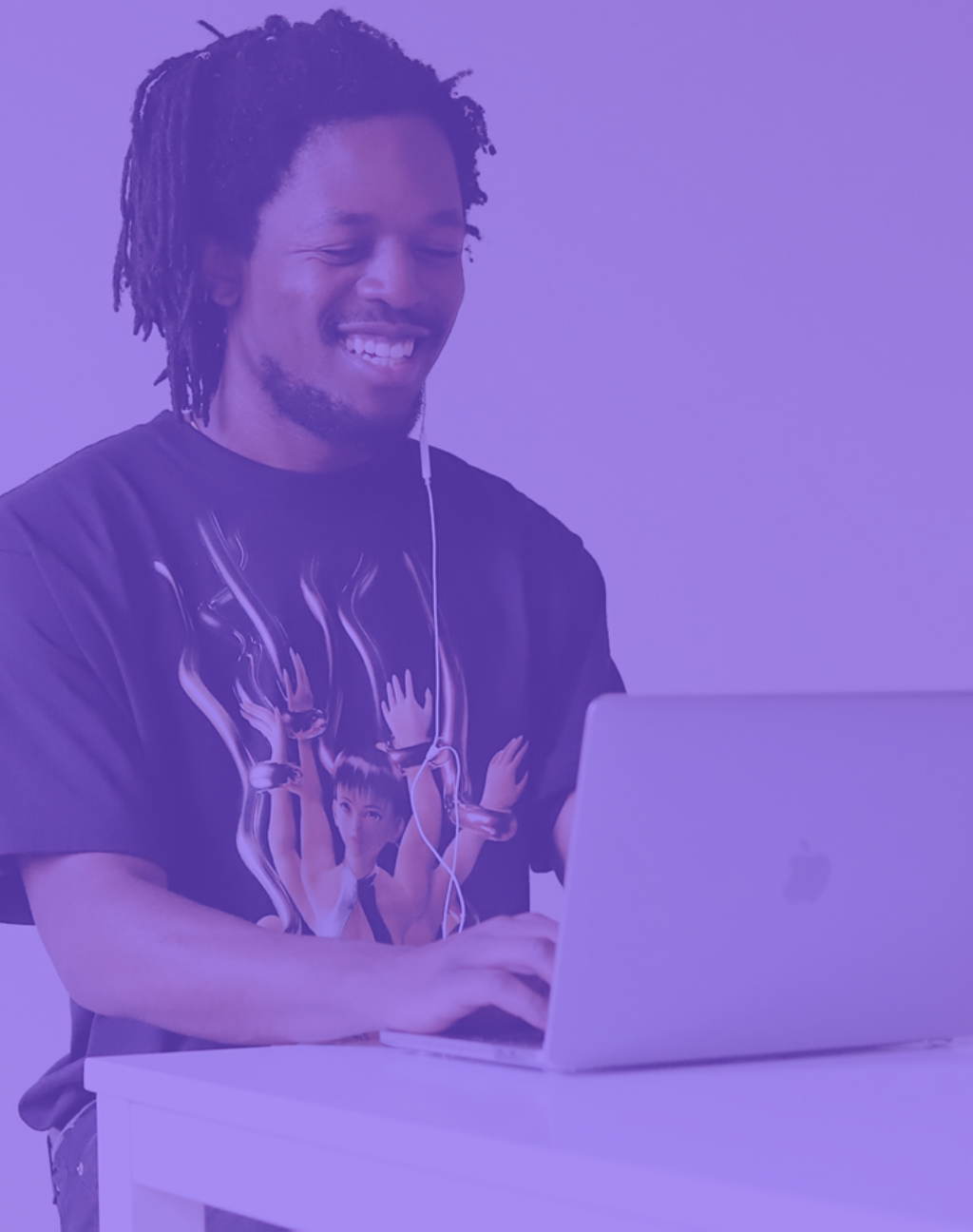
The Young Adult Cancer Book Club brings together young adult cancer survivors and caregivers together over a good book. They connect over shared experiences, anxieties, joys, and so much more through the lens of a shared book. Program participants vote to pick the book and Lacuna Loft donates books to survivors and caregivers upon request. A chapter is discussed each week on our blog. Upon completion of the book, survivors and caregivers join an online book club discussion hosted via video chat. This fiscal year, we read two books together, and 70 copies were sent to young adults facing cancer.

