

ANNUAL REPORT 2020

# HELPING PATIENTS

through the pandemic and beyond





# PAN Foundation

## About us

The PAN Foundation is an independent, national 501 (c)(3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic, and rare diseases with the out-of-pocket costs for their prescribed medications.

Since 2004, we have provided nearly 1 million underinsured patients with \$4 billion in financial assistance. Partnering with generous donors, healthcare providers, and pharmacies, we provide the underinsured population access to the healthcare treatments they need to best manage their conditions and focus on improving their quality of life.



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A message from Board Chair  
**Susan C. Rucker**

“Our goal with these new initiatives is to holistically address the barriers that prevent patients from starting and staying on essential treatment.”

Dear colleagues,

2020 was an unprecedented and extraordinary year for us all. During the PAN Foundation’s 16th year, we continued to serve as a vital safety net by providing \$454 million in financial assistance to help over 170,000 patients with life-threatening, chronic, and rare diseases afford their out-of-pocket treatment costs.

Despite the challenges of the pandemic, PAN made significant progress on our three most important goals:

- Providing essential financial assistance to patients in need.
- Expanding safety net programs to mitigate social determinants of health barriers.
- Advocating for policy solutions that will improve healthcare access and affordability.

In addition to assisting with out-of-pocket medication costs for nearly 70 diseases, we launched a COVID-19 fund to help patients access daily essentials during the pandemic and a transportation fund to address their challenges in paying for travel to their medical appointments. We also surveyed our patients to understand their social determinants of health concerns. Our goal with these new initiatives is to holistically address the barriers that prevent patients from starting and staying on essential treatment.

Pandemic or not, many people still cannot afford their life-saving medications as out-of-pocket treatment costs continue to rise. PAN is committed to helping meet the urgent and growing need for patient assistance across the country, while also advocating for policy solutions that will increase access to affordable healthcare. I look forward to continuing our work on this important mission with PAN’s Board of Directors and leadership team this year.

I would also like to commend our outgoing Board Chair Martin A. Bieber for his leadership and six years of service, as well as my fellow board members, for their unwavering commitment to PAN’s vital work.

On behalf of the Board of Directors, I would like to recognize and thank our donors, partners, providers, pharmacies, and staff for their dedication to and support of the PAN Foundation’s mission during such a challenging year.

Sincerely,

**Susan C. Rucker**  
Board Chair



A message from President & CEO

# Dan Klein

“Our entire community came together to show the world what help looks like, and for that I am immeasurably thankful.”

Dear friends,

Last year, the challenges facing our patients were exacerbated in ways I’ve never seen, making the PAN Foundation’s role more vital than ever. The patients we serve come to us because they cannot afford out-of-pocket costs for their prescription medications. In 2020, they also came to us for help paying for groceries and getting to treatment safely.

Even during the initial uncertainty, the PAN team met the pandemic with ingenuity and determination. We quickly launched a COVID-19 financial support fund that helped more than 8,500 people access essentials, like groceries and medications. We also launched seven new assistance programs, including a fund for transportation and our first mental health program. All the while, we continued to offer nearly 70 disease-specific assistance programs to help patients afford their out-of-pocket treatment costs.

Our country’s healthcare safety net has been failing Medicare beneficiaries who are seriously ill for years. 2020 underscored the urgency for reforms to provide much needed relief to older adults and people living with disabilities. To that end, we accelerated our advocacy work toward long-term policy solutions that center patients’ needs and improve healthcare access and affordability.

I’m grateful to the entire network of organizations and people who made our vital support possible in 2020. Our staff never missed a beat, offering help and hope to patients in every phone call and interaction. Healthcare and pharmacy professionals continued to connect patients with financial assistance, despite significant personal risk.

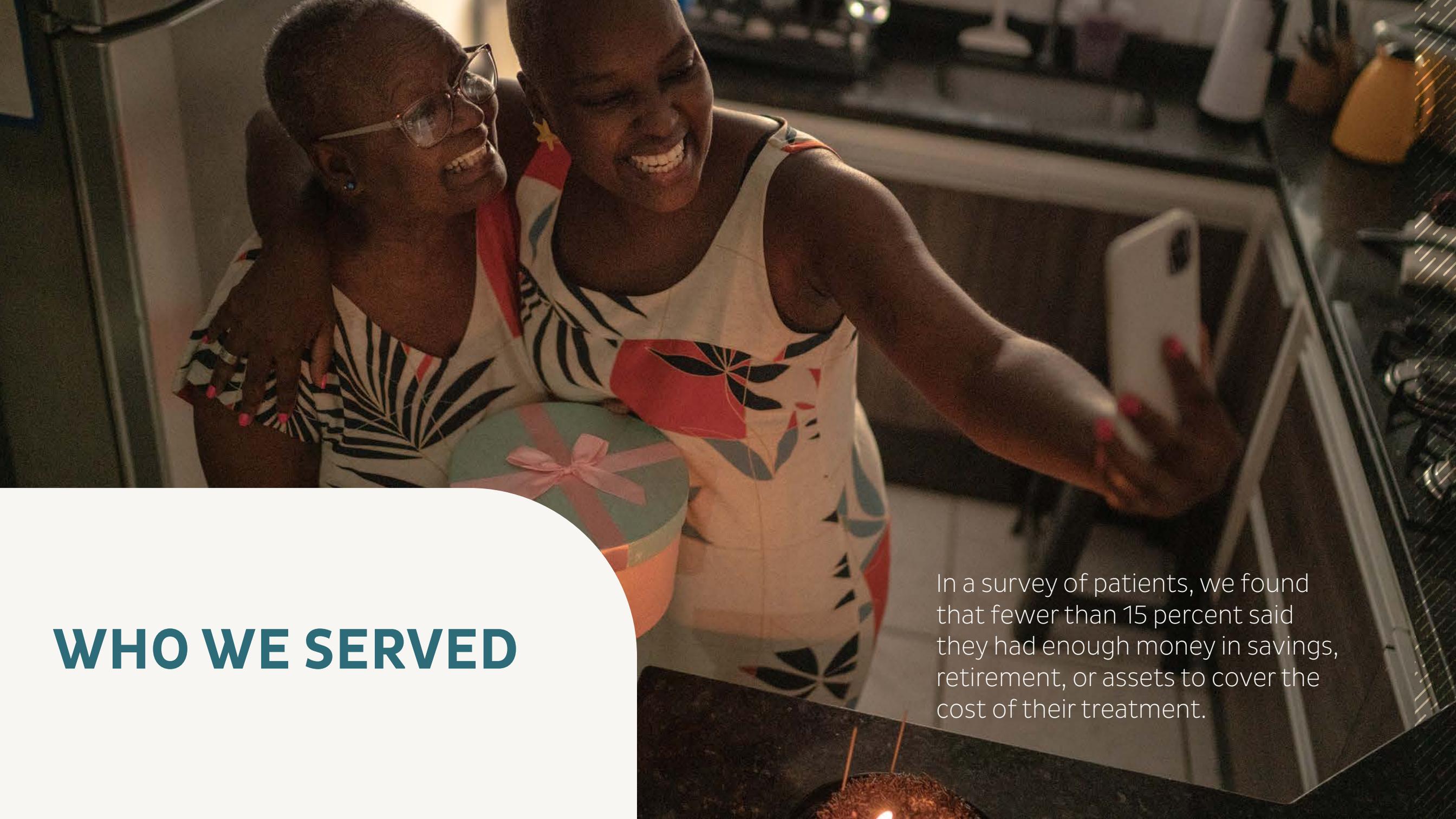
Our dedicated alliance partners followed up with patients to answer their questions and offer resources, providing essential support during an uncertain time. And our generous donors

