

Annual Report

2020



**PulmonaryTM
Fibrosis
Foundation**

OUR MISSION

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.



Dear friends,

This year, the world's attention has been focused on the COVID-19 pandemic—and at the Pulmonary Fibrosis Foundation (PFF), we've worked diligently to maintain activities and to provide information and services to the community during this crisis.

Recognizing that people with chronic medical issues, including pulmonary fibrosis, are at higher risk for serious illness from COVID-19, we've shared multiple resources to help patients and their families stay informed and prepared. Please visit pulmonaryfibrosis.org/covid19 to find PFF guidance on COVID-19, PFF webinars on the coronavirus, answers to frequently asked questions (FAQs) from PF patients, information for transplant candidates and recipients, tips on preparing your home, help with managing anxiety, and much more.

Although the coronavirus has brought new complexity to our work, we continue to find silver linings in our practice of bringing the community together virtually. For instance, we held our annual Washington, D.C. Hill Day via video and telephone calls rather than in person, and we had more participants than ever. A scheduled training for PFF Ambassadors took place online. And the popular PFF Walk went entirely virtual this year.

At our very successful PFF Summit 2019, we discussed future plans for our exciting new partnership with Three Lakes Foundation (TLF), an organization that shares our goal of driving awareness, improving quality of care and support for patients with pulmonary fibrosis (PF), and accelerating the development of new therapies and cures. With TLF's support, we will leverage resources to promote the PFF Registry, expand research and innovation, increase awareness of the disease, and more.

We're delighted, too, about our partnership in one of the largest research grants in the history of the PF community. The study is supported by a \$22 million grant from the National Institutes of Health (NIH) and Three Lakes Foundation, a philanthropic family organization. It's a project with enormous potential to change the course of IPF diagnosis and treatment.

The PFF's overall commitment to research continues to expand. The generosity of several longstanding and new donors enabled us to increase the number of PFF Scholars grants to six this cycle, representing a 50 percent increase.

As we observe our 20-year anniversary at the PFF, we thank you for your ongoing commitment to the Foundation and for everything you do to increase PF awareness, education, advocacy, and research. The support created by our close-knit community fuels the Foundation's progress every day, no matter what challenges that day may bring. Thank you for your courage, commitment, and constancy through a difficult year — you are a valuable and valued ally in our fight to identify new treatments, improve patient quality of life, and find a cure for pulmonary fibrosis.



A handwritten signature in black ink that reads "William T. Schmidt".

William T. Schmidt
PFF President and CEO

A handwritten signature in black ink that reads "George Eliades".

George Eliades
Chair, Board of Directors

New Materials and Videos to Help Patients Navigate Pulmonary Fibrosis and COVID-19

In response to the COVID-19 pandemic, the PFF developed a suite of online resources, guidance, and FAQs for PF patients. In tandem with our COVID-19 response, the PFF launched a blog called “PFF Insights” to provide the latest information about both pulmonary fibrosis and the newest coronavirus developments.

Because support groups could no longer meet in person, the Foundation quickly turned to PFF Ambassadors and Support Group Leaders to provide guidance to shift to virtual meetings. Support Group Leaders were provided Zoom access and thorough trainings to help their support groups continue to meet during scheduled times.



Building upon its library of trusted PF materials, the PFF developed new educational materials for patients, caregivers, and healthcare providers. The new materials include:

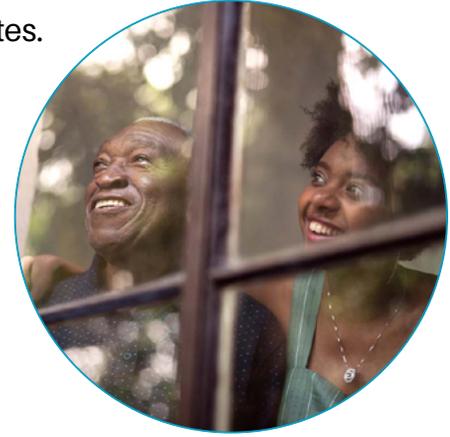
- **Family and Friends Postcard:** Small postcards with quick facts about PF that can be handed out to family, friends, or attendees at events.
- **Questions for your Doctor:** A one-page checklist of important questions that patients might ask their doctors.
- **Spanish Materials:** In response to a growing need for Spanish materials, the PFF translated the Oxygen Basics Booklet, Pulmonary Rehabilitation Pocket Guide, and a “Life With PF” video in Spanish featuring patient and PFF Support Group Leader José Vazquez.
- **Myths & Misconceptions:** A video series debunking common misunderstandings in the pulmonary fibrosis community.
- **Words of Wisdom:** Videos by caregivers, for caregivers. The series provides a platform to share tips and advice for others.
- **Life with PF Video Series:** A new video about using oxygen while living with pulmonary fibrosis. The video features former PFF Ambassador Valeria Hatcher.

