# A BREATH of HOPE

L U N G F O U N D A T I O N



ANNUAL REPORT 2018

# OUR VISION AND MISSION

Defeating Lung Cancer, Bringing hope!

A Breath of Hope
Lung Foundation
is improving lung
cancer outcomes by
funding cutting edge
research, raising
awareness through
education, and
supporting patients
and families.

# TABLE OF CONTENTS

Board Chair & Executive Director Letters 3
Our Programs in Action4
Collaboration in Action 5
Events in Action6
Survivor in Action7
Your Dollars in Action 8
Commitment in Action9
Donors in Action10
Leaders in Action



### 2018 BOARD CHAIR, JULIE OPHEIM

I stepped into A Breath of Hope (ABOH) in 2013 as a volunteer and heartbroken daughter. I had recently lost my mother to stage 4 lung cancer following many months of misdiagnosis, and I was experiencing the various stages of grief. I felt angry and isolated as I grappled with one consistent thought, "How could a perfectly healthy nonsmoking 73-year-old woman die from lung cancer, and why were her symptoms missed over and over again?" It felt unfair and I needed a community that understood.

My values led me to take action and become an advocate and leader for change. When I found ABOH, my feelings were validated, and I knew I had to contribute in any way I could. In 2013, ABOH was a small start-up nonprofit foundation with a courageous executive director and board of directors comprised of doctors, nurses, survivors and family members. They all saw the potential for improving lung cancer outcomes, and they were committed to changing the 15% survival rate of lung cancer.

I organized a team to run in the annual ABOH Lung Run/Walk raising over \$3,500 in memory of my mother, Marie Stenglein. I became a speaker in the ABOH Ambassador Program to share my mother's story and educate others about lung cancer, and I was

honored to become a board member in 2014, board co-chair in 2016 and board chair in 2018. I feel privileged to continue serving and supporting the work of ABOH in memory of my mother and all the other lung cancer warriors I have met through this experience. I am grateful to the founders and those who came after them for their courage and commitment to this movement.



# **EXECUTIVE DIRECTOR, NANCY TORRISON**

For the first time in my seven years at A Breath of Hope, we are seeing real progress in the lung cancer field, and the survival rate continues to creep upwards. An 18.4% survival rate isn't good enough, mind you, but tens of thousands of lives are being prolonged or saved thanks to this progress. Saving lives and bringing hope is the ultimate vision for our organization.

In 2018, we collaborated with other cancer organizations to host meetings focused on improving screening numbers in Minnesota. Meeting participants were physicians and nurses from most of Minnesota's healthcare organizations and the spirit of collaboration rang true at these meetings. Lung cancer screening remains a challenge in America. We continue to focus on getting eligible Americans screened while working to expand preventative screening for a broader audience and earlier detection.

A Breath of Hope's Animated Guide to Lung Cancer (youandlungcancer.com) saw tremendous growth in 2018 with nearly 80,000 patients and family members visiting the site. Of those, most patients said they learned something new and would talk

with their doctor about their treatment. Studies show that a well-informaed patient and the practice of shared decision making between healthcare professionals and patients can lead to improved outcomes, including emotional and physical health.

Finally, our amazing A Breath of Hope fellows from University of Pittsburgh and MIT report progress in their studies about immunology and the biology of women and lung cancer. We are now preparing to launch new awards in 2019. Research, education and patient support matter in this fight to save lives, and I am proud of the many ways we are creating change.

# **OUR PROGRAMS IN ACTION**

#### Research

2018 can best be explained as a year of rebuilding to prepare for expansion of this program with more dollars for greater impact. Along with our attention to developing a robust research committee and expert review panel, we continued to fund Drs. Stabile and Burns at the University of Pittsburgh and began funding Dr. Spranger at MIT.

The Stabile/Burns project reports progress by their multidisciplinary research team in understanding how the female sex hormone, estrogen, promotes a pro-tumor immunosuppressive lung tumor microenvironment that allows the tumor to evade the immune system. Their project strives to improve the activity of immunotherapy using anti-estrogens.

The Spranger project focuses on understanding how the diversity of anti-tumor immune responses influence tumor control by tumor infiltrating T cells. This will be crucial to improve current immunotherapy approaches.

### **Awareness & Education**

Thanks to a restricted gift from a new donor during the summer of 2018, we were able to double our public education impact during National Lung Cancer Awareness Month. We reached nearly 2,000,000 people with important messages about lung cancer, stigma and screening. From presentations by our speaker's bureau to marketing campaigns that included billboards, radio, print and social media ads to growing awareness events, A Breath of Hope continues to educate for earlier detection and an end to an inaccurate and unkind stigma.

