Pulmonary™
Fibrosis
Foundation

Research. Investment. Impact.
2024 Annual Report

Letter from our President and CEO

DEAR FRIENDS,

This year has been a period of remarkable growth for the Pulmonary Fibrosis Foundation and for the entire pulmonary fibrosis (PF) community. As we expanded and invested in research initiatives like the PFF Community Registry and PFF Scholars, we have increased opportunities for engagement through our nationwide Walk program and the PFF Summit 2023. The impact of the Pulmonary Fibrosis Foundation has never been greater, and we are deeply grateful for everyone who has supported us in advancing our mission.

One of our proudest achievements, which took place at the beginning of the fiscal year, was celebrating the 1,600 participants in the Community Registry on its one-year anniversary. We invited patients, caregivers, family members and lung transplant recipients affected by pulmonary fibrosis to be a part of the solution by joining the Registry. As more individuals across the country contribute their data to the Registry, this transformative research tool becomes even more powerful in answering critical questions about the diagnosis and treatment of PF. By the end of the year, enrollment in the Community Registry surpassed 2,000 participants – a milestone that underscores the growing momentum behind our efforts.

We also expanded access to expert, multidisciplinary care by adding seven Clinical Associate sites to the PFF Care Center Network (CCN). These new sites provide care to patients in rural. communities across the U.S., each paired with a larger CCN site.

This collaboration offers patient education, clinical care, and access to research opportunities, including clinical trials, bringing the total number of CCN sites to 88.

Our community came together at the PFF Summit 2023, where we welcomed more than 800 healthcare experts, alongside patients, caregivers, and industry leaders from 43 states and 15 countries. Returning to an in-person format for the first time since the pandemic, the conference offered insightful sessions on precision medicine, genetics and supplemental oxygen, among other important topics. It was an unparalleled opportunity for our communities to connect, share knowledge, and discuss the latest advancements in managing and treating PF and ILD.

Throughout the pages of Empowering Every Breath: A Year in Review, you'll find countless examples of the PFF's unwavering commitment to education, support, and advocacy. From research to awareness, none of this would be possible without your continued support and involvement. Together, we are driving meaningful change for the pulmonary fibrosis community.

With gratitude,

Scott Staszak
President and CEO

Volunteers, Advocacy and Education: Driving Change and Impact

WEBINAR ATTENDEES
1,684

AMBASSADOR APPEARANCES
59

HELP CENTER INQUIRIES
5,184

EDUCATION MATERIALS ORDERS
618

The PFF welcomed 13 members of the PF community to its Ambassador Class including patients, caregivers and lung transplant recipients after receiving a record number of applications this year.

These volunteers lent their voices to the PF cause in a number of ways, including presenting at patient education events, and speaking with support groups that serve as lifelines for those navigating the challenges of PF.

In alignment with our mission to serve as a trusted resource for people living with PF and ILD, we developed a new education resource on the topic of palliative care. *Symptom Management for PF: How Palliative Care Can Improve Quality of Life* was created to help patients, caregivers and family members understand more about this specialized medical care.

We also developed a vital new emergency preparedness resource, *Preparing for Emergencies: A Guide for People Living with Pulmonary Fibrosis*. This guide is designed to empower members of our community to stay safe and prepared during challenging circumstances such as natural disasters.

The PFF's advocacy efforts resulted in Congress adopting our recommendations for language about the importance of PF research in the report accompanying the Fiscal Year 2024 funding bill for the National Institutes of Health. This demonstrates that Congress recognizes the importance of PF related research.

In addition, the PFF's advocacy for oxygen reform continued with outreach to members of Congress calling for support for the Supplemental Oxygen Access Reform (SOAR) Act, legislation that aims to ensure that people enrolled in Medicare who need supplemental oxygen can access the correct type and levels of oxygen needed for them to live full and active lives.

The PFF held its fourth annual ILD Day with eight partner organizations during Pulmonary Fibrosis Awareness Month and presented a webinar focused on oxygen as a physiological problem in individuals with ILD and why supplemental oxygen is recommended.

PFF Ambassador Arturo "Hito" Bazan Found Hope and Purpose Through the PFF

I had never heard of pulmonary fibrosis (PF) or interstitial lung disease (ILD) before the spring of 2020.

