



# ANNUAL REPORT

Pulmonary Fibrosis Foundation

Year Ended **2017**

Pulmonary Fibrosis

FOUNDATION

[pulmonaryfibrosis.org](http://pulmonaryfibrosis.org)

## ABOUT THE PULMONARY FIBROSIS FOUNDATION

The Pulmonary Fibrosis Foundation mobilizes people and resources to provide access to high quality care and leads research for a cure so people with pulmonary fibrosis will live longer, healthier lives.

We are proud to serve as the leading patient advocacy organization of pulmonary fibrosis and are committed to funding research to find effective therapies and, hopefully one day, a cure.

## A LETTER FROM OUR INTERIM CEO

Dear Friends,

As a result of your partnership and support, the Pulmonary Fibrosis Foundation has made great strides in 2017 toward improved care and outcomes for individuals living with pulmonary fibrosis.

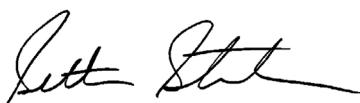
The PFF continues to fund research toward a cure. In 2017, we provided research funding to eight scientists who are working toward the PFF's vision of a world without pulmonary fibrosis. The PFF grant portfolio includes a commitment to growing the pipeline of early stage researchers. This year Guoyung Yu, PhD of Yale University and Jerry Yu, MD, PhD of the University of Louisville received funding. Their work in the role of thyroid hormone and the body's nervous system represent potential treatment targets under investigation. We also supported Vinicio de Jesus Perez, MD of Stanford University and Koji Sakamoto, MD, PhD of Nagoya University to study critical functions of lung cells involved in scar tissue development.

The stars aligned beautifully on February 26, 2017 for a dazzling *Broadway Belts for PFF!* which raised a record-breaking \$250,000. Julie Halston led a cast of Grammy and Tony award winners in a smash hit at the Edison Ballroom in New York City. It was a truly memorable evening for all who attended the 7th annual celebration.

This report also features details about the milestone enrollment of the 1,000th patient in the PFF Patient Registry (p. 5), the PFF's first Hill Day in Washington D.C. (p. 6), and several outstanding fundraising events, including the Hales Run-Walk-Hike for PF, Pete Devito Memorial Foundation Golf Outing, and Take a Bite Out of PF (p. 8).

Thank you for your continued commitment and efforts on behalf of the PFF. All that you do brings us ever closer to achieving our shared vision of a world without pulmonary fibrosis.

Sincerely,



Scott Staszak  
Interim Chief Executive Officer



## PULMONARY FIBROSIS FOUNDATION

Pulmonary fibrosis is a devastating and complex lung disease which most people have never heard of. The term pulmonary fibrosis (PF) literally means scarring of the lungs. Patients sometimes go years without being diagnosed – in fact, many are misdiagnosed – wasting precious time during which they could be receiving proper care and potential treatment.

The Pulmonary Fibrosis Foundation (PFF) exists in order to mobilize people and resources to provide access to high-quality care and to lead research for a cure so that people with PF will live longer, healthier lives. With help from donors, we will advance this ultimate goal on multiple fronts: breakthrough research, new therapies, and increased efforts in advocacy and education.

Key programs in need of sustainable funding include:

- **PFF Patient Registry:** A valuable research tool consisting of patient medical information which is used to discover the causes of and help lead us toward a cure.
- **PFF Care Center Network:** A growing group of medical centers with expertise in accurately diagnosing and treating people living with PF.
- **Patient Education:** Critical materials that provide patients and caregivers with the necessary tools to live with the disease.
- **PFF Therapeutics Network:** Resources to improve the level of development in therapies and facilitate participation in clinical trials.
- **Research Grants for Jr. and Sr. Investigators:** Support for projects that have a high likelihood of improving the understanding of PF.
- **Patient Advocacy:** An effort to drive federal policy to benefit patients and the pulmonary fibrosis community.

The PFF is the only organization exclusively focused on research, education and advocacy efforts for the PF community in the United States.

