



Lacuna Loft

young adult cancer resources
no matter where you are

ANNUAL REPORT

JULY 1, 2018 – JUNE 30, 2019

TABLE OF CONTENTS

WHY YOUNG ADULT CANCER, MISSION, + VISION.....	3
MEET THE TEAM – BOARD OF DIRECTORS.....	4
MEET THE TEAM – LETTER FROM THE CEO.....	7
MEET THE TEAM – SCIENTIFIC/MEDICAL ADVISORY BOARD.....	8
SUPPORT PROGRAMS.....	9
SUMMARY OF REVENUE.....	12
SUMMARY OF EXPENDITURES.....	12
IMPACT.....	13
WHERE WE ARE HEADED.....	14
THANK YOU	

WHY YOUNG ADULT CANCER?

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

Each year, 70,000 young adults (ages 18-39) hear the words, “you have cancer” and the future they had once planned for changes in an instant. Before Lacuna Loft, no comprehensive support resources were available online to provide young adult cancer patients, survivors, and caregivers with psychological, social, and emotional support unique to their age group.

At a time when their peers are moving up the corporate ladder, pursuing advanced degrees, planning for new additions to their families, young adult cancer patients, survivors, and caregivers face time away from school, work, and home to facilitate treatment and recovery. While the rest of their age group is moving forward, their lives are put on pause. They lose the control they once had over their young adult busy lifestyles, feel isolated from their peers, face challenges to education and career advancements, have concerns about relationships and fertility, and are overwhelmed by the daunting financial burdens they face.

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 lifestyle 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 towards this young adult population, Lacuna Loft decreases isolation and improves wellbeing and quality of life.

We connect those 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 MISSION AND VISION

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 peer support 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.

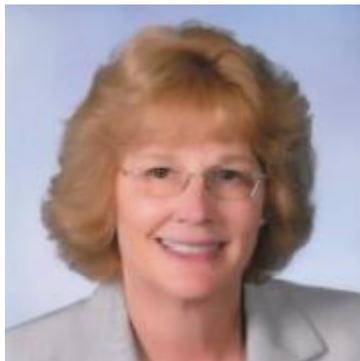
MEET THE TEAM

BOARD OF DIRECTORS



Mallory Casperson – CEO + Founder, President, Board of Directors

Mallory has an MS and half a PhD in Aerospace Engineering from the University of Illinois at Urbana-Champaign. Several months after serving as a primary caregiver for her mother during the final months of her life, Mallory was diagnosed with Hodgkin’s Lymphoma at the age of 24. Several years after her diagnosis, Mallory realized that her new survivorship needs didn’t fit into the work-life balance mold enforced by her graduate school research schedule. After leaving graduate school, Mallory was challenged to ‘do anything she wanted’ for an entire year. That year, Lacuna Loft was launched. She now manages operations, programs, and development at Lacuna Loft where online support programs and resources are provided to young adult cancer survivors in the comfort of their own homes. Mallory is an avid lover of animals, running, biking, swimming, hiking, dog training, being outside, reading, and TV or movie marathons.



Patricia McDonald – Treasurer, Board of Directors

After first her young husband’s, and later her father’s difficult battles with cancer, Patti co-founded a cancer support center to encourage, educate, and empower patients and families experiencing cancer in their lives. She later went on to serve as Founding Executive Director for a second cancer wellness center in the Chicago area. Patti serves as a Lacuna Loft Board Member to do what she can to ensure young adults facing cancer have access to the innovative, age-appropriate, and impactful programs and resources they need to improve their quality of life and well-being - no matter how challenging the circumstances. With over 20 years of experience as a nonprofit leader and fundraising executive, Patti is currently working in advancement for higher education.



Shelly Whitsitt – Secretary, Board of Directors

Shelly works as a director of research and strategy at a qualitative market research and creative agency, Fusion Hill. She started her career in marketing at a start-up in South America and her first experience with qualitative research was with women farmers in India. At Fusion Hill, she enjoys turning rich, qualitative research into key insights that help clients achieve their business goals. Shelly has a BA in Psychology and Spanish and an MBA with a concentration in Marketing from the University of Illinois at Urbana-Champaign. Key experiences in her MBA program include a yearlong project on Product Innovation in Subsistence Marketplaces, and serving as CEO of a student-run 501(c)(3). Shelly enjoys spending time with family and friends, TV binging on Netflix, or getting cozy with a book. She loves traveling and exploring new cultures, trying new and different foods, and being active outdoors.