As a member of the Houston Police Department and an active member of my community, I had the next ten years of my life planned out before retirement. Unfortunately, like all of us in the spring of 2020, my life was about to be forever changed in multiple ways. On June 19, 2020, I woke up with a fever and thought I was coming down with a cold or COVID-19. However, my wife Sheryle, a Registered Nurse, quickly realized it was something much worse. I can honestly say that she saved my life because of her quick thinking.

Sheryle used a pulse oximeter on me, and it showed that my oxygen levels were in the 70% range. After seeing my oxygen levels, we quickly drove to the hospital, where I was admitted and diagnosed with COVID-19 and double pneumonia. My vitals kept falling, and no one knew what exactly was happening.

I was induced into a medical coma for two months. To wake up and realize that I had missed out on two months of my life was heart-wrenching.

I was diagnosed with pulmonary fibrosis resulting from the long-term effects of COVID-19. The doctors told me I would need a lung transplant to survive. I was at the lowest point of my life after hearing my diagnosis, and I thought this would be the end of my life. After I was discharged, I remember being in the parking lot with Sheryle and feeling we had no direction on what to do next. Despite our feelings of hopelessness, we decided together that we were going to fight this disease.

I was unprepared for this disease's emotional toll on me. I had to retire early from my career as a police officer because I could no longer perform my job.

All of these personal setbacks led me to a feeling of extreme isolation.

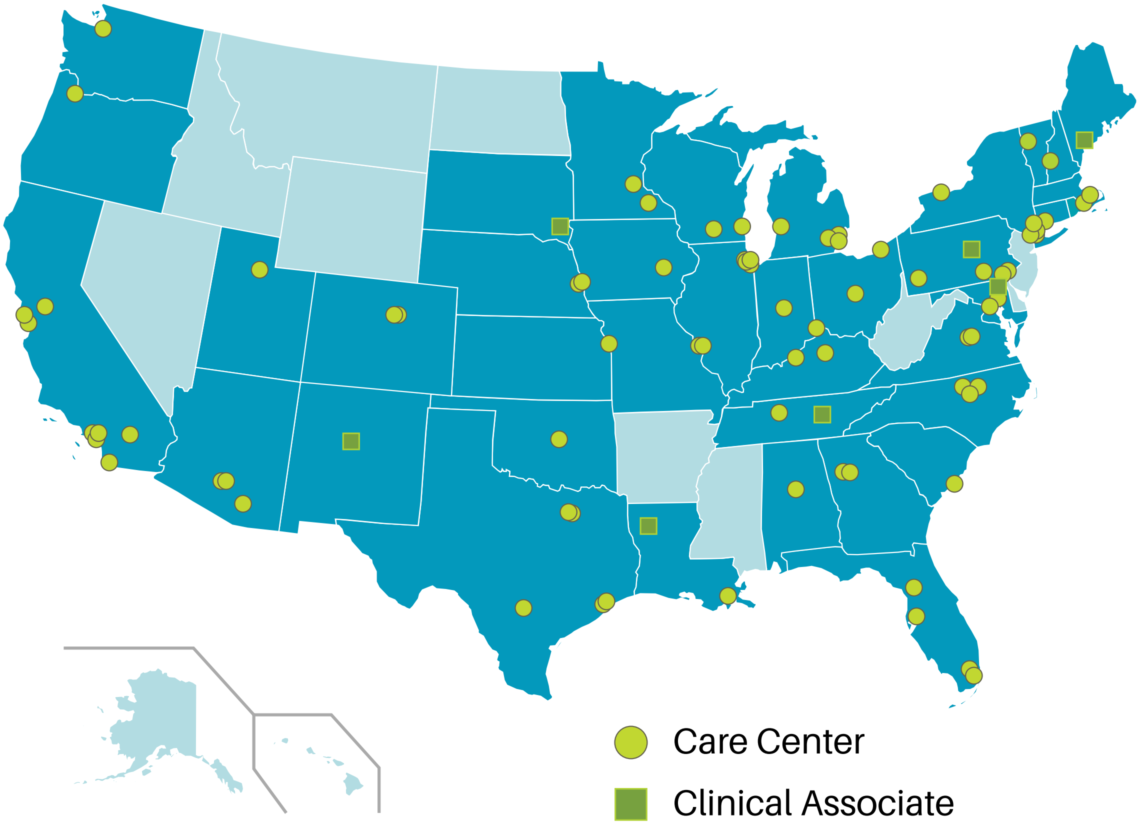
My wife found the Pulmonary Fibrosis Foundation (PFF), and we both devoured all the information that the Foundation provided. Before finding the PFF, I was constantly frustrated and depressed because I had never had any health obstacles before my PF diagnosis.