The PFF has all of the necessary pieces in place to make significant progress in the quest for a cure.

# We Imagine A World Without Pulmonary Fibrosis

Thank you for joining with us to ensure this vision becomes reality.

## PFF PATIENT REGISTRY REACHES MILESTONE ENROLLMENT TARGET



The Pulmonary Fibrosis Foundation (PFF) Patient Registry enrolled its 1,000th patient in the groundbreaking study tracking data from pulmonary fibrosis (PF) patients across the country. Patient participation is on track to achieve the Registry's enrollment goal by 2018.

Data from the Registry will provide researchers with a better understanding of the pulmonary fibrosis patient profile, disease progression, and effectiveness of treatments.

"There are great advances being made in the treatment of multiple types of fibrotic lung disease," said Kevin Flaherty, M.D., M.S., Steering Committee Chair of the PFF Care Center Network and the PFF Patient Registry. "The Patient Registry will serve as a powerful tool in fully understanding how to diagnose, treat and eventually cure pulmonary fibrosis."

The Registry is operated through the PFF's Care Center Network (CCN), a network of over 40 medical centers throughout the country that use a multidisciplinary

approach to deliver comprehensive care to people living with PF. Using CCN sites to collect data ensures standard procedures and controls for maximum data integrity, while allowing patients to enroll as they receive care.

Participants may also choose to contribute blood samples to a biorepository for use in future research. When combined with the information in the Registry, these samples have the potential to help researchers better understand the pathobiology of PF, identify whether treatments are working, improve the ways doctors monitor the progression of the disease, and help discover new treatments.

"The strong enrollment in the Registry reflects the unwavering commitment of patients with pulmonary fibrosis to fight this disease and advance the science," said Benjamin Kramer, M.D., vice president, Immunology and Ophthalmology, U.S. Medical Affairs at Genentech. "We are proud to support this incredibly important initiative to further research and impact the lives of people in the pulmonary fibrosis community."

## PF COMMUNITY RALLIES TO CREATE LEGISLATIVE CHANGE



PFF staff and advocates from throughout the United States rallied together to visit elected officials on Capitol Hill.

As part of a push to increase the Foundation's presence in legislative issues, PFF staff and volunteers visited Capitol Hill in Washington, D.C., on May 22 for the inaugural PFF Hill Day. The 22 participants held 56 meetings with congressional staffers to spread awareness and support for PF research funding.

"We had three asks: increase funding for the National Institutes of Health by \$2 billion in fiscal year 2018, provide a total of \$2.8 billion in funding for the U.S. Food and Drug Administration (FDA) in FY2018, and increase awareness of PF among members of Congress," says Kate Gates, PFF Director of Programs.

Through a simultaneous social media campaign, volunteers who weren't able to travel to Washington communicated the same requests to their legislators from home.

The PFF has participated in previous Hill trips focusing more generally on rare diseases, but this is the first time a visit has been devoted solely to increasing awareness and action for PF.

"This was an exciting milestone for us, the first chance we had to go in and speak about the specific issues. This summer, the Graham-Cassidy plan and the Better Care Reconciliation Act (BCRA) were proposed with the intent to repeal and replace the Affordable Care Act (ACA). As the plans were debated in the U.S. Senate, the PFF stepped up its advocacy efforts in this area.

"Members of our community are really dependent on their health care services, and vulnerable members could be strongly affected if they lost some of those services," Gates explains. With the support of the PFF medical team, "We sent messages, mostly through social media, encouraging our constituents to contact their senators to advocate for keeping the basic protections in the ACA, including pre-existing conditions and Medicaid expansion.

## BROADWAY BELTS FOR PFF!

Broadway stars performed show-stopping hits from *Hamilton*, *Legally Blonde*, and more at the seventh annual *Broadway Belts for PFF!* on February 27 at the Edison Ballroom. The celebration was the biggest yet, raising a record \$250,000.