Lauren Creel – Member, Board of Directors

Lauren is a 6 year Hodgkin lymphoma survivor who was diagnosed with cancer at the age of 23. After treatment, Lauren was inspired to use her personal cancer experience to help other cancer patients, specifically young adults, which is why she is thrilled to be involved with Lacuna Loft. She is passionate about cancer survivorship, specifically dealing with issues of isolation, resilience, and fear of recurrence. After graduating from George Fox University and working for a few years, Lauren returned to academia, earning a Master's in Public Health and a Master's in Social Work from San Diego State University. Lauren now works as a Program Administrator at City of Hope National Medical Center, building comprehensive programs for cancer survivors and academic programs for physicians. When she's not at work, Lauren loves drinking coffee, cooking, and travelling with her brand new husband Dave.



Marc Korobkin – Member, Board of Directors

Marc joined the Lacuna Loft board in 2018 and is excited to be involved in this groundbreaking organization. Marc has been a tireless advocate for improving the health care system and increasing support for patients and caregivers. He has extensive volunteer and leadership experience in the nonprofit sector, including over six years at the Center for Patient Partnerships at UW-Madison, an interdisciplinary program that trains graduate and professional students in patient advocacy. He has also been a caregiver for family members with serious illnesses, including his brother Bryan, who passed away in 2016 from complications of a stem cell transplant. Marc received his JD from the University of Wisconsin Law School in 2009 and lives in Milwaukee, Wisconsin. In his free time, he enjoys hiking and nature photography.



Aerial Donovan – Member, Board of Directors

Aerial is dedicated to helping the cancer community learn about resources, education about patient rights and encouraging engagement through her work at GRYT Health as Director of Programs. GRYT’s app is first and foremost peer support with educational and community programs, which Aerial coordinates. She has a sports medicine and healthcare background, through studying integrative physiology and medicine. Aerial is passionate about ensuring not only patients get the support system they need, but caregivers, advocates, and others affected by cancer as well. After caregiving for her dad, she is determined to continue that support on through the end of treatment. She has experience volunteering with several cancer organizations including Imerman’s Angels, Stupid Cancer, and Lacuna Loft.

LETTER FROM THE CEO

Mallory Casperson – CEO + Founder, President, Board of Directors. Hired in September 2017.



Being a caregiver as a young adult and then becoming a young adult cancer survivor was like a death by a thousand paper cuts. All of a sudden, I felt so much of who I was shift. I went from being able to constantly output and work to needing much more rest and self-care boundaries. I went from being courageous and carefree to feeling nervous and anxious. I went from being active and energetic to continually fatigued. I went from feeling excited to get married and have a family to wondering if I'd survive long enough to see either of those futures. I went from feeling connected and in line with my peer group to feeling left behind, out of sync...totally isolated.

Each of these shifts, all on its own, doesn't seem like much. But add them all together. Suddenly, I was no longer the person I was. I couldn't connect with my friends the way I had before. I couldn't do my job the way I had before. I couldn't think about my future the way I had before. I felt my whole world slipping out from under me, like I was dying from a thousand small uncertainties and changes that were out of my control.

Lacuna Loft saved my life. I met young adult cancer survivors who were experiencing the same anxieties, the same feelings of isolation, the same hesitation about the future. They made me feel sane again at a time when my whole world and perspective were turning themselves upside down after cancer.

With Lacuna Loft, I created exactly what I needed: a connection to young adult cancer survivors who could validate one another's concerns, fuel one another's passions for life, and support one another through their biggest transformation yet, becoming a survivor. **But Lacuna Loft has become so much more than that.** *Lacuna Loft is a safe haven, a safe space in the midst of a world where cancer shifts everything and your 'normal' peer group understands very little, where everyday heroes step up for one another in powerful ways, and where our voices combine to create deep and meaningful change.*

Thank you for being such a big part of this change!

A handwritten signature in black ink that reads "Mallory". The signature is written in a cursive, flowing style.