With the support of the PFF, I connected with their Ambassador Program and finally heard that I was not alone in this journey. Listening to the stories of fellow Ambassadors gave me hope. There were people who had the same disease as me, and they were still going on vacations, being active, and living life to the fullest.

Since connecting with the PFF, my family and I have participated in the 2022 and 2023 PFF Walk - Dallas, and I have become a PFF Ambassador. One of the critical things I learned when talking to the other PFF Ambassadors was that I needed to change my mindset about my life. I needed to understand that just because I have PF doesn't mean that my future is over; it has just changed.

Whenever I engage with the PFF, I leave in the best mood. I always feel relieved that I learned something new and, most notably, that I have hope.

Ten Years of Expert Pulmonary Fibrosis Care



The CCN has grown significantly from a collection of nine medical centers in 2013 to 88 sites across the U.S. today that advance the understanding and treatment of PF and ILD.

These medical centers offer multidisciplinary expertise, conduct pioneering ILD research and provide educational events and resources for the PF community.

Seven Clinical Associate sites joined the CCN this year, each partnered with a Care Center site to collaborate on diagnosis, treatment, and research. The first group of these new members included medical centers across the Northern Plains and southwest regions, areas previously underserved by the CCN.

The CCN Rural Health Outreach Committee also provided resources to patients and providers in community areas that are far from a CCN site in the form of position statements. This year, the PFF teamed up with the Pulmonary Hypertension Association to develop a position statement for both patients and healthcare providers on the relationship between pulmonary hypertension and ILD.

Through new partnerships and expanded outreach, the CCN is at the forefront of combatting these devastating diseases. The PFF's commitment to growing the Care Center Network promises improved outcomes and a brighter future for all those affected.

With the introduction of a new membership category, Clinical Associate, the CCN is expanding its reach to transform the landscape of PF care by reaching patients in rural communities.

Uniting the Community and Sharing Stories through Fundraising

Since its inception the PFF Walk has raised over
$5 million
with over10,000 participants.

The PFF's 14th annual *Broadway Belts for PFF!* shattered previous records and raised
$516,000.

Our annual fundraising appeal brought in over
$291,000.

In its seventh year, the **PFF Walk** brought families and friends together in cities across the country – Pittsburgh, New York City, San Francisco, Chicago, Washington D. C. and Dallas.

For those in different areas of the country, National Walk Day provided an opportunity for people to create their own experiences in their hometowns. This year, we created a special new "Mission Moment" to recognize all members of the PF community – people living with PF, caregivers and family members as well as those who lost a loved one.

The PFF's 14th annual ***Broadway Belts for PFF!*** shattered previous records and raised $516,000 to support patients and their loved ones. This year's sold-out event took place at Sony Hall and attracted more than 1,000 virtual attendees. During the event, PFF Ambassador, Dionn Tunis shared her story of being diagnosed with myositis-associated ILD at age 42. She had to quit her job as a social worker, begin using supplemental oxygen, and move back in with her parents. Although she was used to helping others through her work, Dionn learned to ask for help from her family and the PFF. She began pulmonary rehabilitation, joined a support group and became a pulmonary fibrosis advocate.

As part of the ***Broadway Belts for PFF!*** celebration, the Hales Family Foundation was honored with the Ralph Howard Legacy Award in memory of the late Thomas Hales.

This Spring, we shared the story of PFF Ambassador, Sam Kirton, in our seasonal fundraising appeal. Sam was diagnosed with idiopathic pulmonary fibrosis in 2017. Like many people, Sam had never heard of pulmonary fibrosis before his diagnosis. Fortunately, he received care at a PFF Care Center Network site and received education and support as part of his treatment.

