



# Lacuna Loft

young adult cancer resources  
no matter where you are

ANNUAL REPORT

JULY 1, 2015 – JUNE 30, 2016

## TABLE OF CONTENTS

WHY YOUNG ADULT CANCER?.....	3
LACUNA LOFT'S MISSION AND VISION.....	3
MEET THE TEAM – BOARD OF DIRECTORS.....	4
SUPPORT PROGRAMS.....	6
KEY IMPACT NUMBERS.....	8
WHERE LACUNA LOFT IS HEADED.....	10
THANK YOU.....	11

## WHY YOUNG ADULT CANCER?

*Imagine feeling lost, afraid, and alone during one of the most important and stressful points in your life because of cancer.*

Each year, 70,000 young adults (ages 18-39) are diagnosed with cancer, and the future they had once planned for is dramatically altered. Currently, few comprehensive resources are available to help young adult cancer patients, survivors, and caregivers meet their unique psychological, social, and emotional needs.

At a time when their peers are advancing their education, careers, and families, young adult cancer patients, survivors, and caregivers face time away from school and work to facilitate treatment and recovery. They often feel an intense sense of loss of their once busy lifestyles, experience social isolation 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 in their 20s and 30s dealing with cancer 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 improves wellbeing and quality of life.

## 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.

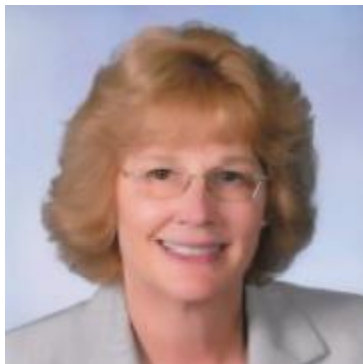
## MEET THE TEAM

### 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, swimming, hiking, 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.



Sarah Goodell – Member, Board of Directors

Sarah is the newest member of the Lacuna Loft board and is thrilled to have the opportunity to contribute to this amazing organization. She is a Senior Analyst in Digital Communications and Corporate Social Responsibility at Mead Johnson Nutrition where she works on a variety of projects, from managing social media campaigns to coordinating CSR efforts. Prior to her work here, she was a Program Manager at Cancer and Careers, where she ran a number of their programs as well as coordinated social media and PR initiatives. During her years working in the cancer community she became very passionate about supporting survivors, particularly young adults, and helping them thrive after a diagnosis. Sarah is originally from Minneapolis but currently lives in Chicago, and is an avid rollerblader, yogi, and brunch enthusiast.

## 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. Over 70 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.

### 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 WORKSHOPS

Lacuna Loft offers periodic creative workshops entitled *#LetsMakeStuff @LacunaLoft*. The program launched its initial, 2-hour session as a Drawing Workshop, bringing together 10 young adult cancer survivors via online video chat, with great success. The Creative 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 workshop, free of charge to the young adults who participate.

### UNSPOKEN INK: CREATIVE WRITING GROUP

Lacuna Loft launched an initial online creative writing group, aided by volunteer Jennifer Peckham (University of Rochester Medical Center), to 10 young adult cancer survivors with much success. Each online creative writing group (Unspoken Ink: Young Adult Cancer Creative Writing Group) session is 10 weeks long and meets for 2 hours each week via video chat. Participants are given several 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 judgment. This writing exercise helps young adults gain more control over their journey and feel less alone in their healing process.

## GUIDED MEDITATION IN PARTNERSHIP WITH HEADSPACE

In partnership with Headspace through their Get Some / Give Some program, Lacuna Loft offered free, year-long subscriptions to their guided mindful meditation app to 500 young adult cancer survivors and caregivers.

## 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. Several rounds of the book club (each round corresponds with one book read) happen every year. Two rounds occurred during our July 2015 – June 2016 fiscal year. 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.

This year our young adult cancer survivors and caregivers read *Planet Cancer: The Frequently Bizarre Yet Always Informative Experiences and Thoughts of Your Fellow Natives* and *Everything Changes: The Insider's Guide to Cancer in Your 20s and 30s*.







## JOURNALING


Participants sign up to receive a journaling prompt sent each week 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.