MEDICAL/SCIENTIFIC ADVISORY BOARD

Marcie Ellis – *Program Coordinator at UC Davis Medical Center, BA*

Cassandra Falby – *Program Director at Women’s Cancer Resource Center, MS LMFT*

Karla Hitchcock – *Oncology Services Consultant, BSN MPH*

Cathy Moe – *Dean of Nursing at Lakeview College of Nursing, BSN, MS, Ed.D.*

Diane Radford – *Surgical Oncologist and Breast Surgeon, MD*

Kelly Tschannen, *Nurse Manager at Siteman Cancer Center, RN, BSN, OCN*

OUR PROGRAMS

YOUNG ADULT VOICES

Young Adult Voices is Lacuna Loft's blog where contributors from all walks of life, on the young adult cancer/caregiver 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 survivors and caregivers. Articles feature everything from yoga and exercise to death and dying, diy activities to cooking during/after treatment, fertility to dating and sex, and so much more. Many young adult cancer survivors and caregivers write for the blog and articles go live every Monday – Friday. 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 146 blog posts as part of our Young Adult Voices program in our last fiscal year.

LIFESTYLE SUPPORT

Becoming a young adult cancer survivor or caregiver isn't an easy transition. Lacuna Loft provides lifestyle support in the form of groups, workshops, and voices to help young adult cancer survivors and caregivers adapt to their new normal, during and after treatment. Young adults share advice on self-care, style advice for dealing with bodily changes caused by treatments, cooking during treatment, and much more. Sometimes you need advice on what medication will save your life, but sometimes you need to know how to adjust *every other* piece of your life to your new realities, in between treatments and into survivorship.

CREATIVE ART WORKSHOPS

Lacuna Loft offers monthly creative art workshops entitled *#LetsMakeStuff @LacunaLoft*. This program is a participant favorite and this year, Lacuna Loft offered 10 workshops and connecting 171 young adult cancer 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 creative art workshop, free of charge to the young adults who participate. 84% of participants report feeling less isolated and 88% reported feeling more connected to other young adult cancer survivors after participating in a creative art workshop.

UNSPOKEN INK: CREATIVE WRITING WORKSHOP

Lacuna Loft's Unspoken Ink: Young Adult Cancer Creative Writing Workshop continued as a favorite program this year. Led by volunteer Jennifer Peckham (University of Rochester Medical Center), Unspoken Ink was delivered via online video chat to 75 young adult cancer survivors through 3, 8-week sessions and 3 one-night Open Write 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. This writing exercise helps young adults gain more control over their journey and feel less alone in their healing

process. 97% of participants report feeling less isolated and 96% reported feeling more connected to other young adult cancer survivors after participating in a writing workshop. Lacuna Loft was also accepted as a program session at Stupid Cancer's CancerCon where we delivered an in-person Writing Workshop.

HOW TO TURN YOUR STORY INTO ADVOCACY WORKSHOP

The newest program at Lacuna Loft, the How to Turn Your Story Into Advocacy Workshop, later renamed the How to Turn Your Story Into Change 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. In the first workshops held over the 2018-2019 fiscal year, 12 young adult cancer survivors attended this workshop via video chat and 100 attended the workshop at the City of Hope AYA Cancer Summit.

YOUNG ADULT CANCER BOOK CLUB

The Young Adult Cancer Book Club brings together young adult cancer survivors and caregivers together over a good book. Program participants vote to pick the book to read and Lacuna Loft donates 24 books to survivors and caregivers upon request. Then, each week on the Young Adult Voices blog, a chapter is discussed. Upon completion of the book, survivors and caregivers join an online book club discussed hosted via video chat. Each round of the book club corresponds to a book read and this July 2018 – June 2019 fiscal year, one book club round occurred. Whether the book chosen is directly about cancer or not, the young adult cancer book club brings together these survivors and caregivers, showing them each week, they are not alone. They connect over shared experienced, anxieties, joys, and so much more through the lens of a shared book.

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 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. Connecting this otherwise isolated patient population is the number one focus, and the YAC Hangouts have become a favored, informal program. This past July 20178 – June 2019 fiscal year, we continued attaching themes to these informal gatherings. *Just Craft* was an overall favorite so far.

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 – 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. This program

MEDITATION GROUP

A collaboration with Help with Hope, the online Meditation Group brings together young adult cancer survivors and caregivers for an hour of meditation and mindfulness once each month. Helping these young adults to access their inner calm and activate their ability to heal physically, emotionally, and psychologically.