While an overwhelming amount of anxiety and fear was communicated on social media as the community adjusted to the “new normal,” PFF Ambassadors participated in a campaign called the Positivity Project. The Positivity Project featured Ambassadors who shared their own words of hope and inspiration, and spoke about how they were keeping busy and staying positive while in lockdown.

PFF Registry Continues Making Strides

The PFF Registry is a crucial research tool in the fight against PF. Since 2016, the PFF Registry has enrolled and followed the care of thousands of patients within the PFF Care Center Network. Data gathered from these patients are being used by researchers to discover the causes of PF, improve treatments, and help lead us toward answers. In only a few years’ time, PFF Registry data have played a key role in over 30 research studies that have been completed or are underway. If each of these studies had been conducted without the use of the Registry, the research costs would have totaled an estimated \$32 million.

Looking ahead, the Registry will significantly expand to capture more participants across various care settings and regions within the United States. Appropriately renamed the PFF Care Center Registry, this database will resume and maintain enrollment of over 2,000 patients in up to 68 PFF Care Centers. Launching in 2021, the new PFF Community Registry will rely on ongoing participant-reported data provided directly from PF patients, including those who have a lung transplant, caregivers, and family members.



The Community Registry's goals are to:

- Develop a more representative understanding of PF
- Stimulate research and assist in clinical trial recruitment
- Engage, unify, and energize the PF community

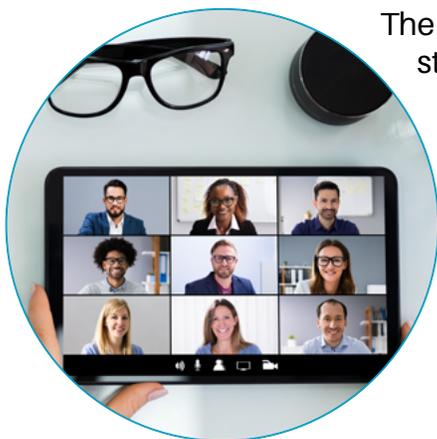
Participants will complete biannual surveys via an easy-to-use online portal. In turn, they will receive periodic newsletters and mailings to highlight how their information is helping to shape the future of PF research. Further, additional surveys and studies will occur throughout the year to present opportunities to participate in unique research studies.

Visiting Care Center Network Sites Remotely Amid the COVID-19 Crisis

The PFF Care Center Network (CCN) is comprised of 68 medical centers that comprehensively evaluate and care for patients with PF. The healthcare providers in the PFF CCN have proven experience and specific expertise in treating people with fibrotic lung diseases.

To better understand how the pandemic affected centers, the CCN Steering Committee developed a COVID-19 survey for site directors and nursing staff. In particular, the questionnaire focused on managing patient visits through telehealth and participation in clinical trials. A manuscript is being developed to share this important information.

Further, the CCN achieved several important goals. Highlights include completing two position statements, "Role of Surgical Lung Biopsy in ILD Diagnosis" and "Genetic Counseling and Testing in Adults with ILD." All position statements are available on the PFF website [here](#).



The PFF Benchmarking proposal, designed to develop common ILD clinic standards for CCN sites, has moved into its next phase. This working group chaired by Joyce Lee, MD, Director of UC Health's ILD Clinic, surveyed CCN sites for details on their components, staffing makeup, and treatment approaches. Clinical directors from the CCN were also surveyed to elicit complementary responses on essential clinical resources.