made it possible for us to provide grants for out-of-pocket costs to thousands of people living with serious illnesses. Our entire community came together to show the world what help looks like, and for that I am immeasurably thankful.

When we started 2020, we had no idea what was in store for us, and even now, it’s hard to picture a post-pandemic world. But one thing is certain—PAN will be there to help.

With gratitude,

**Dan Klein**  
President & CEO



## WHO WE SERVED

In a survey of patients, we found that fewer than 15 percent said they had enough money in savings, retirement, or assets to cover the cost of their treatment.

WHO WE SERVED

# The people we helped

Our patients are living with life-threatening, chronic, and serious illnesses across all U.S. states and overseas territories.

In 2020, we helped 170,814 patients by providing \$454 million in assistance. Each grant helped an economically vulnerable patient afford prescription co-pays, transportation to get to the doctor, and even groceries and daily expenses for those affected by COVID-19.

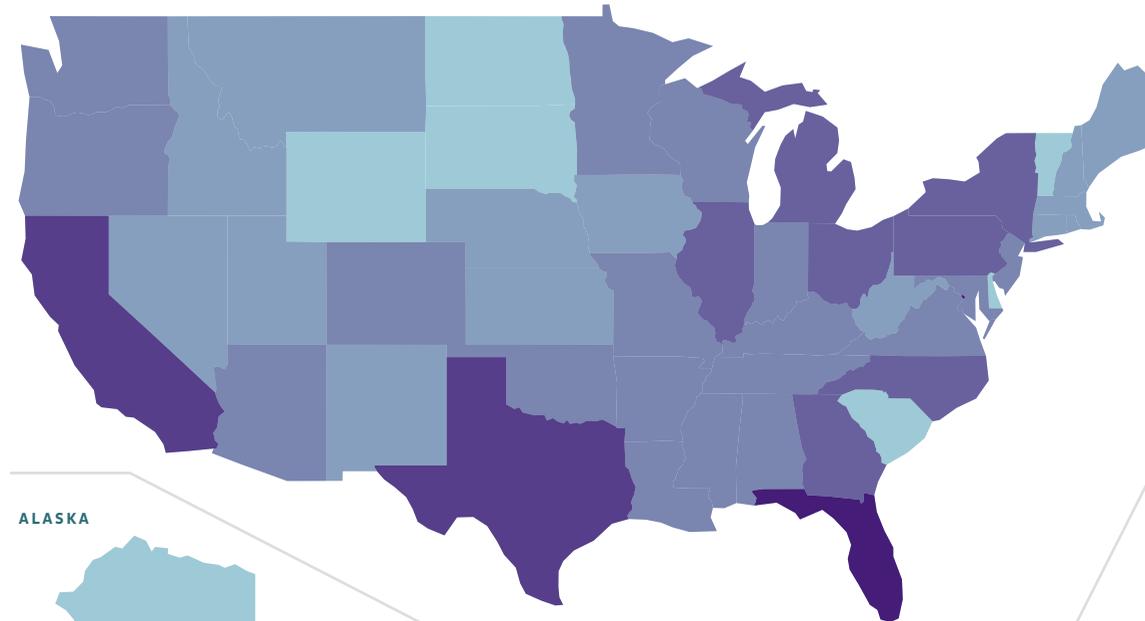
170,814

patients helped in 2020

\$454 million

in assistance provided

CONTINENTAL U.S.



ALASKA



HAWAII



GUAM



U.S. VIRGIN ISLANDS



AMERICAN SAMOA



NORTHERN MARIANAS ISLANDS



PUERTO RICO



NUMBER OF PATIENTS ASSISTED



WHO WE SERVED

# Meet Caroline, a grant recipient we helped in 2020

**INSURANCE**

Medicare

**LIVES IN**

Inverness, FL

**GRANTS WITH PAN**

Asthma and multiple sclerosis co-pay assistance grants, transportation assistance grant

**ANNUAL INCOME**

\$35,500



“My partner and I live on a limited, fixed income, so we can’t afford to be anything but healthy.

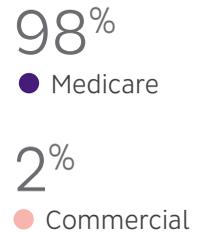
When we couldn’t afford the monthly co-pays for my medications, I had to either skip doses or skip other bills. We can’t drive anymore, so I was also having trouble getting to my doctor’s appointments. It’s why I’m so grateful for the PAN Foundation. Beyond the co-pay and transportation assistance, they also referred me to another organization that connected me with a virtual support group. It has made a huge difference for me this year.”

# About our grant recipients

The people we serve are underinsured and financially vulnerable.