SPEAKER SERIES

The Speaker Series offers video content for the first time to our young adult cancer survivors and caregivers at Lacuna Loft. They hear periodically from various speakers, always with young adult cancer in mind. Our Speaker Series talks have included personal stories, searching for purpose, genetic testing and hereditary cancers, how legislation affects the young adult cancer community, and more. We have so far hosted 6 Speaker Series, with a total of 251 young adults consuming the videos.

SEPHORA – ONLINE BRAVE BEAUTY IN THE FACE OF CANCER CLASS FOR CONFIDENCE

Lacuna Loft was proud to continue our partnership with Sephora this past fiscal year. With one of their Pro Artists, Lacuna Loft helped Sephora pilot an online edition of the Brave Beauty in the Face of Cancer Class for Confidence. This July 2018 – June 2019 fiscal year, Lacuna Loft then delivered their Brave Beauty kits to another 200 young adult cancer survivors. Sephora and Lacuna Loft delivered techniques and products that address some of the effects of cancer treatments, skin care tips, and more. All products provided by Sephora were vetted against the Campaign for Safe Cosmetics guidelines.

JOURNALING

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 July 2018 – June 2019 fiscal year, Lacuna Loft delivered 11 journal prompts to 166 young adult cancer survivors and caregivers.

OUTREACH

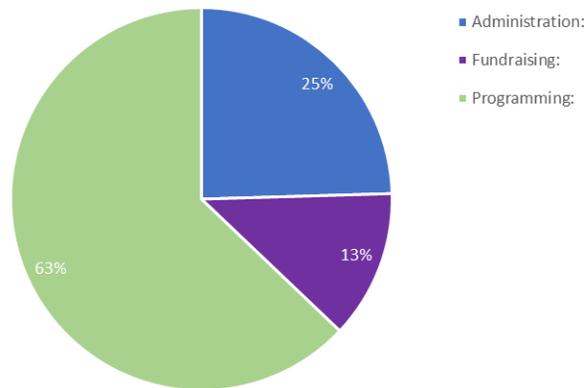
Lacuna Loft actively participates in a number of young adult oncology related conferences throughout the year, reaching out directly to survivors and caregivers as well as to referral sources that include nonprofit professionals and healthcare providers working in the field of young adult oncology. At Stupid Cancer's CancerCon and Young Survival Coalition's YSC Summit, Lacuna Loft reaches directly to young adult cancer patients, survivors, and caregivers. At the conferences of the American Society of Clinical Oncology (ASCO), the American Psychosocial Oncology Society, and the Oncology Nursing Society (ONS), Lacuna Loft reaches the healthcare and nonprofit professionals who advocate and work on behalf of young adult cancer patients, survivors, and caregivers. By letting the world know that Lacuna Loft is here, providing important programs and support, we reach more of the young adults we serve. Lacuna Loft also provides brochures for cancer resource centers, both free-standing and within hospitals, and actively networks with these institutions around the country.

SUMMARY OF REVENUE

Individual Contributions	\$29,568.60	52%
Shop Revenue	\$53.10	< 1%
Event Revenue	\$11,572.63	20%
Restricted Corporate Contributions	\$2,000.00	4%
Restricted Foundation Contributions	\$11,500.00	20%
Unrestricted Corporate Contributions	\$1,097.15	2%
Peer to Peer Contributions	\$802.00	1%
TOTAL REVENUE:	\$56,593.48	

3% increase from our past fiscal year (July 2018 – June 2019).

SUMMARY OF EXPENDITURES



Lacuna Loft's programs remained solid and steady during our July 2018 – June 2019 fiscal year. While the model of offering cancer support programs and resources is not a new one, Lacuna Loft has continued to bring cancer support to a whole new population and in an entirely new way, opening accessibility of supportive psychosocial care like never before. Prior to Lacuna Loft, there was no one-stop-shop for young adult cancer survivors and caregivers to receive the age-appropriate support they deserved through a medium that fit their lifestyle. While survivorship conferences allow for isolated instances of interaction and connection between the young adult cancer patient and survivor population, Lacuna Loft's online programs offer unparalleled accessibility to this vital peer connection year-round, while simultaneously expanding supportive and creative programming to the otherwise isolated and inpatient, young adult cancer patient populations. By offering online support programs and wellness resources to any young adult cancer survivor or caregiver, regardless of diagnosis, stage of disease, or geographic location, Lacuna Loft continues to revolutionize the world of young adult cancer support.