With incredible support from the CCN, we have made extraordinary strides in developing programs that benefit people with pulmonary fibrosis, their families, and healthcare professionals despite a very challenging year impacted by COVID-19.

PFF Summit 2019

The PFF Summit 2019, held November 7-9 in San Antonio, Texas, opened its doors to 950 attendees from 44 states, the District of Columbia, and ten other countries—our largest Summit attendance to date. The conference kicked off on Thursday with an all-day session tailored for community pulmonologists and ILD fellows, a new half-day session designed for nurses and allied healthcare professionals, and an afternoon session created for newly diagnosed patients and their caregivers.



Plenary sessions included keynote addresses by Edith A. Perez, MD of the Mayo Clinic, who presented “Translational Genomics: The Future is Now” on Friday, and Saturday’s presentation by Bray Patrick-Lake, MFS of Evidation Health, was entitled “Opportunities for Patient Engagement in the Development of Clinical Trials.”

Professional sessions this year featured new topics on senescence, transcriptomics, and the importance of PF registries. Previous PFF research awardees delivered summaries of ongoing projects at the start of two scientific sessions. This year’s academic poster winners also provided summaries of their research during several sessions.



PFF Summit 2019 co-chairs (from left to right) Anoop Nambiar, MD, Dot Delarosa, and Joseph Lasky, MD.

For patients, caregivers, transplant recipients, and those who have lost a loved one, the PFF introduced new content on grief writing, health and wellness with PF, emergency preparedness, and the value of meditation, mindfulness, and movement.

Also new this year was the Clinical Trials Innovation Series, with presentations about new research and the development of innovative therapies from ten of our sponsoring companies. You can view more than 70 full-length Summit sessions on the PFF’s YouTube channel. Visit youtube.com/pulmonaryfibrosisfoundation to watch. Additionally, past PFF Summit archival information is available on the PFF Summit website pffsummit.org.

PFF’s PROLIFIC Consortium Aims to Break Down Barriers in IPF Research

Proteins in your blood, known as biomarkers, could give doctors information about what a future with PF could be. And, the presence or absence of a biomarker could predict whether a specific medication would help. This is the promise of precision medicine. It’s also the goal of PROLIFIC, the Prognostic Lung Fibrosis Consortium, a new group created by the PFF and Bristol Myers Squibb Company to facilitate drug development. Until now, companies haven’t had a way to share basic scientific information with competitors. The PROLIFIC consortium’s goal is to change that. The PFF will develop a PROLIFIC website next year to provide more information on this major initiative. For questions, more information, or to join PROLIFIC, contact partnerships@pulmonaryfibrosis.org.

Helping Patients Find Clinical Trials and Understand the Importance

The PFF launched the PF Drug Development Pipeline on October 1, 2019. The Pipeline tool was designed to educate the PF community about drug development in relevant areas of interstitial lung disease, including IPF, hypersensitivity pneumonitis, rheumatoid arthritis associated-ILD, systemic sclerosis associated-ILD, sarcoid-ILD, chronic cough, and lung transplant.

In coordination with this launch, the PFF unveiled a clinical trials video at PFF Summit 2019. As a part of our “Life With PF” video series, the video demonstrates the importance of clinical trial participation and provides an overview of the different phases in trials.

To further our clinical trials education efforts, the PFF added new features to the Clinical Trials Education Center. Enhancements include a glossary of terms used in drug development and clinical studies and a Clinical Trials 101 section. You can visit our Clinical Trials Education Center at pulmonaryfibrosis.org/clinicaltrials.

Pulmonary Fibrosis Awareness Month: Uniting for A Cure

Pulmonary Fibrosis Awareness Month in September brings together the PF community from all around the world. The month presents an opportunity for everyone who has been touched by PF to unite, share trusted information, tell personal stories, and raise awareness on social media with our popular **#BlueUp4PF** hashtag.

In 2019, the Foundation marked September 30 as its inaugural Day of Giving. Letters, emails, and social media posts told the story of Tom Frey, a 9/11 first responder who was diagnosed with PF. More than \$30,000 was raised on the Day of Giving. In a new call to arms in the fight against PF, Three Lakes Foundation and the PFF joined forces to combat the disease. The partnership was announced in September during PF Awareness Month.