Sam joined support groups through the PFF, which helped him prepare for the lung transplant he received in 2021. His gratitude and sense of responsibility led him to volunteer for the PFF as co-lead of the PFF Lung Transplant Community Support Group and to launch a support group near his home in Virginia. Sam believes that by working together as one team, the PF community is unstoppable.

A Path to Hope and Healing: Jennifer's Story

I discovered the PFF Walk in 2018, two months after losing my mother, my hero, Kathy Paul, to pulmonary fibrosis (PF).

Her passing was a devastating shock to our entire family. You see, Mom also had an autoimmune disease, Sjögren's Syndrome, and its effects were clearly visible to us. But what we couldn't see was how PF was scarring her lungs and taking her breath away.

National Walk Day is a special opportunity to raise funds and build awareness for PF wherever you live. Walking for Mom gives me a profound sense of comfort and accomplishment.

We continue the fight against PF, knowing our participation makes a real difference. This Walk reminds me of two important truths: the Pulmonary Fibrosis Foundation (PFF) is making great strides on behalf of patients, and none of us is alone on this journey.

I wish I had known about the PFF when Mom was diagnosed with pulmonary fibrosis in 2013. She told us about her diagnosis, but we rarely discussed it. I realize now that she didn't want our family to know how sick she was. Mom was always positive – a cheerleader for everyone else. Now, through the PFF Walk, we channel her positivity and grace, cheering for patients and families nationwide.

PFF Community Registry Surpasses Milestone Enrollment

By the end of the year, enrollment in the Community Registry surpassed **2,000 members of the PF community.** This milestone included achieving participation by people **in all 50 states.**

The PFF's priorities remain clear: faster and more accurate diagnoses, better treatments and a cure for PF and ILD.

The path to reach these goals is through research and the PFF Community Registry is the most efficient tool we have for providing researchers the data they need. Along with patient data, the Community Registry is the first of its kind to include caregiver and family member data, including data from those who have lost a loved one.

To mark the one-year anniversary of the Community Registry, the PFF celebrated the 1,600 patients, caregivers, family members and lung transplant recipients who enrolled in this major research initiative.

The anniversary also provided an opportunity for recruitment to encourage more members of the PF community to join and strengthen this research tool by contributing their data. The PFF showcased the voices of Registry participants to demonstrate the need to fast-forward medical research and improve the lives of patients and their families for today's and future generations.

As the Registry continues to grow, the data becomes increasingly valuable to researchers as they will be able to see how survey responses change or remain the same over time. Once we have thousands of engaged participants completing each survey, we will be able to conduct new research and find answers quickly.

Embrace your breath: Pulmonary Fibrosis Awareness Month

Every September, the pulmonary fibrosis community comes together around the world to raise awareness of the disease, its symptoms, and the importance of seeking support by celebrating Pulmonary Fibrosis Awareness Month (PFAM).

2023’s theme was “*Embrace Your Breath.*” The Pulmonary Fibrosis Foundation showcased how the PFF community can stand together in the fight against this disease with daily social media content highlighting your stories, portraits, donations, lung poses, and PF spirit.

With your help, we spread awareness and reached over 130,000 people online!

#BlueUp4PF
Unique buildings or landmarks in communities across the country joined in PFAM through the #BlueUp4PF activity by changing their evening lights to blue. Blue buildings were shared on social media during September

Portraits of PF
Every day a short story was shared from people living with PF, caregivers, lung transplant recipients, those who have lost a loved one, and healthcare professionals. These heartfelt stories help others understand the many journeys’ people affected by PF have experienced.

Lung Pose
New this year, the lung pose challenge invited those in the PF community to strike a pose to raise awareness. Participants took a photo of themselves striking the lung pose by joining their second knuckles together and place them over their chest. This symbolizes the lungs. These photos were then shared on social media.

30 Facts In 30 Days
Each day on social media a fact about PF or ILD was shared to spread information about this disease. Followers then liked, shared, or commented on the post to increase engagement.

ILD Day
On Wednesday, September 13, 2023, the PF community celebrated the third annual ILD Day. In honor of this day the PFF hosted a very special webinar presentation, Breathing Better with Supplemental Oxygen.