They often require expensive medications, and for the nearly 98 percent of PAN patients on Medicare, there is no cap on out-of-pocket costs. We are proud to ease that burden for each of these resilient, determined, and hopeful patients.

## INSURANCE TYPE



## AGE



## TYPE OF ILLNESS



## AVERAGE GRANT AMOUNT

\$5,926

## AVERAGE PATIENT INCOME BY FEDERAL POVERTY LEVEL

215%

Less than \$27,434 for a single-person household in 2020

# OUR IMPACT

**“As a retired public school teacher with Medicare and supplemental insurance, I felt I would have no worries with medication costs.** Little did I know that some of the five different treatments I’ve been on would cost as much as \$23,000 a month. I am truly living as well as I am today because of the generosity of PAN.”

**Theresa Grigsby**  
Grant recipient



# A stronger safety net



“I am on social security with no pension or other income sources. My co-pay for the medication that I need for my stage IV cancer is over \$600 per month, which I personally cannot afford. Without financial assistance, I’d have to stop taking this medication.”

**John Thomas Wilson**  
Grant recipient

## In 2020, we launched seven new assistance programs:

- Bipolar disorder
- COVID-19 financial support
- Pancreatic cancer
- Sickle cell disease
- Small cell lung cancer
- Spinal muscular atrophy
- Transportation support



OUR IMPACT

Before receiving a PAN grant, more than half of patients reported skipping doses or not taking medications as prescribed.

After receiving financial assistance, more than 90 percent of patients reported that PAN's support helped them:



Take medications as prescribed



Reduce their family's stress



Cover other medical bills and expenses



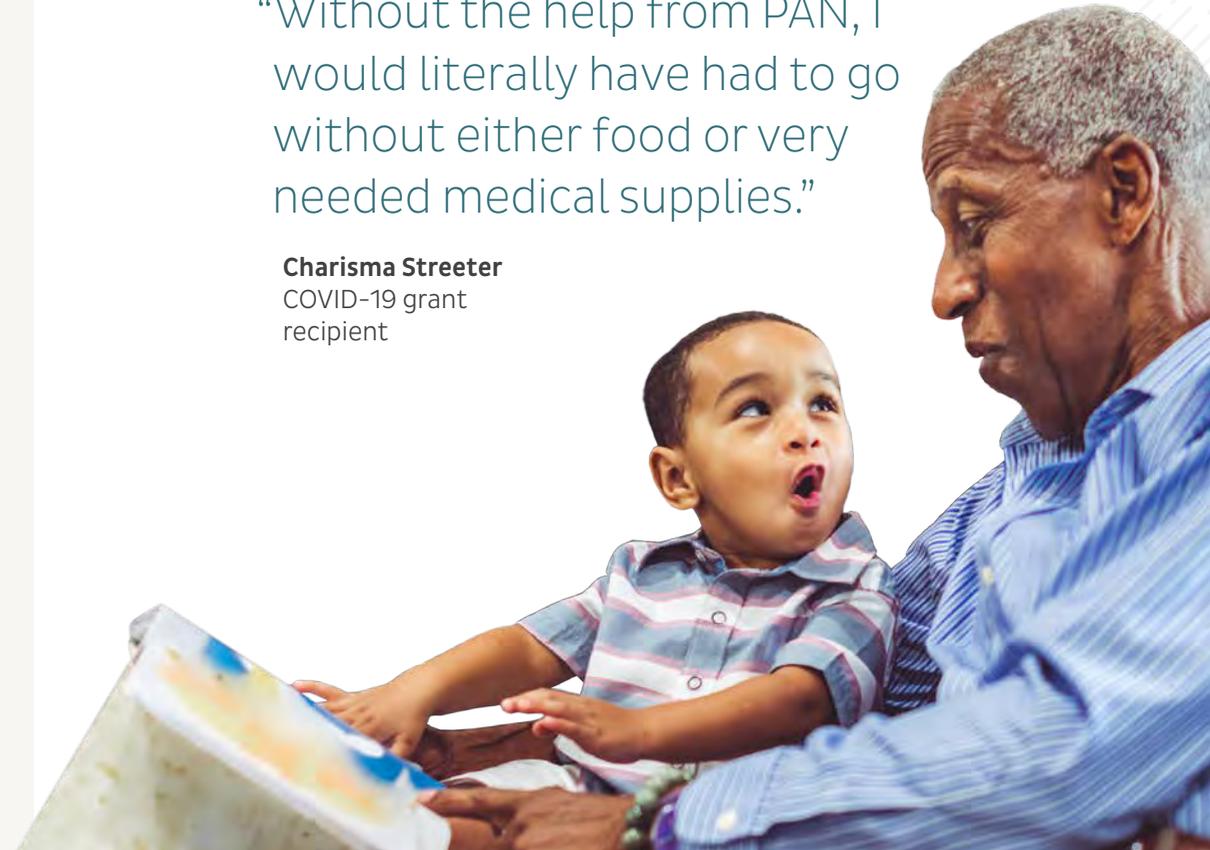
Improve their overall quality of life

**COVID-19 emergency response**

We raised more than \$2.7 million to help over 8,500 people pay for essentials like groceries, medications, and transportation at the onset of COVID-19.

“Without the help from PAN, I would literally have had to go without either food or very needed medical supplies.”

**Charisma Streeter**  
COVID-19 grant recipient



# World-class service



408,022

Calls answered from patients, providers, and caregivers



9.7/10

Patient satisfaction score



1,011,581

Claims processed on behalf of patients



36,351

Healthcare providers and pharmacies in our network



25

Number of languages used to support patients

“Whenever I have called the PAN Foundation with a question, they have been so kind and helpful. The customer service is impeccable.”

**John Thompson**  
Grant recipient





**HEALTHCARE  
HEROES**

HEALTHCARE HEROES

# Showing up for patients during a crisis



In 2020, healthcare and pharmacy professionals' commitment to their patients showed us what help truly means.

Without their tenacity, many of the 170,000 people PAN served would not have received financial assistance. We thank and recognize our healthcare heroes for their dedication and commitment throughout 2020. Meet just a few of these amazing professionals.