None of this would have been possible without the donors, volunteers, and corporate/foundation contributors who gave to support Lacuna Loft. These supporters believed in our mission as our program set has grown and as we have learned to evaluate the effectiveness of those programs. They are responsible for the impact we provide. Lacuna Loft merely serves as a conduit through which these supporters serve today's population of young adult cancer survivors and caregivers in a whole new way.

Over the course of our July 2018 – June 2019 fiscal year, the Young Adult Voices blog served over 30,000 unique users (unique visitors to the site). Each week a Young Adult Cancer Book Club post went live, an average of 100 people came to the article, and 24 young adult cancer survivors and caregivers received a free book to read and participate. People from over 30 countries used our programs and resources at Lacuna Loft, deepening our reach in the international sphere. Our Creative Workshops program, comprised of our Creative Art Workshops and Creative Writing Workshops, offered via video chat, grew enormously. 171 young adult cancer survivors and caregivers took part in a creative art workshop and 75 young adult cancer survivors participated in the writing workshop. When anonymously surveyed, 89% of participants felt less isolated after taking part in a program and 90% felt more connected to their young adult cancer peers. And so much more.

Studies of young adult cancer patients, have shown that these young adults value connection to peers who understand what they are going through.¹ These young adults experience a distinct lack of control over their lives during treatment and into survivorship, as well as changing perceptions of self-worth and body image.¹ Studies have also shown that "opportunities for social interaction can help ease the stress of coping with illness and renew young people's adaptive capacities" and that "...opportunities for adolescents and young adults to retain or re-establish engagement with same-age peers will promote successful achievement of healthy identity and development and well-being."¹ By participating in Lacuna Loft's programs, these young adults feel less isolated. The face-to-face video chat delivered Creative Workshops Program has further been shown to reduce isolation, building connections and community.⁴ They regain some control over their lives and simultaneously connect with their peers facing cancer. By providing an outlet for healthy expression of feelings through art and writing, Lacuna Loft is providing quality of life benefits to these young adults and improving emotional functioning.^{2,3}

References:

1. Zebrack, Brad J. "Psychological, Social, and Behavior Issues for Young Adults with Cancer." *Cancer* 2011; 117(10 suppl): 2289-94.
2. Warner, Echo L., Kent, Erin E., Trevino, Kelly M., Parsons, Helen M., Zebrack, Bradley J., and Kirchoff, Anne. C. "Social Well-Being Among Adolescents and Young Adults with Cancer: A Systemic Review." *Cancer* 2016; 122: 1029-37.
3. Milbury, Kathrin et al. "Randomized Controlled Trial of Expressive Writing for Patients with Renal Cell Carcinoma." *Journal of Clinical Oncology*. 2013; 50: 3532.
4. Casperson, M.C., Peckham, J.L., "*Bringing a creative writing intervention for young adult cancer survivors online.*" Poster session presented at: ASCO Cancer Survivorship Symposium: Advancing Care and Research; 2018 Feb 16-17; Orlando, FL.

WHERE WE ARE HEADED

With the continued, overwhelmingly positive response and interest in our programs, the next year at Lacuna Loft will be dedicated to explosive growth and expansion of our existing infrastructure. We've developed the logistics. We've grown an engaged group of participants. It is time to significantly deepen our roots and to further our impact. We're going to continue listening to our group of constituents, continue to learn from their needs and pain points as we work to continually improve our program offerings and services. This past fiscal year we hired our CEO as the first, official staff member, and began to grow our Board of Directors team. Immediately, on the first day of this next fiscal year, Lacuna Loft will hire a Chief Program Officer and will grow the Board of Directors to further our mission, to help as many young adult cancer survivors and caregivers as we can.

At Lacuna Loft, we will work hard to grow upon our existing donor base, our existing corporate contributors base, and continue to seek new outside funding through grants and foundations. While during the July 2016 – June 2017 fiscal year Lacuna Loft focused almost exclusively on growing our program base and our participant base, during the July 2017 – July 2018 fiscal year we grew exponentially and established the financial foundation upon which Lacuna Loft expanded, and over the most recent July 2018 – June 2019 fiscal year we remained solid and steady, this coming fiscal year is dedicated to strengthening the financial foundation upon which Lacuna Loft will sustainably operate for years to come. Securing this financial foundation will ensure our programs reach even more young adult cancer patients, survivors, and caregivers, from all walks of life, so that no one feels isolated or alone while dealing with young adult cancer.