The event was hosted by award-winning actress and comedienne, Julie Halston, who launched *Broadway Belts for PFF!* in 2011 as a tribute to Associated Press theater critic, Michael Kuchwara.

This year's performers included Grammy-winner Stephanie Mills (*The Wiz*), Mandy Gonzalez (*Hamilton*, *In The Heights*) and Orfeh (*Legally Blonde*) among the stars who graced the stage.



## TEAM PFF EVENTS

### NYC RUN-WALK-HIKE FOR PULMONARY FIBROSIS

Terence and Thomas Hales, along with family, friends, and the public, celebrated the 10th annual NYC Run-Walk-Hike for Pulmonary Fibrosis on June 24 in Central Park. Since its inception, the Walk has raised more than \$600,000 for PF research and patient services.

Spearheaded by board member Terence Hales, the event provides hope and inspiration for the PF community. Hales' father, Thomas Hales, is a transplant recipient and previously served on the PFF's board.



### PETE DEVITO MEMORIAL FOUNDATION GOLF OUTING

On June 16, family and friends of Pete DeVito gathered for the 7th Annual Pete DeVito Golf Outing & Dinner in Mount Sinai, NY. Golfers enjoyed contests on the course, a lovely dinner, raffle prizes and a spectacular fireworks display at the end of the evening.

The event was hosted by PFF board member, Nick DeVito, in memory of his father. The event raised \$35,000 toward awareness and research aimed at helping to find a treatment and possible cure for idiopathic pulmonary fibrosis.



### TAKE A BITE OUT OF PULMONARY FIBROSIS

Jane Nelson was 25 years old and following her dream of attending the Culinary Institute of America in California when she was diagnosed with pulmonary fibrosis. Her illness required that she return to New York to be close to family and friends. Jane received a double lung transplant in 2016. Fifteen months after her transplant, Jane hosted a dinner fundraiser called "Take a Bite Out of Pulmonary Fibrosis" in New York which raised \$30,000. Jane's mother, Joanna Bateman said, "This was meaningful to us both as well as our friends and family who were very supportive. Jane made information cards with about 20 facts about PF which were placed on each table; guests discussed these facts and were amazed at the rarity of this illness and the lack of a cure."





## RESEARCH

The Albert Rose Established Investigator Awards and the I.M. Rosenzweig Junior Investigator Awards support projects that offer a high likelihood of improving the understanding of pulmonary fibrosis in the following areas: basic science, translational research, clinical medicine/research, and social science/quality of life.

### ALBERT ROSE ESTABLISHED INVESTIGATOR AWARDS



#### **Guoying Yu, PhD / Yale University**

##### *Thyroid Hormone As A Novel Therapeutic Agent In Lung Fibrosis*

A growing body of evidence shows thyroid hormone (TH) plays a significant role in protecting cells from death and injury. Most recently, hypothyroidism has been associated with increased mortality in a large cohort of patients with IPF. Studying the effect of TH on models of PF in mice, Dr. Yu and his colleagues discovered that TH supplementation remarkably weakened experimental fibrosis in hypothyroid mouse lungs. “These observations suggest that TH supplementation is an attractive therapeutic candidate for lung fibrosis considering the cost effective advantage of an already known safety profile, evidence that significantly reduces hurdles to initiate a clinical trial,” says Dr. Yu. “The overall objective of this proposal is to develop a clinical formulation of T3, one of the thyroid hormones, as a novel, long-term and efficient anti-fibrotic or preventive therapeutic intervention.



#### **Jerry Yu, MD, PhD / University of Louisville Research Foundation, Inc.**

##### *The Vagus Nerve In Pulmonary Fibrosis*

*Funded by a grant from Boehringer Ingelheim Pharmaceuticals, Inc.*

Increasing evidence indicates that the neuroendocrine system controls immune and cellular responses, and that alteration of the system influences progression of many pulmonary diseases. Dr. Yu hypothesizes that this neuroendocrine system is essential for lung repair: lung injury activates the system, which then promotes fibrogenic (fiber-forming) cells and molecules to cause PF. “Our preliminary data show that the neuroendocrine system is activated following treatment with bleomycin, a medication for treating cancer, yet removing the vagus nerve decreases fibrogenic factors and weakens fibrosis formation,” says Dr. Yu. “Therefore, over-activation of the system would contribute to disease progression.” The award will allow Dr. Yu’s team to further examine physiology, biochemistry, and histology of the fibrotic lung in a mouse model to assess the neuroendocrine system in relation to the severity of the lung fibrosis.