## HEALTHCARE HEROES



### Shawna Blackmore

Financial counselor

Shawna Blackmore is a financial counselor at a medical center in New Orleans, Louisiana. Each day, she meets with oncology patients, reviews their insurance benefits, and helps them understand their out-of-pocket costs for care at the clinic. She also looks for financial assistance for patients in need, if it's available.

"The pandemic has really taken a toll on most of my cancer patients. I've witnessed COVID-19 positive patients experience faster disease progression and depart before their expected time," Shawna said.

For healthcare professionals, 2020 was a year unlike any other. Shawna stayed motivated knowing that her patients needed her as a

reliable source during their treatment and someone to talk to outside of quarantine. "There was a strong urge for me to be one of the people my patients did not lose," she added.

The financial counseling that Shawna provides is often critical for patients with serious illnesses to afford the costs of treatment.

"Since working with PAN, my patients have received over \$100,000 in funding for their out-of-pocket costs," Shawna said. "I am grateful to have such an efficient program to work with that gives me the updates I need to keep track of funding for my patients."



### Crystal Condo

Patient assistance navigator

When Crystal Condo was the sole financial navigator at a medical center in northern Maine, she single-handedly increased the number of patients served from 10 to more than 150 annually. So it's little surprise that, in her new role as a patient navigator for the Nikki Shields Agency, Crystal has already helped more than 250 clients.

"Knowing that my patients had nowhere else to turn kept me coming in every day—even when I was terrified of catching COVID-19 myself or bringing it home," Crystal said. "Many of them struggle with a basic understanding of making phone calls and getting online to manage or find grants."

Now, she helps pharmacies, nursing homes, home health agencies, and low-income housing facilities across the state of Maine ensure their patients have access to financial navigation services and a chance at assistance.

Crystal recalls one couple who were maxing out their credit cards to pay for medications, and then skipping or taking smaller doses when they could no longer afford them. Not only did Crystal help this couple find assistance, she then worked with her colleagues to identify other patients at risk of not taking treatment as prescribed and helped find them grants.

## HEALTHCARE HEROES



### Zeenal Patel

Outpatient pharmacy clinical coordinator

Zeenal Patel is a clinical coordinator for three outpatient pharmacies at the Alta Bates Summit Medical Center in Berkeley, California, two of which are specialty pharmacies for oncology and HIV.

“This past year has been unlike any other for our pharmacy,” Zeenal said. “Our day-to-day roles have evolved, requiring us to come up with creative ways to get medications to our patients safely and quickly. As the experts in oral oncolytic therapies, our focus was not only to help providers select oral alternatives to intravenous therapies, but to also investigate ways to ensure we limit financial toxicity.”

Because patients with cancer are vulnerable and prone to infection, Zeenal noted that it has been a major challenge to balance the delivery of high-quality continuous care, while minimizing the risk of exposure to COVID-19.

“Patients that are financially impacted by the pandemic are the ones we see most that decide to delay or even refuse to start treatment altogether,” Zeenal said. “Our low-income patients who have limited resources and poor access to technology have been affected disproportionately.”

Zeenal’s commitment to her patients helped her stay motivated through the challenges of the year.

“Being of service to others as a pharmacist has always given me purpose and meaning in my life,” she said. “In fact, this year has renewed my passion for being a pharmacist.”

“My role as a pharmacist has expanded significantly and I have been given many more opportunities to use my skills to make a difference,” Zeenal added. “Putting myself in my patients’ shoes helps me go the extra mile to deliver the compassionate care they deserve.”



### Natasha Olson

Oncology pharmacist

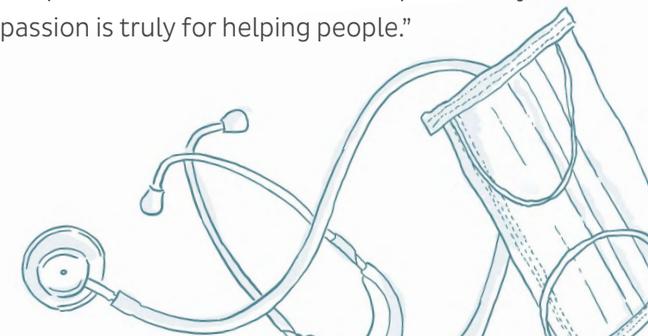
The pandemic altered Natasha Olson’s job significantly. As an oncology pharmacist in an outpatient setting in Washington state, Natasha’s patients were often scared to come in, making routine needs like prescription refills and labs a major challenge. Since people with cancer often have suppressed immune systems, they are more at risk for COVID-19, causing additional stress.

Finances, which are already a challenge for patients going through cancer treatment, were especially strained. Most of the patients she sees are older and do not have much disposable income. Sometimes, patients refuse treatment because of the cost.

“Besides ‘I cannot afford it,’ a phrase I often hear is ‘I do not want to have to burden my family with that cost,’” Natasha said.

Fortunately, Natasha was there to ease some of her patients’ concerns and locate financial assistance for those who needed the support.

“I knew that every day I came to work I had the opportunity to make a difference in someone’s life,” Natasha said. “To me, it does not matter if I received recognition or even if the patient knew what I did to help them. My passion is truly for helping people.”



**EXPANDING THE  
SAFETY NET**



EXPANDING THE SAFETY NET

# Serving patients in a public health crisis

## Launching an emergency COVID-19 response

The arrival of COVID-19 changed the world overnight. Vulnerable seniors with serious illnesses, including those who receive support from the PAN Foundation, were among those most impacted. Within a few weeks, millions of older adults and people with disabilities lost their jobs and faced difficulties in paying for essentials like food, medications, and housing, as well as months ahead of physical and social isolation.



**The PAN Foundation rapidly responded to the COVID-19 crisis by offering direct financial aid through an emergency COVID-19 fund to help people on Medicare with serious and chronic illnesses affected by the pandemic.**

People with pre-existing conditions who were diagnosed with or affected by the virus could apply for a \$300 one-time grant for food and groceries, transportation to medical appointments, prescriptions, and other treatment needs through our COVID-19 Financial Support Fund. Thanks to the generosity of our donors, we raised over \$2.7 million dollars to serve more than 8,500 members of our patient community during the pandemic.

We also launched a weekly newsletter for our patients to provide reputable public health resources at the onset of the pandemic and created a COVID-19 Financial Resource Directory to help patients find additional sources of financial aid.