## Young Adult Voices Blog

Young Adult Voices is Lacuna Loft's blog where contributors across the young adult cancer spectrum share their stories to help end isolation. The stories range from personal details of their cancer experience to tips they've learned along the way that are applicable to other young adults facing cancer. Articles feature everything from yoga to death and dying, diy activities to cooking during treatment, fertility to dating and sex, and so much more. Many young adult cancer survivors and caregivers write for the blog. These courageous young adult cancer survivors and caregivers prove, every day to that next young adult diagnosed, they are not alone. There is someone out there who understands and is ready to lend a helping hand. Lacuna Loft published 115 blog posts as part of our Young Adult Voices program in our last fiscal year.



# Summary of Revenue



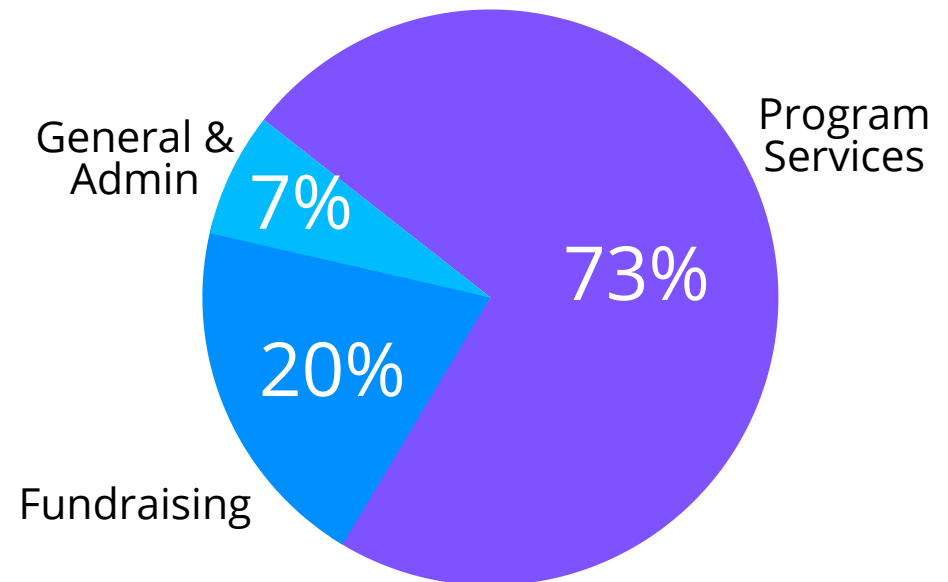
Restricted Corporate Gifts	\$111,585	55%
Individual Contributions	\$41,595	20%
Unrestricted Corporate Gifts	\$35,640	17%
Foundation Contributions	\$10,200	5%
Special Events	\$3,490	2%
Other Revenue	\$1,785	1%
<b>Total Revenue</b>	<b>\$204,295</b>	

**82% growth**

in revenue over fiscal year 2019-2020

# Summary of Expenditures

Program Services	\$120,795	73%
Fundraising	\$33,295	20%
General & Admin	\$12,010	7%
<b>Total Expenditures</b>	<b>\$166,100</b>	



# Where We're Headed

With the continued, overwhelmingly positive response and interest in our programs, the next year at Lacuna Loft will be dedicated to expanding our reach among young adults facing cancer. We've developed our programs. We've grown an engaged group of participants. It's time to continue to deepen our roots and further our impact.

It's time to hire more dedicated staff and grow our Board of Directors and Advisory Boards so we can continue to further our mission to help as many young adult cancer patients, survivors, and caregivers as we can. This next fiscal year, we will hire a Chief Operations Officer to focus on streamlining our logistics and operations, building our marketing and communications, and growing our fundraising and grant writing efforts. We will continue to work hard to grow our donor base and corporate contributors, and continue to seek new funding through grants and family foundations. We will also focus on expanding our contractor and volunteer base so we have the resources and talent to run more diverse programs.

While we love what the name "Lacuna Loft" stands for, there have been challenges, including confusion about what it means, how to spell and pronounce it, and the impression that it is a physical place. We spent the past 9 months asking questions and listening to our community. We hosted a large survey, had discussions with key members of the community individually, held small creative focus groups, and took the time to really learn what it is about our work that most stands out to the most important among us, the young adults facing cancer whom we serve. We see this as an opportunity to take an honest look at what can be done to reach more people and build an even stronger brand. So, in the coming fiscal year, we will be unveiling our new organizational name and brand.

Most importantly, we will continue striving to ensure that our programs reach even more people so that no one feels isolated or alone while facing cancer.







# Thank you!

## Stay Connected

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[www.LacunaLoft.org](http://www.LacunaLoft.org)