86%
of Americans do
not know the
symptoms
of PF

Moving the Needle on PF Awareness

As part of the “Not Everyone Breathes Easy” awareness campaign, the PFF hit the ground running this year with a national consumer survey revealing that 86% of Americans do not know the symptoms of PF. In an effort to highlight the need for more awareness of PF, key findings from the survey were shared in radio, TV, and print advertisements resulting in 23 million impressions.

New Partnerships Raise Awareness and Strengthen Programs

The 2019 fall appeal highlighted the new relationship with Three Lakes Foundation (TLF) by showcasing two animated spokescharacters, Norm and Jennifer, who were designed to represent a PF patient and caregiver. The appeal shared Norm’s journey after being diagnosed with PF and how partnering with the PFF has helped him and his family understand the disease and obtain much-needed support.

Also in fall 2019, TLF launched an awareness campaign, “More Than A Cough,” featuring Norm and Jennifer. The two characters were introduced in digital, social media, broadcast, and print advertisements in Chicago and San Antonio, TX. Further, funding from TLF is helping to maximize the visibility of the PFF Registry. TLF also became a sponsor of the PFF Summit 2019 in San Antonio. In spring and summer of 2020, the PFF and the TLF expanded the “More Than A Cough” campaign into Birmingham, AL, Scottsdale, AZ, and Nashville, TN. Through a special partnership with Google, numerous iterations of ad creatives and messaging were tested to identify the best performing ads.

In spring 2020, the PFF shared the story of McKenzie Swider, a 26-year-old mother of five who was diagnosed with IPF. In her story, McKenzie described how the PFF helped her find the strength she needed to live with the disease. Thanks to the generosity of the PF community, \$215,000 was raised through both fundraising appeals.

Celebrating 10 Years of *Broadway Belts for PFF!*

The Foundation's largest fundraiser, *Broadway Belts for PFF!*, celebrated ten years of glitz, glamor, and Broadway's best on Monday, February 24, 2020 at the Edison Ballroom in New York City. Actress and comedienne, Julie Halston, hosted the star-studded evening showcasing Broadway's biggest performers belting out their favorite tunes to benefit the PFF. The glittering event raised nearly \$400,000, which brought the 10-year total to more than \$2 million!



Bernadette Peters,
Broadway Belts for PFF! 2020

PFF Walk Expands

The PFF Walk continues to grow as we welcomed Dallas as our fourth location.

Almost 400 walkers joined the event which was held at Cypress Waters in late October of 2019. All-together, more than 1,700 patients, caregivers, healthcare professionals, and friends united in the search for a cure.

When the COVID-19 pandemic took hold of the U.S in spring 2020, the PFF pivoted from live Walk events to a fully virtual experience. With just a few weeks to make the shift, the PFF Walk - New York City on April 25 was the first in which participants successfully found new ways to actively share their passions and fundraise for the PF community. In total, the PFF Walk raised \$655,000 this year.



Nearly 400 walkers joined the first PFF Walk Dallas in 2019.

Meet the 2020 PFF Scholars

The PFF Scholars program engages emerging researchers in the field of pulmonary fibrosis. With the goal of advancing research that could translate into successful therapies for PF, the PFF Scholars program is designed to support and enable promising researchers to obtain independent funding and continue their cutting-edge research.

(continued on next page)



Jeremy Katzen, MD

Perelman School of Medicine, University of Pennsylvania

Funded by Boehringer Ingelheim Pharmaceuticals, Inc.

Alveolar type-2 (AT2) cells are important cellular components of normal lung function and repair. It is believed that when AT2 cell function is impaired—for example, in the way these cells process essential proteins—cellular death ensues. This may contribute to the initiation and progression of the fibrotic process in the lung. To investigate this process, Katzen’s team developed a mouse model in which human mutations in one of the essential genes produced in AT2 cells can be turned on and off and the abnormal processing of specific proteins with associated spontaneous fibrosis can be studied. “We hope this will lead to an enhanced understanding of the events regulating the initiation and progression of lung fibrosis,” Katzen says.