# **Patient & Family Support**

A Breath of Hope (ABOH) provides online, highly visual patient education worldwide at youandlungcancer.com, as well as local direct services such as patient or grief support groups and rides to treatment. In 2018, we gave hundreds of rides making it possible for patients to continue their treatment.

Testimony from Mary Ann, a program participant: "I remember our first ride with A Breath of Hope. Before our driver even picked us up, we were so thankful. Part of me wondered if these free rides were too good to be true - but fast forward to today and Joe and I do not know what we would do without A Breath of Hope and their wonderful Ambassadors. The compassion and care shown by each A Breath of Hope driver truly lifts our spirits. These drivers are a major part of our support system. Each driver is prompt and courteous; it shows that they really do respect and care for us."







# COLLABORATION IN ACTION

# **Midwest Lung Cancer Summit**

Lung cancer is associated with high levels of depression and anxiety which can lead to reduced quality of life and survival. A Breath of Hope (ABOH) partners with professionals to bring needed psychosocial support and a loving community to adults living with lung cancer.

With three large group sessions and eleven breakout sessions, the 2018 summit offered excellent education, tools and resources to help families cope with lung cancer. Presenters were experts from Mayo Clinic, University of Minnesota/Masonic Cancer Center, North Memorial Health, Regions Hospital (HealthPartners), Allina/Courage Kenny/Virginia Piper Cancer Institute, Hennepin Health, American Cancer Society, Cancer Legal Center, Wooddale Church, The Marsh and more. With nearly 100 percent 'excellent' ratings, the summit will continue as an annual event offered each fall during Lung Cancer Awareness Month.





## **Screening**

More than 70 percent of lung cancer cases are diagnosed in stage 3 or 4 when it is difficult to beat. Based on the results of the National Lung Screening Trial and the NELSON study, the USPSTF and most professional organizations recommend annual screening for lung cancer with low-dose computed tomography (LDCT) in adults aged 55 to 80 years who have a 30 pack-year smoking history and currently smoke or have quit within the past 15 years.

Sadly, as much as we work toward expanded guidelines to bring screening to more Americans, less than 5% of currently eligible folks have been screened which hurts the movement and contributes to a high mortality rate. In 2018, ABOH partnered with American Cancer Society and American Lung Association to host 'Thought Leader' meetings for healthcare professionals from 25 Minnesota organizations (including ten healthcare organizations). This group of leaders has committed to continue working together to reduce late stage diagnoses through improved awareness and access to lung cancer screening in Minnesota.







## Radon

Radon is a cancer-causing radioactive gas and a serious public health concern in the U.S. The average level of radon in Minnesota's tested homes is 4.6 pCi/L – more than three times the national average of 1.3 pCi/L. Based on epidemiological and ecological studies, it is recommended that we test our homes for radon annually, and mitigate if dangerous levels of radon are found. The Environmental Protection Agency estimates that residential radon causes approximately 21,000 lung cancer deaths in the United States each year. Radon is considered the leading cause of lung cancer after smoking.

ABOH is partnering with radon mitigation contractors and the Minnesota Department of Health to educate communities about lung cancer, encourage testing, and help families find affordable mitigation services when unsafe levels of radon are found in their home.

# EVENTS IN ACTION























# SURVIVOR IN ACTION

# **CHELSI TERWEY**

Chelsi began having chest pains and shortness of breath during the spring of 2015. As a healthy 37-year-old wife and mother, she knew something was wrong. It didn't feel normal. She went to urgent care and was told she had pneumonia. She was prescribed antibiotics and told to come back for a follow-up visit in a few weeks.

Chelsi began feeling better and wasn't going to return for the re-check, but something nudged her to go back. At this visit, Chelsi was told that since she was feeling better, it was not necessary to do an x-ray. Chelsi was not comfortable with this decision and insisted. Later that day, she received a call from her doctor telling her that something cloudy showed up in her chest x-ray, so she returned the following day for a low-dose CT scan. The scan showed unexplained spots that led Chelsi to a PET scan. It was this scan that finally revealed a mass on her right lung and a smaller mass on her left lung. The cancer had spread to her lymph nodes, and a biopsy of the mass determined that she had stage 3b non-small cell lung cancer - adenocarcinoma.

About 40% of lung cancers are adenocarcinomas. These cancers start in early versions of the cells that would normally secrete substances such as mucus. This type of lung cancer occurs mainly in current or former smokers, but it is also the most common type of lung cancer seen in nonsmokers like Chelsi. It is more common in women than in men, and it is more likely to occur in younger people than other types of lung cancer.