Over 750 people registered for this one-hour presentation.

Meet the PFF Scholars!

Each year, the Pulmonary Fibrosis Foundation accepts applications from researchers who are studying pulmonary fibrosis. After a peer-review process and acceptance, each researcher is awarded a $100,000 research grant.

The PFF Scholars program is designed to help talented researchers obtain independent funding to continue their studies. Each PFF Scholars class tackles some of the most urgent questions about pulmonary fibrosis. Our goal is to accelerate the Scholars' research and support them in securing more substantial grants to continue their impactful work.

$100,000
RESEARCH GRANTS PER SCHOLAR

FIVE
PFF SCHOLAR GRANTEES

ASRES BERHAN, PHD
Postdoctoral Scholar in the Division of Pulmonary, Critical Care and Sleep Medicine

University of California, San Diego

This proposal is funded by The Hastings Foundation

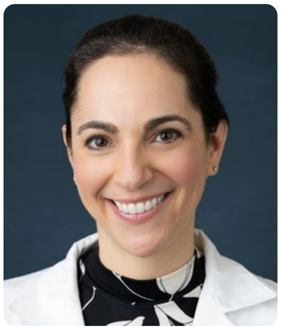
Dr. Berhan is investigating the phenotypic plasticity of idiopathic pulmonary fibrosis (IPF) vs normal human alveolar epithelial cells (AEC) using a three-dimensional (3D) organoid model together with single cell multiome analysis to elucidate mechanisms that regulate AEC plasticity in IPF. He hopes to identify novel signaling pathways and potential drug targets to treat IPF by bridging the fields of pulmonary fibrosis, lung bioengineering and regeneration.

KSENIJA BERNAU, PHD
Associate Scientist in the Division of Allergy, Pulmonary and Critical Care Medicine

University of Wisconsin-Madison

This proposal is funded by Boehringer Ingelheim Pharmaceuticals, Inc.

Dr. Bernau's research combines her expertise in molecular biology of pulmonary fibrosis and molecular imaging with a long-term goal of developing novel probes for improved diagnosis and assessment of pulmonary fibrosis disease activity.



ANNA GERSTEN, MD

Interstitial Lung Disease Team

Johns Hopkins

This proposal is funded by The Buckeye Foundation, the Chuck and Monica McQuaid Family Foundation, and Ms. Holly Harralson

Dr. Gersten's research focuses on understanding the palliative care needs in patients with pulmonary fibrosis and studying novel approaches to address these currently unmet needs.

STEPHEN GURCZYNSKI, PHD

Assistant Professor, Department of Microbiology and Immunology

University of Michigan

This proposal is funded by Boehringer Ingelheim Pharmaceuticals, Inc.

Dr. Gurczynski has begun to study how coronavirus infection alters tryptophan metabolism and how those alterations can feed pro-inflammatory networks leading to exacerbations of interstitial lung disease. Dr. Gurczynski's long term goals are to utilize the results of this research to develop treatments targeting specific enzymes responsible for these pro-inflammatory metabolic alterations.

MATTHEW MCCARRA

Instructor, Division of Pulmonary, Allergy, and Critical Care Medicine

Stanford University School of Medicine

This proposal is funded by The Hastings Foundation

Dr. Mathew McCarra's research interests include lung stem cell biology with a focus on defining the expression of telomerase at the cellular level given the clear association of telomerase mutations with fibrotic lung disease. His overarching goal is to use findings at the bench to develop novel therapeutics that will improve the quality and longevity of the lives of his patients with interstitial lung disease.

Meet the PFF Board of Directors

The Pulmonary Fibrosis Foundation is proud to have a committed Board of Directors to help guide the activities that support our important mission. Members of the Board are actively involved in the PFF's activities and participate in fundraising, promoting awareness, and advocating for the pulmonary fibrosis community.

The PFF's Directors lay the groundwork for the Foundation's strategic vision and contribute significantly to resource development. A central focus of the Board of the Directors is fundraising.