Sarah O’Beirne, PHD

Joan and Sanford I. Weill Medical College of Cornell University

Funded by Boehringer Ingelheim Pharmaceuticals, Inc.

Hypersensitivity pneumonitis (HP) is a complex syndrome of lung diseases caused by the inhalation of a variety of organic particles and low molecular weight chemical compounds. This provokes an exaggerated immune response in the airways and lung tissue of susceptible individuals and leads to the development of interstitial lung disease (ILD). To better understand the genes aberrantly activated or repressed in the lung, O’Beirne’s team is performing cell-specific RNA sequencing of activated cellular constituents—lymphocytes and macrophages—obtained during bronchoscopy. “We’ll obtain a better understanding of the mechanisms underlying the abnormal immune response to different inhaled proteins and particles and possibly identify a cellular signature for diagnostic and prognostic use,” O’Beirne says.



Kerri Aronson, MD

Joan and Sanford I. Weill Medical College of Cornell University

Funded by the Chuck and Monica McQuaid Family Foundation

Chronic hypersensitivity pneumonitis (CHP) may result in a diverse set of symptoms that impact patients’ function and overall well-being. Standard assessments of disease severity—pulmonary function testing, high resolution CT scans, and lung pathology—often do not correlate with the impact of the disease. Patient-reported outcomes, such as Health Related Quality of Life (HRQOL) questionnaires, offer patient-centered perspectives on disease severity and treatment effectiveness and enhance shared decision-making. Aronson’s team is developing the first CHP-specific HRQOL tool to enable reliable and relevant patient assessments by uncovering disease effects and treatments specific to CHP. “Our long-term goal is to develop a reliable approach to assess and quantify therapeutic effects that are most important to patients living with CHP,” Aronson explains.



Erica Farrand, MD

University of California, San Francisco

Funded by the Cohen, Veilleux, Tocher, and Feiger Families in fond memory of Eli Cohen.

Acute deteriorations or exacerbations of idiopathic pulmonary fibrosis (AE-IPF) are unpredictable and highly morbid events, but only limited data guides AE-IPF treatment strategies, including the use of anti-inflammatory therapy. The use of real-world data methods is a novel approach to closing the evidence gap. Electronic health records provide powerful tools for clinical research that have proven successful in evaluating disease epidemiology, healthcare resource utilization, management patterns, and outcomes. “We’ll use real-world data from two large healthcare systems, University of California San Francisco and Kaiser Permanente Northern California, to study AE-IPF epidemiology, the nature and variability of clinical management of AE-IPF across care settings, and the impact of recommended management strategies for AE-IPF on clinical outcomes,” Farrand says.



John Kim, MD

Rectors and Visitors of the University of Virginia

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

Modifiable risk factors may be therapeutic targets that slow and prevent IPF. Kim’s research has focused on components of lipids or “fat” in the blood, polyunsaturated fatty acids (PUFAs), as a potential risk factor in ILD. “My central hypothesis, based on my preliminary data, is that higher plasma levels of omega-3 fatty acids will be associated with less disease severity and progression in adults with IPF,” he says. His team will evaluate the role of specialized pro-resolving lipid mediators in PUFAs and maintenance of the length of telomeres, structures that protect the ends of chromosomes. Both have been important modifying factors in other diseases and IPF.



Andrew Haak, MD

Mayo Clinic

Idiopathic pulmonary fibrosis is an aggressive and fatal disease of the lung characterized by uncontrolled deposition and diminished clearance of fibrous connective proteins (scar tissue). Therapies to treat this pathological process are limited, making further investigations to understand the mechanisms which drive this fatal disease highly relevant. The processes which promote the chronic nature and prevent resolution of pulmonary fibrosis are not understood. Haak’s team will investigate the role catecholamines—hormones made by our adrenal glands, including dopamine, norepinephrine, and epinephrine—play in regulating the pathology of pulmonary fibrosis and “set out to identify a potential therapeutic strategy that not only halts the progression of fibrosis but promotes reversal of the disease,” Haak says.