## RESEARCH

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### I.M. ROSENZWEIG JUNIOR INVESTIGATOR AWARDS



**Vinicio de Jesus Perez, MD / Assistant Professor of Pulmonary and Critical Care Medicine, Stanford University**

*HH-10: A novel therapeutic for idiopathic pulmonary fibrosis*

Fibrosis in IPF is due to excessive collagen production by fibroblasts (connective tissue cells) following lung injury that triggers an inflammatory response. One potential approach to treat fibrosis is to restore the production of anti-inflammatory cytokines (a type of substance in cells of the immune system) capable of shutting down inflammation and suppressing collagen production in fibroblasts. Among known anti-inflammatory cytokines, interleukin (IL) 10 is an attractive therapeutic candidate as it has both anti-inflammatory and anti-fibrotic properties. “We have developed a novel inhaled IL 10-based compound, HH-10, capable of both preventing and reversing lung fibrosis in mice, leading us to propose a possible therapeutic role in IPF,” says Dr. de Jesus Perez. “Our ultimate goal is to demonstrate that HH-10 can both prevent and treat lung fibrosis in IPF prior to pursuing clinical studies in patients afflicted with the disease.”



**Koji Sakamoto, MD, PhD / Designated Assistant Professor, Department of Respiratory Medicine, Nagoya University Graduate School of Medicine**

*The role of LincRNA FENDRR as a novel regulator of myofibroblast differentiation in idiopathic pulmonary fibrosis*

*Partially funded by the Jenny H. Krauss and Otto F. Krauss Charitable Foundation Trust, in memory of Stephen N. Dirks*

IPF represents a disease paradigm in which gene-environment interactions, often regulated by epigenetics (nongenetic influences on gene expression), significantly determine the susceptibility of patients to developing this progressive disease. Ribonucleic acids, or RNAs, are essential to the coding, decoding, regulation, and expression of genes. Long intergenic non-coding ribonucleic acids (lincRNAs) are an understudied class of RNAs whose critical role as epigenetic regulators has recently received increased attention. “We discovered that FENDRR— Fetal-lethal non-coding developmental regulatory RNA— a lincRNA highly involved in lung development, was the most decreased lincRNA in lungs of IPF patients,” says Dr. Sakamoto. The award will support further exploration of his team’s hypothesis that decreased FENDRR in IPF lungs renders them susceptible to disease development, and that restoring its levels within the fibrotic lung may exert a therapeutic role.

# FINANCIAL SUMMARY: SELECT FINANCIAL DATA

## STATEMENT OF FINANCIAL POSITION

AUDITED NUMBERS: JUNE 30, 2017

Total Assets	\$	10,614,119
Total Liabilities		4,899,554
<b>Total Net Assets</b>	<b>\$</b>	<b>5,714,565</b>

## STATEMENT OF ACTIVITIES: YEAR ENDED JUNE 30, 2017

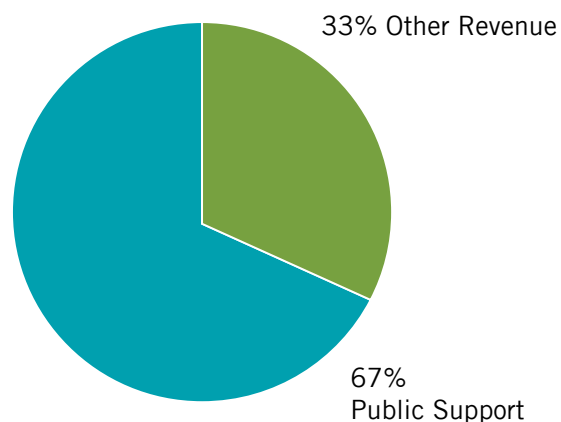
AUDITED NUMBERS: YEAR ENDED JUNE 30, 2017