## OUTREACH

Lacuna Loft actively participates in 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 reached directly to young adult cancer patients, survivors, and caregivers. At the Critical Mass Annual Conference, 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.

## July 2015 - June 2016 Lacuna Loft Impact

	participants from 26 countries	} From the USA to Guatemala, Iran to Spain, Lacuna Loft serves young adults facing cancer around the world.
	> 2000 participants "walk" through our "doors" every month	} Each month, Lacuna Loft's website receives > 2000 visits/sessions.
	100 participants "attend" the book club each week	} Participants interact with our book club when a new chapter is discussed.
	\$16,746 raised by individual donors	} Grassroots funds raised by 20 donors.
	> 70 young adult voices contributors	} Courageous volunteers, sharing their stories daily on our blog to help end isolation.
	100% of program participants feel less isolated than before	} Comparing pre- to post-program surveys, our participants feel more connected to their peers.

 **Lacuna Loft**  
young adult cancer resources  
no matter where you are



Lacuna Loft's programs were met with overwhelming success during our July 2015 – June 2016 fiscal year. While the model of offering cancer support programs and resources is not a new one, Lacuna Loft brought cancer support to a whole new population and in an entirely new way. 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 there is a blossoming movement to host several-day conferences for this population of young adults facing cancer, a gap in support during the rest of the year was apparent. By offering online support programs and resources to any young adult cancer survivor or caregiver, regardless of diagnosis, stage of disease, or geographic location, Lacuna Loft is revolutionizing the world of young adult cancer support.

None of this would have been possible without the 20 donors who gave to support Lacuna Loft. These donors believed in our mission before there were programs to prove our effectiveness. They are responsible for the impact that we have provided. Lacuna Loft merely served as a conduit through which these donors served today's population of young adult cancer survivors and caregivers in a whole new way.

Over the course of our July 2015 – June 2016 fiscal year, the Young Adult Voices blog served 19,567 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. People from 26 countries used our programs and resources at Lacuna Loft, allowing us to very quickly move into the international sphere. We gifted 500 young adult cancer survivors and caregivers with subscriptions to Headspace's guided meditation app. Our Creative Workshops and Writing Group programs engaged participants more deeply via video chat. We served 11 young adult cancer survivors in a creative workshop and 10 young adult cancer survivors in a 10-week session of our writing group. When anonymously surveyed, 100% of participants would recommend Lacuna Loft's programs to a friend and 100% of participants feel less isolated than before partaking in a program.

Studies of young adult cancer patients, have shown that these young adults value connection to peers who understand what they are going through.<sup>1</sup> 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.<sup>1</sup> 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."<sup>1</sup> By participating in Lacuna Loft's programs, these young adults feel less isolated. 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 helping to provide quality of life benefits to these young adults and improve physical functioning.<sup>2,3</sup>

#### 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 Kirchhoff, 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.

## WHERE WE ARE HEADED

With the overwhelmingly positive response and interest in our current programs, the next year at Lacuna Loft will be dedicated to growth and expansion of our existing infrastructure. Our Creative Workshops will bring together young adult cancer survivors and caregivers twice each month and the Unspoken Ink: Young Adult Cancer Creative Writing Group will meet three times each year for 10-week sessions. The Young Adult Cancer Book Club will begin hosting online book discussions once a book has been completed, via video chat. Several new programs will launch, bringing together young adult cancer survivors and caregivers from varying backgrounds and with varying interests in new and innovative ways. At the conferences of the American Society of Clinical Oncology (ASCO), the Association of Pediatric Hematology/Oncology Nurses (APHON), the Academy of Oncology Nurse and Patient Navigators (AONN), the Association of Oncology Social Work (AOSW), the Oncology Nursing Society (ONS), and Critical Mass, Lacuna Loft will further reach the healthcare and nonprofit professionals who advocate and work on behalf of young adult cancer patients, survivors, and caregivers.

At Lacuna Loft, we will work hard to grow upon our existing donor base while simultaneously seeking outside funding through grants and foundations. While during the July 2015 – June 2016 fiscal year Lacuna Loft focused almost exclusively on growing our program base and our participant base, this coming fiscal year is dedicated to establishing the financial foundation upon which Lacuna Loft will sustainably operate for years to come.