EXPANDING THE SAFETY NET

## COVID-19 Financial Support Fund

Raised over \$2.7 million to offer help to people already living with a serious illness impacted by COVID-19.

Helped more than

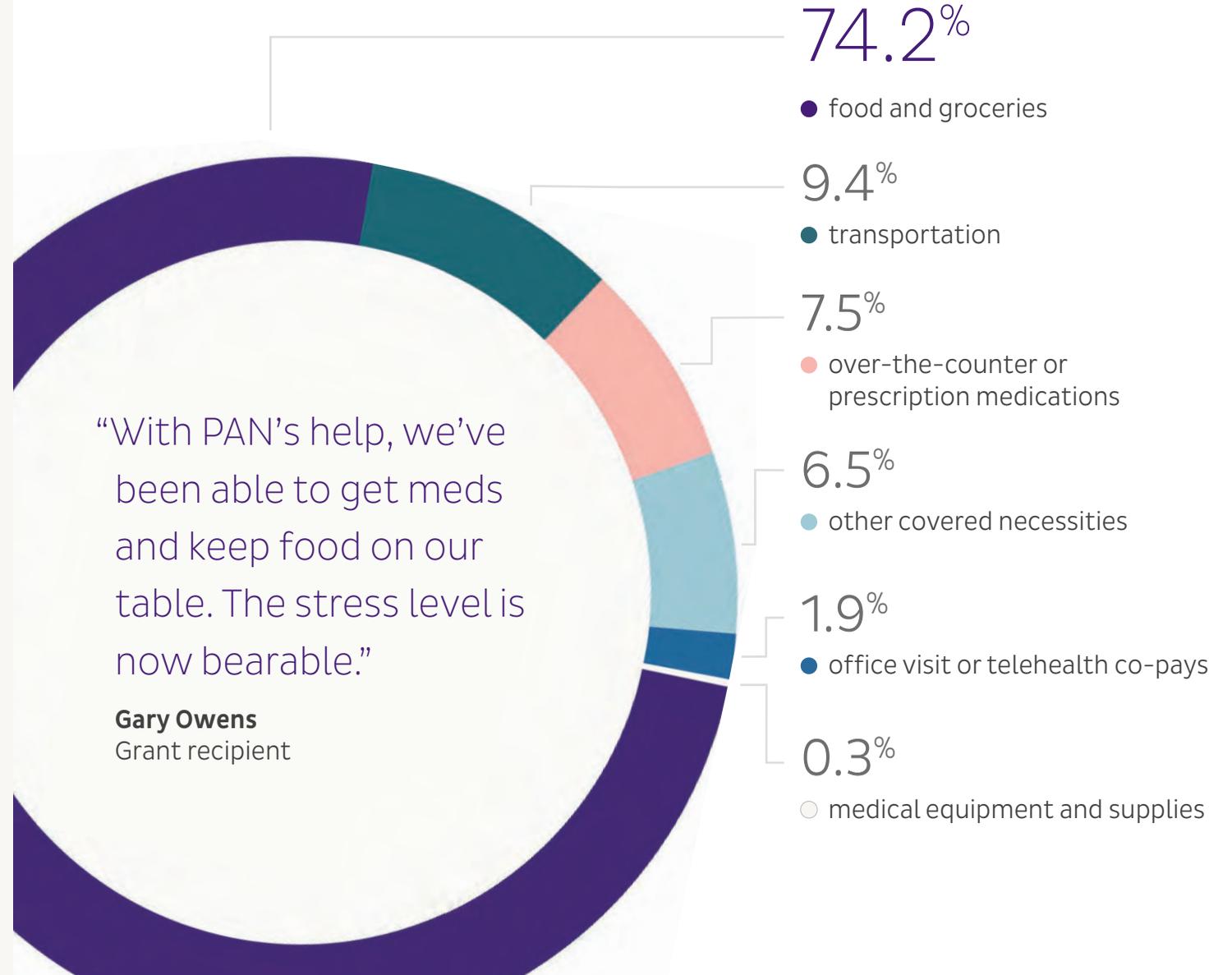
# 8,500 people

access essentials like groceries, medications, and transportation during the pandemic

# 7 out of 10 people

who received a COVID-19 grant reported incomes of less than \$26,000 a year and said the pandemic made paying for necessities difficult

## COVID-19 GRANT SPENDING



## EXPANDING THE SAFETY NET

# Paying it forward during the pandemic

**Sue Greene**  
COVID-19 grant recipient



Sue Greene has a compromised immune system and lives on a fixed income. For her, social distancing isn't just a recommendation, it's essential to her health.

Sue lives in a community for seniors in Napa Valley, and she stretches her budget by riding her bicycle to all the grocery stores in the area to shop the produce sales. Because of the pandemic, she wasn't able to shop around or even go to the grocery store. Sue was eligible for PAN's COVID-19 assistance fund, which provided her with a prepaid debit card to help her fill the gaps in her budget for everyday essentials.

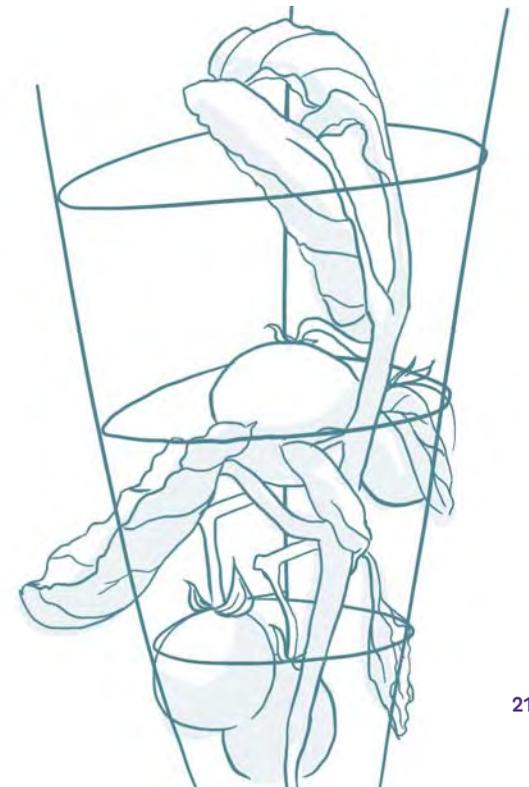
"A big thing is that a lot of times, at least in our culture, seniors aren't valued. It feels like PAN values seniors," she said.