Total Revenue		
Unrestricted	\$	7,389,307
Temporarily Restricted		1,336,368
Total Expenses		8,725,675
		7,350,418
<b>Change in Net Assets</b>	<b>\$</b>	<b>1,375,257</b>

## SOURCES OF FY 2016-2017 REVENUE

Public Support	\$	5,815,754	67%
Other Revenue		2,909,921	33%
<b>Total Revenue</b>	<b>\$</b>	<b>8,725,675</b>	<b>100%</b>

## SOURCES OF REVENUE

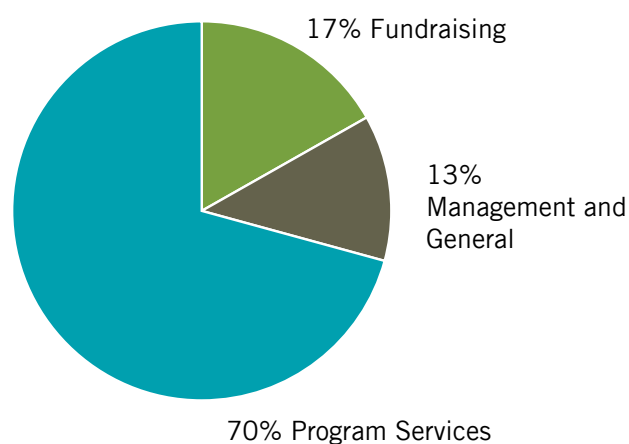


## ALLOCATION OF FY 2016-2017 EXPENSES

AUDITED NUMBERS: YEAR ENDED JUNE 30, 2017

Program Services by Category			
PFF Care Center Network	\$	344,927	
Education		749,459	
Legislative Advocacy		39,222	
Outreach and Awareness		666,620	
Patient Communication Center		38,530	
PFF Patient Registry		2,228,967	
PFF Summit		105,139	
Program Support		451,092	
Research Grants		296,682	
Support Groups		196,325	
<b>Program Services Total</b>		<b>5,116,963</b>	<b>70%</b>
<b>Management and General</b>		<b>952,395</b>	<b>13%</b>
<b>Fundraising</b>		<b>1,281,060</b>	<b>17%</b>
<b>Total FY2016-2017 Expenses</b>	<b>\$</b>	<b>7,350,418</b>	<b>100%</b>

## ALLOCATION OF EXPENSES



## THANK YOU TO OUR DONORS

With the dedicated support of individuals like you, the Pulmonary Fibrosis Foundation is launching some of our largest and most extensive programs yet to make a difference in the lives of those affected by pulmonary fibrosis.

### \$500,000 and greater

Boehringer Ingelheim  
Genentech

### \$100,000 – \$499,999

Elwyn Berlekamp, PhD  
Chuck & Monica McQuaid

### \$10,000–\$99,999

Sherry Allen  
American Association for  
Respiratory Care  
Alan Cirilli  
Doug & Gay Lane Charitable  
Foundation  
Mary Lou Edmunds  
Erwin & Isabelle Ziegelman Foundation  
The GE Foundation  
The Goldhirsh-Yellin Foundation  
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Shanahan Family Foundation  
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Dave Steffy  
The Uhrig/Vournas Charitable Fund  
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### \$5,000–\$9,999

Martin & Colleen Attwell  
B & W Quality Growers, LLC  
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Broadway Cares/Equity Fights Aids  
Butler Family Fund of the  
Community Foundation  
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Vania & Barbara O'Connor  
Cheryl O'Meara  
The Reg and Patricia Bradley Trust  
Pat Rosa  
Rosenthal Family Foundation  
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Michael Sharp  
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Victoria Zoellner