Chelsi's journey has been challenging. The very chemotherapy meant to destroy the cancer caused her kidneys to fail. This is a rare side effect. The chemo was successful in shrinking the tumors, so she was given a six-month break to recover from the harsh side effects. After six months with no treatment, scans showed the tumors had grown, and the cancer had metastasized to her brain. Immunotherapy was used with no success. Thankfully, gamma knife radiation to her brain was successful. Chelsi is now on a new chemotherapy drug, and she prays that this treatment will be long-lasting and successful.

Lung cancer has not stopped Chelsi from enjoying life. Her two children bring her unending joy. She knows each moment spent with her family is special, and she finds that her work brings a welcome normalcy to the chaotic world of cancer. Chelsi wants everyone to know about lung cancer, be aware of the many causes and symptoms, and advocate for themselves in the doctor's office. She continues to work with A Breath of Hope Lung Foundation to change the lung cancer smoking stigma, and bring a kinder and more accurate understanding of lung cancer to the public.

# "I hate that everyone's first question is always 'did you smoke'. Why? Would I then deserve it?"



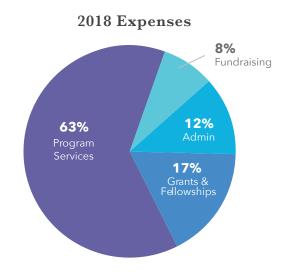




# YOUR DOLLARS IN ACTION

# Income

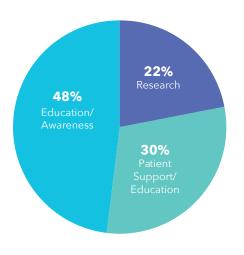
Total Income	868,546.00
Interest Income	185.00
Merchandise Sales (Net of Expense)	971.00
Event Registration Fees	93,177.00
Special Event Revenue (Net of Expense)	90,688.00
In-Kind Donations	41,571.00
Memorial & Honorarium Donations	57,497.00
Circle of Light Donations	59,019.00
Grant Revenue	145,000.000
Contributions	380,438.00



# **Expenses**

<b>Total Net Assets or Fund Balance</b>	429,105.00
Total Liabilities	30,389.00
Total Assets	459,494.00
Total Expenses	700,007.00
Total Expenses	908,539.00
Payroll Expenses (80% Program)	413,710.00
Operating Expenses (80% Program)	66,573.00
WRAP Program (100% Awareness)*	187,503.00
Research Fellowships	151,332.00
Patient Support Expenses	89,421.00

# 2018 Program Service Expenses



Awareness events, Animated Patient Program, billboards, media campaigns, public speaking engagements, social media outreach, targeted emails

A Breath of Hope Lung Foundation (ABOH), a 501(c)(3) charitable organization, works diligently to earn the trust of our donors. ABOH is in excellent standing with the Charities Review Council and has earned a Gold Seal of Transparency from GuideStar. For a full report of our 2017 financial activities, view our 990 on our website: abreathofhope.org or visit smartgivers.org.





<sup>\*</sup>White Ribbon Awareness Program:



# **COMMITMENT IN ACTION**

# A SPECIAL THANKS TO OUR 2018 CIRCLE OF LIGHT MEMBERS

Incandescent Light: John and Wanda Benjamin, Mary and Bill Zimmer

Spot Light: Joan Maclin, Katie Mann

**Key Light:** Curt Anderson, Raymond Byrne, Matthew and Katherine Graczyk, Steve and Kelly Link, Sally Mccabe, Julie and Eric Swedberg, Paul Thurmes

Reflection Light: Mary Jane Benjamin, Gary and Rosey Brausen, Steve Dale, Sarah and Jim Diebel, Arkadiusz and Edyta Dudek, Kristi Flann, Georgia and Mark Helvick, Randy Hertog, Janet and Mark Huss, Jennifer Jones, Jeffrey Kendall, Jeff Nybeck, Julie and John Opheim, Mark and Sara Solfelt, Margaret Ungerman, Todd and Beverly Wadsworth