Sue didn't want to waste any of her grant to pay for delivery fees, so she used her card to order groceries from the one local store that would shop for her and then place the groceries in her trunk.

"I felt that maybe I could splurge and get apples or orange juice, even if they weren't on sale—I'm normally very strict with my purchases," she said. "Not only did it help my budget, it was a psychological relief."

Before the pandemic, Sue helped with food distribution programs for her neighbors. She explained that senior hunger is a serious issue, even more so in 2020. While she needed to be cautious because of her health, she still wanted to help her neighbors. She replaced her grocery store bike trips with rides around nearby vineyards, stopping at community gardens, and fruit trees in public spaces. She even started a garden in a friend's yard with some of the seeds she collected. She also started bringing home all the produce she could carry on her bicycle and leaving bags for her neighbors in need.

"I can't help as many people [as I used to], but I've found ways to still be helpful," she said.



EXPANDING THE SAFETY NET

# Helping patients get to their treatment

## PAN's new transportation assistance program

Transportation is a pain point for many patients who struggle to find rides, can no longer drive themselves, or are unable to take public transportation due to compromised immune systems.



**Our transportation pilot program and surveys in 2019 confirmed that our patient population needed this extra support.** More than 60 percent of our patients reported that they needed help getting to their doctor or pharmacy to pick up a prescription. In the fall of 2020, we launched the PAN Foundation Transportation Assistance Program, offering customizable support to all qualifying PAN grantees, regardless of their diagnosis. This program was created to expand our safety net to cover a more complete patient journey and in the face of the pandemic, the need was even greater.

The program provides qualifying patients with a \$500 prepaid debit card that they can use to supplement the cost of the transportation service they need, whether that be a rideshare, non-medical transport, or even a flight to a treatment center that's far from home.

We recognized that even with the grant, patients may not know where to start looking for transportation, so we also created two directories, pointing them to transportation resources as well as other financial resources to help pay for additional medical travel needs. Since our program launch, hundreds of patients have been able to get to their providers and maintain their treatment.

EXPANDING THE SAFETY NET

“My immune system is compromised, so it is not safe for me to take public transportation. Because of this, I have to take a cab or car delivery service. Having to pay for transportation to and from chemotherapy is a big burden.”

**Maria Cabrera**  
Grant recipient



## The cost of getting to and from treatment

\$1,920

the estimated annual cost to take a taxi to medical appointments twice a month



\$1,000

the average round-trip airfare to see a specialist



\$450

the average cost for a three-night stay at a hotel



# A patient gets past the roadblocks

## Katie Bushnell

### Transportation assistance grant recipient



When Katie Bushnell was first diagnosed with metastatic breast cancer in 2018, she prepared for the worst. In the years since, her cancer has spread, but so has her determination.

“They said I wouldn’t still be here. But as you can see, I’m still here,” Katie said. “I’ve been scrambling to stay here for three years.”

She lives and works in the San Francisco Bay area, but her main job—according to Katie—is scouring the internet for grant opportunities and financial assistance. She’s gone without her medication for several months when she didn’t have a grant and couldn’t afford the more than \$4,000 a month co-pay.

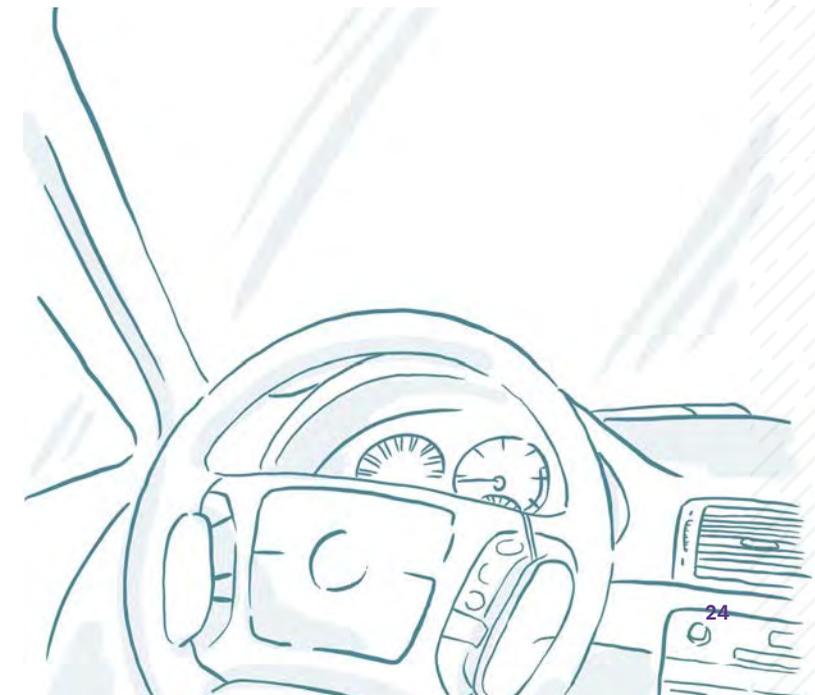
When she received a co-pay grant through PAN, Katie was able to apply for transportation support as well. It’s made a huge difference. Although a friend generously offered use of her car, Katie isn’t always able to drive herself after the physical and emotional strain of treatment. Her driving time varies but can take up to two hours each way.

“It’s pretty upsetting to go to these appointments. Every time, they pretty much tell me I’m not going to make it. But here I am making it,” she said.

She’s used her transportation grant to fill her public transportation pass, pay tolls, and even take a rideshare when she isn’t able to drive or find a ride. The autonomy of the program has also been a relief, particularly during the pandemic when public transportation isn’t an option because of her compromised immune system.

“It’s been helpful to at least have the assistance from PAN, to know that I have money when I need it,” she said. “I don’t have to worry about how I’m going to get to an appointment.”

She’s still hoping for “radical remission.” Until then, Katie’s thankful to have a support system, her 14-year-old cat, Squeaker, and the support of the PAN Foundation.