### \$2,500–\$4,999

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Columbia Univeristy Medical Center  
Connors & Ferris, LLP  
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The France Foundation  
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Robert & Amy Starling  
John Stauffer, MD  
Brandon Steckel  
Team Jeffery for PF  
Thrivent Choice

Evans Wilson  
The Yale Center for Interstitial Lung  
Diseases, Section of Pulmonary,  
Critical Care and Sleep Medicine at  
Yale School of Medicine

### \$1,000–\$2,499

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AIG Matching Grants Program  
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Bernard Costello  
Country Square Quilters  
Janice Culver

Donna Daley  
Vicki David & Family  
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Heather Kundert  
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Jerry Kurr  
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Bruce & Cindy Lightsey  
LiveOnNY Foundation  
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Kathryn Lucas  
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 Moglia Family Foundation  
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 Paulina Muzzio  
 The NFL Foundation  
 Suzanne Nofz  
 Jennifer O'Connell  
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 Services, Inc.  
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 Tami Overby  
 Bert & Susan Oyama  
 Thomas Panaggio  
 Stephen Paskoff  
 Rhalene Patajo, PharmD  
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 Pliant Therapeutics  
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 Mark Plourde  
 Cindy Pohlen  
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 Scott Staszak & Laure Dussubieux  
 Robert Steely  
 Stan Stock  
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 Swingley, DO  
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 Claire Tardy  
 Susan Thomasson  
 Todd Thornell  
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 Shawn Tubman & Family  
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 The Bernie Valkenaar Family  
 Elizabeth A. Van Pelt  
 Carolyn Vanderberg  
 Michael Verga, PharmD  
 Herron & Cary Weems  
 Where 2 Get It, Inc.  
 Alvena White  
 Eric White, MD  
 White Mountains Advisors, LLC  
 Harriet Wolf  
 Eileen Zilvetti  
 Marlene Zoob, PharmD

### \$500–\$999

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 North America  
 Joanna Bateman  
 Bears Care  
 Biogen, Inc.  
 Dennis & Sharon Burke  
 Campbell Scientific, Inc.  
 Cheryl A. and John M. O'Meara  
 Charitable Foundation  
 Ronae Thaelke

Christopher Adams  
 Kristin Adams  
 Patrick & Katy Ahern  
 Mark Aimone  
 Anne-Marie Ainsworth  
 Michael Akimori  
 Clifford Allison  
 Larry Allomong  
 Ameriprise Financial Employee  
 Matching Gift Program  
 Anna Marie Anderson  
 Grant & Betsy Anderson  
 Sonica Aron  
 Shirley Arseneau  
 Doris Aschke  
 Nour Assad, MD  
 Cordell Bahn  
 Andrea Barbier  
 Vincent Barrett  
 Barway Consulting  
 Bay State Federal Savings  
 Charitable Foundation  
 Linda Bechtel  
 Melanie Beck  
 Todd Belvo & Anita Hart  
 Alice Bemand  
 Ross Berbeco  
 Monique G. Bergeron  
 Big Red Tomato Packers, LLC  
 Arda Blevins  
 Boeing Company Gift  
 Match/BPAC Program  
 James Bogush  
 Philip Bolas  
 Brian Borkan  
 Joe & Carolyn Borus  
 Lisa Boyd  
 Trish Bradley  
 Robert Bransten  
 Christopher Bridges  
 Dale & Trixie Brommerich  
 James & Carol Brosnahan  
 Lauren Bruning  
 Nancy Bunney  
 Burke Health & Rehab  
 Joseph Burkhart  
 Hilarie Burton  
 BW Contracting  
 Marilyn Cahill  
 Capital Group Companies  
 Charitable Foundation  
 Betty Carlson  
 Carroll Family Fund of The  
 Greater Cincinnati Foundation  
 Casella Waste Systems, Inc.  
 Mary Celenza

William & Beverly Chalmers	Jeannine Edmundson	William H. Hayes
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