STATEMENT OF FINANCIAL POSITION AS OF JUNE 30, 2020

Audited Numbers

Total Assets	\$	10,892,804
Total Liabilities		3,594,974

Total Net Assets	\$	7,297,830
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STATEMENT OF ACTIVITIES YEAR ENDED JUNE 30, 2020

Audited Numbers

Total Revenue		
Without Donor Restrictions	\$	12,079,613
With Donor Restrictions		(907,273)

11,172,340

Total Expenses		11,938,259
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Change in Net Assets	\$	(765,919)
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SOURCES OF REVENUE

Public Support	\$	8,494,379	76%
Other Revenue		2,677,961	24%

Total Revenue	\$	11,172,340	100%
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ALLOCATION OF EXPENSES

Audited Numbers

Program Services by Category		
Education	\$	586,932
Legislative Advocacy		387,765
Outreach and Awareness		2,540,164
PFF Help Center		84,563
PFF Care Center Network		561,608
PFF Registry		2,137,832
PFF Summit		1,201,863
Program Support		954,691
Research Grants		432,133
Support Groups		223,418

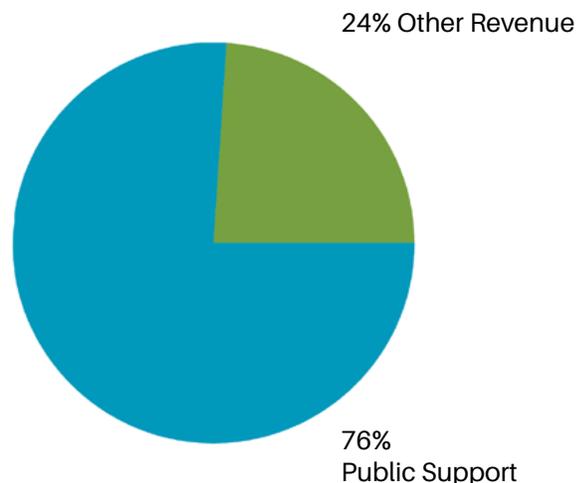
Program Services Total		9,110,969	77%
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Management and General		1,103,628	9%
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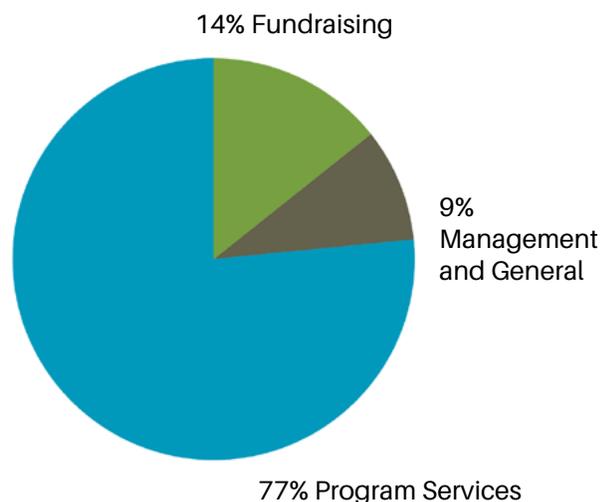
Fundraising		1,723,662	14%
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Total Expenses	\$	11,938,259	100%
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SOURCES OF REVENUE



ALLOCATION OF EXPENSES



The full audited financial statements are available online at pulmonaryfibrosis.org or can be requested by calling 888.733.6741.

PFF Senior Leadership

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William T. Schmidt
President and Chief Executive Officer

Scott Staszak
Chief Operating Officer

Laura Sadler
Chief Marketing Officer

Gregory Cosgrove, MD
Chief Medical Officer

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Education and Awareness

Sonye Danoff, MD, PhD
Senior Medical Advisor,
PFF Care Center Network

Kevin Flaherty, MD, MS
Steering Committee Chair, PFF Care
Center Network and PFF Registry

Joyce Lee, MD, MS
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Research and Health Care Quality

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\$1,000-\$2,499

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Artlin Consulting, LLC
Gladi Baker
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Margery Brittain
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The Burke Family Charitable Gift Fund
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Ralph & Elynn Kennedy
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Patricia Knapsack
Linus Koopmeiners
Emily Kozel
KRN Mosaic Fund
Michael & Karen Kronenfeld
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