EXPANDING THE SAFETY NET

# Access to mental health treatment

Financial assistance and support services are integral to the health of people living with bipolar disorder



**According to the National Institute of Mental Health, bipolar disorder affects approximately 5.7 million adults in the U.S.** Although bipolar disorder can be life-threatening, it is treatable. But if someone can't afford treatment—whether that's medication or therapy—there is often nowhere to turn for help.

In September 2020, the PAN Foundation announced a pivotal new program to help economically vulnerable people with bipolar disorder pay for their medications and connect with essential support services.

With the launch of PAN's Bipolar Disorder Assistance Program, people struggling to afford the out-of-pocket medication costs for the disorder could apply for a 12-month grant to help pay for the prescriptions associated with their treatment.

## EXPANDING THE SAFETY NET

### Partnership with the Depression and Bipolar Support Alliance

In September, PAN also launched its partnership with the Depression and Bipolar Support Alliance (DBSA), a national organization providing hope, help, support, and education for the 21 million people across the U.S. who live with mood disorders like depression and bipolar disorder. DBSA reaches an estimated four million people each year with education, advocacy, resources, and support. They offer programs and resources online through the DBSA website, with 130 chapters that offer 500 support groups across the country.

Thanks to this partnership, individuals who come to the PAN Foundation seeking assistance can also receive life-saving mental health and support services from DBSA.



**Depression and Bipolar  
Support Alliance**



“During a time when COVID-19 is exacerbating access to mental health treatment, we are honored to offer financial support and are grateful for our partnership with the Depression and Bipolar Support Alliance.”



**Dan Klein**  
President & CEO  
PAN Foundation

“Thanks to our partnership with the PAN Foundation, not only will we be supporting people during a critical moment in their care journey, we’ll also stay with them to provide resources and support over the long term.”



**Michael Pollock**  
CEO  
Depression and Bipolar Support Alliance

EXPANDING THE SAFETY NET

# Social determinants of health

Social determinants of health are the conditions in which people are born, grow, live, and work that shape their health, like housing and socioeconomic status. These factors have huge implications on health outcomes, particularly among patients who are already struggling to pay for medications.

## Supporting the whole patient

As one of the nation's largest charitable organizations helping the underinsured, we know all too well the plight of patients with high out-of-pocket prescription costs. To date, we've served nearly 1 million patients, about half of whom are living on less than \$26,000 a year—under 200 percent of the Federal Poverty Level. We will be working hard over the next year to better address concerns about social determinants of health among the people we serve, based on a survey of 7,500 PAN grant recipients we conducted in 2020.



## EXPANDING THE SAFETY NET

In order of importance, our survey found that patients were most concerned with:

1. Affording healthcare services
2. Affording housing and utilities
3. Support with daily activities
4. Lack of social support networks
5. Affording food and groceries
6. Access and affordability of transportation

Based on these results, we created a survey tool with strategic screening questions. We will be leveraging screening questions to better support patients and provide meaningful referrals to partner organizations. We believe that understanding social determinants of health is critical for patient support and improving treatment adherence, so we've made this new tool available for free to any patient support organization or healthcare professional.



## Key findings of the social determinants survey

72%

of patients indicated that it was “very hard” or “somewhat hard” to pay for their basic needs, such as food, housing, doctor’s visits, transportation, and heating

27%

of patients reported food security concerns, double the national average

88%

of patients said they spend most of their time alone, but would rather socialize with other people more often



EXPANDING THE SAFETY NET

# FundFinder update



“The peace of mind FundFinder has given me is priceless. I need co-pay assistance to afford my expensive medication. I used to call 40 foundations three times a week to see if they had funding available. Now, I just click the icon for FundFinder, and in less than a minute, I know whether funding is available or not.”

**Chuck Boyce**  
Grant recipient

We celebrated FundFinder’s second anniversary in 2020 by doubling our users to more than 33,000. We continue to offer each of these users a simple way to quickly search the availability of more than 200 assistance funds across nine charitable organizations.

We also added patient advocacy organizations to the search function. Now users are able to search for financial assistance for their medications, get notifications when funding is available, and find support organizations all in one place. The directory includes 150 organizations and counting, which provide help lines, peer-to-peer counseling, education, and more.

We know that many older adults are living on a fixed income, and they have to make their dollars stretch as far as possible. So most importantly, we have continued to provide this app to all users for free.