Ambience Light: Mark and Anne Bacigalupo, Justin and Shanna Ballsrud, Shelly and Joseph Blanchette, Myrnell and Thomas Brusegaard, Peter and Katie Bucka, Myrna and Harry Camp, Ed and Antoinette Egan, Jody and Paul Eifert, Kiara Ellis, Emily and Jason Elswick, Wendi Engebretsen, Naomi Fujioka, Girl Scout Troop 10181, Bobby and Phyllis Jensen, Shirley Kern, The Mac LeFevre Family, Linda and Bruce Machmeier, Manish and Sheetal Patel, Lynn and Mitch Prust, Lori and Brent Ryan, Len Thayer, Jill and Steve Tigner, Jerry and Nancy Torrison, Ed and Audrienne Vidmar, Chris White, The Family of Ruth Zibble

# DONORS IN ACTION

# 2018 Foundation, Corporate & Business Gifts

# \$25,000 - \$49,999

Bristol-Myers Squibb Celgene Corporation Medtronic, PLC Northfield Lines, Inc. The Richard M. Schulze Family Foundation

### \$10,000 - \$24,999

Juels Corporation Karst & von Oiste, LLP The Robert E. Fraser Foundation Russell B. Hagen Foundation

# \$5,000 - \$9,999

Great Clips, Inc. Minnesota Oncology Mystic Lake Casino Hotel North Memorial Health

#### \$2,500 - \$4,999

Allina Health Genentech, Inc. The Merck Company Foundation Peregrine Capital Management, LLC St. Paul Radiology State of Minnesota Department of Health Suburban Radiologic Consultants, LTD. Surgical Care Affiliates, Inc. **UBS Financial Services** Unitech Medical, Inc.

\$1.000 - \$2.499 **AJK Cutters** Allianz Life Insurance Company American Express Foundation American Family Insurance Dreams Foundation Bjorn Timeless Portraits Fairview Health Services Healthcare Convention & Exhibitors Association **HealthPartners** Hennepin Healthcare J.K. Medical, Inc Koch Foundation L & B Theis Farms Lancer Insurance Company Motor Coach Industries, Inc. Mechanical Systems, Inc. Micro Control Company Moss & Barnett Telin Transportation Group, LLC University of Minnesota, Twin Cities Verizon Wireless Wells Fargo & Company Foundation Zinpro Corporation

#### \$500 - \$999

Barbara McGraw and Steven Mosow Fund Eli Lilly & Company Girl Scout Troop 10181 Grazzini Brothers & Company Group Delphi **Groves Real Estate** Lee Health M. Carlson Painting Pinnacle Building Services, Inc. Lions Club of Rogers RSP Architects, Ltd. Schienian Family Foundation The Chris Draft Family Foundation The Randy and Susan Sampson Foundation Total Wine and More Eli's Food and Cocktails

# \$250 - \$499

**Abundant Companies** Bremer Wealth Management Chestnut Cambronne PA G & O Logistics Georgetown University Kennedy & Graven, Chartered McEllistrem, Farione, Landy, Rorvig & Eken, P.A. Minnesota Twins Baseball Club Oberle, Tully & Company Park-Port Lioness Club Redfin

# **Up to \$250**

Alex and Ani, LLC

Affiliated Insurance Services, LLC

Allodium Investment Consultants Amazon Smile American Airlines Bemis Company, Inc. **Boston Scientific** CA Clips, Inc. Conversations with Kelly **EnPro Industries** Frank Properties, LLC Huffman Productions, Inc. Hugo Painting And Drywall, Inc. Junk Bonanza Kalamuna MEI-Total Elevator Solutions Mutual Of America National Network Of Public Health Institutes Nemer Fieger Paquette Construction Perttula Construction, LLC Richard and Mary Ann Pedtke Charitable Foundation Share The Journey, LLC StuartCo Sunny Days Home Watch, LLC Target Corporation Willis And Moore, Inc. Zoey



# LEADERS IN ACTION

# 2018 Board of Directors

Julie Opheim - Chair

Jeffrey Kendall, PsyD, L.P. - Vice Chair

Curt Anderson - Treasurer

Janet Huss, M.S., L.P. - Secretary

Mark Bacigalupo

Justin Ballsrud

Peter Bucka

Gary Brausen

Arkadiusz Dudek, MD, PhD

Jody Eifert, RN, BSN, OCN

Dan LeFevre

Lori Ryan, MD MPH

Mark Solfelt, MD

Paul J. Thurmes, MD

Kiara Ellis

**Emily Elswick** 

Nancy Torrison - Executive Director

(ex-officio)

# 2018 Key Staff

Nancy Torrison

**Executive Director** 

Jennifer Prock

Finance Director

Beth Nault

Marketing Director

Mary Norbeck

Support & Outreach Program Coordinator

Anna Hall

**Event & Awareness Program Manager** 

# Follow Us on Social Media!