David McNinch
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Laurie Chandler, CFP
VICE-CHAIR, TREASURER

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SECRETARY

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Kenneth C. Fang, MD

Terence F. Hales

Julie Halston

Jeff Harris

Susan S. Jacobs, RN, MS

Heather Kagel

Pankaj "PJ" Kamani

Devi Kumar-Nambiar, JD, MBA

Wayne T. Pan, MD, PhD, MBA

William T. Schmidt

MEMBERS EMERITI

Retiring members of the PFF Board of Directors who have made exceptional contributions to the Foundation are honored with the status "Member Emeritus."

Daniel M. Rose, MD
Chairman Emeritus

Colleen Attwell

Joseph Borus, Esq.

Thomas E. Hales

Mike Henderson
Chairman Emeritus

Dave Steffy

Stephen A. Wald, PhD

Financials

STATEMENT OF FINANCIAL POSITION AS OF JUNE 30, 2024

Audited Numbers

Total Assets	$	15,320,155
Total Liabilities		3,865,441
Total Net Assets	**$**	**11,454,714**

STATEMENT OF ACTIVITIES YEAR ENDED JUNE 30, 2024

Audited Numbers

Total Revenue		
Unrestricted	$	11,049,867
Temporarily Restricted		(907,755)
		10,142,112
Total Expenses		10,422,647
Change in Net Assets	**$**	**(280,535)**

SOURCES OF REVENUE

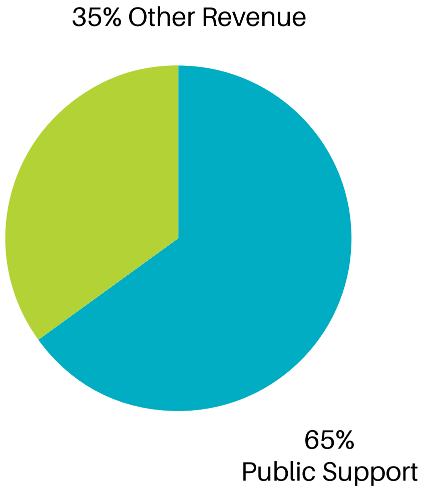
Public Support	$	6,605,471	65%
Other Revenue		3,536,641	35%
Total Revenue	**$**	**10,142,112**	**100%**

ALLOCATION OF EXPENSES

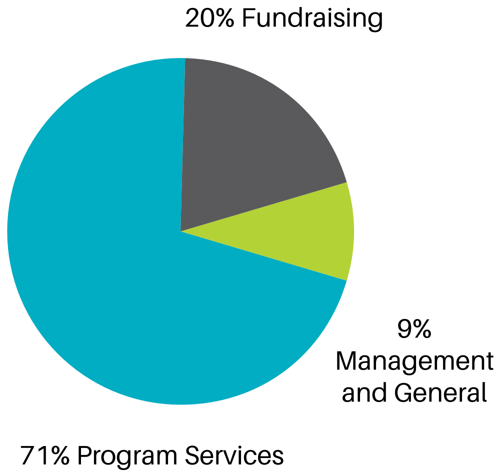
Audited Numbers

Program Services by Category			
Education	$	856,356	
Legislative Advocacy		211,715	
Outreach and awareness		843,940	
PFF Care Center Network		646,622	
PFF Patient Registry		1,527,128	
PFF Summit		1,213,499	
Program Support		800,895	
Research Grants		902,682	
Support Groups		336,695	
Program Services Total		7,339,532	71%
Management and General		969,502	9%
Fundraising		2,113,613	20%
Total Expenses	**$**	**10,422,647**	**100%**

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 2024 Donors

$250,000 AND GREATER

Boehringer Ingelheim
Chuck & Monica McQuaid
Genentech
H & A Trust

$100,000-$249,999

Amgen, Inc.
The Hales Family Foundation, Inc.
The Hastings Foundation
The Estate of Grace Placente
Pliant Therapeutics
The Valhalla Fund

$50,000-$99,999

The Paul Barimas Estate
Bristol-Myers Squibb
Patricia Campbell
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Doug & Gay Lane Charitable Foundation
Steffy Family Foundation Fund
Tvardi Therapeutics
United Therapeutics Corporation
The Estate of Margaret Vaugh

$10,000-$49,999

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$5,000-$9,999

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Randy Harris
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$2,500-$4,999

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Leonard Weiser-Varon
Nipul & Nita Zalavadia

$1,000-$2,499

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