# 33,231 total users

## TYPE OF USER

52.5%  
● Patient

19.0%  
● Healthcare provider

9.2%  
● Caregiver

9.2%  
● Pharmacy

2.9%  
○ Patient advocacy organization

7.2%  
● Other

## The impact of FundFinder in 2020

400,000+ texts and email notifications sent

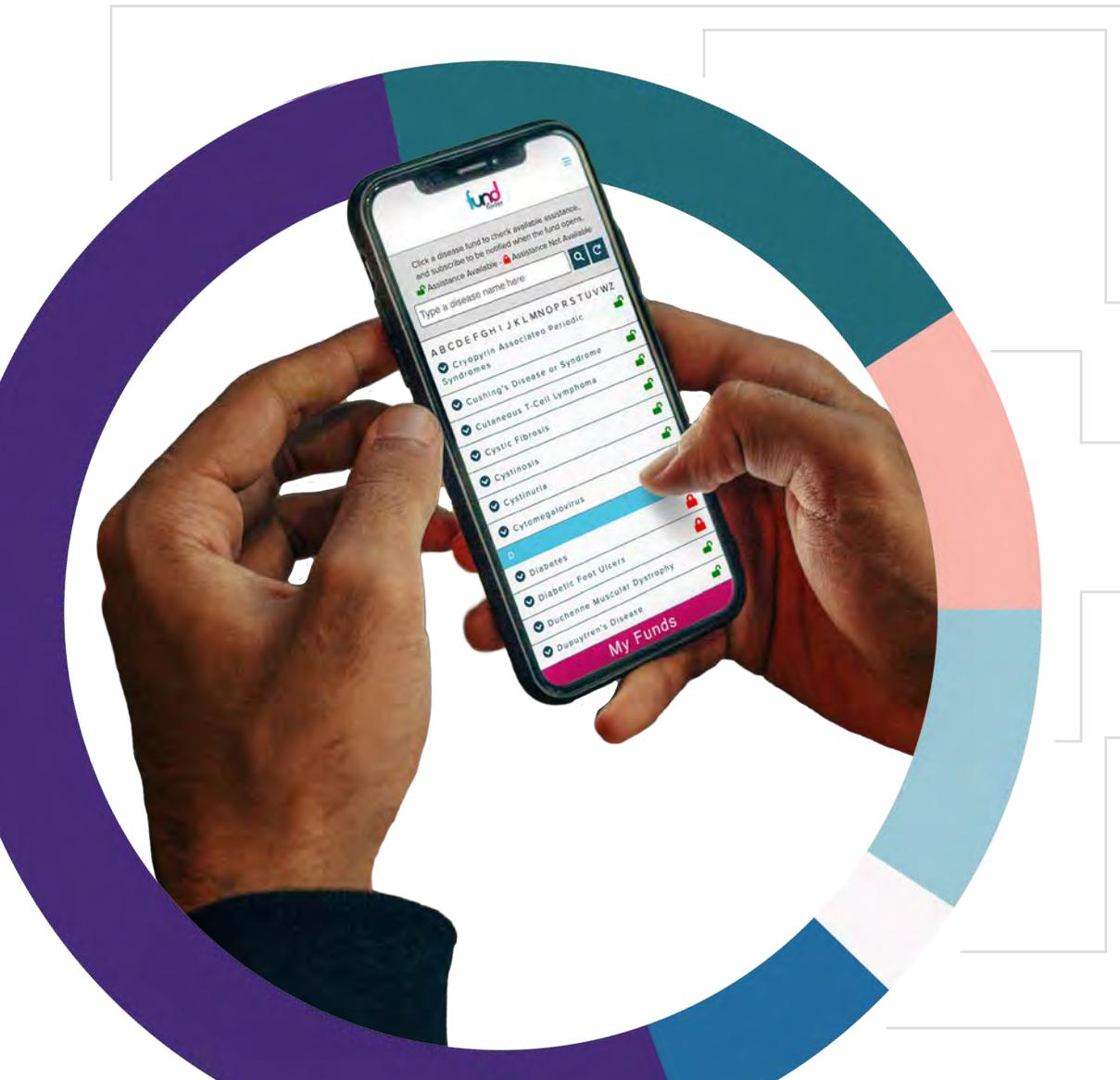
33,000+ total users

200+ funds

150 patient support organizations listed

Top five funds followed by users:

1. Multiple sclerosis
2. Prostate cancer
3. Breast cancer
4. Non-small cell lung cancer
5. Colorectal cancer



# PATIENT SUPPORT & EDUCATION



# Our leading alliance partner network

## Supporting the entire patient journey

Patients who seek financial assistance for their out-of-pocket treatment costs often face challenges beyond their financial concerns. When people are struggling with serious illnesses, the last thing they need is another complicated process or another reason to do research to find additional support.

Fortunately, patients who reach out to the PAN Foundation for financial assistance can choose to connect with one of our alliance partners. These trusted patient support organizations provide disease-specific education and support for their respective patient communities.

“The Multiple Sclerosis Association of America is grateful to call the PAN Foundation a partner in helping meet the needs of the multiple sclerosis community.”



**Gina Ross Murdoch**  
President & CEO  
Multiple Sclerosis Association of America

# Alliance partner services



## Disease-specific education

Alliance partners connect patients with education and resources to help them understand and manage their disease.



## Emotional support

Dealing with a serious illness can have a profound impact on the emotional health of patients, caregivers, and family members. Many of our alliance partners provide support groups or can connect patients with counseling services.



## Other support services

From wheelchair assistance programs to dedicated support hotlines, each alliance partner offers resources and services tailored to the needs of the patient community they serve.

Financial barriers are just one of many factors that can prevent patients from accessing treatment.

Social determinants—including social isolation and access to food, groceries, or transportation—play a significant role in a person's ability to start and stay on their treatment plan. Our alliance partner network is one important way we address the holistic needs of patients.

We also work closely with our alliance partner network to advocate for legislative reform that improves healthcare access and affordability. Together, we collaborate on issues of mutual interest concerning access to affordable healthcare for patients with life-threatening, chronic, and rare diseases.

# Our alliance partners

American Liver Foundation

American Lung Association

Aplastic Anemia & MDS  
International Foundation

Amyloidosis Foundation

Bladder Cancer Advocacy Network

Colorectal Cancer Alliance

Cushing's Support and Research Foundation

Cutaneous Lymphoma Foundation

Depression and Bipolar Support Alliance

International Waldenstrom's  
Macroglobulinemia Foundation

Melanoma Research Foundation

Mended Hearts

MPN Advocacy and Education International

Multiple Sclerosis Association of America

National Hemophilia Foundation

National Kidney Foundation

National Osteoporosis Foundation

Parkinson's Foundation

Prevent Blindness

SHARE

The Skin Cancer Foundation

ThyCa: Thyroid Cancer  
Survivors' Association

Us TOO International Prostate Cancer  
Education and Support Network

## Our network's impact

# 23 alliance partnerships

with national patient education and  
support organizations

# 33,000

patients referred to our partners for  
follow-up support

# 76%

of PAN patients reported needing help  
beyond co-pay assistance



**ADVOCATING FOR  
HEALTHCARE  
ACCESS &  
AFFORDABILITY**

# Patient-centered policy solutions

Rising premiums, deductibles, co-pays, and coinsurance are leaving more Americans underinsured and unable to afford treatment. As the pandemic strained a healthcare system that is already unaffordable to many, we expanded our advocacy work and urgently called on policymakers to implement solutions that would provide relief to the millions of patients who make impossible choices to afford their medications or forgo treatment because of the cost.

## **Our top policy priorities for Medicare beneficiaries:**

- Place an annual cap on out-of-pocket prescription medication costs
- Smooth out-of-pocket costs evenly throughout the benefit year
- Expand the federal Extra Help program income eligibility criteria and streamline the application process

# Advocacy impact

15

key policy recommendations to improve healthcare access



6

national polls on seniors' experiences with out-of-pocket healthcare costs



13

policy letters sent to Congress and the administration in support of healthcare access and affordability reforms



15+

opinion pieces, blogs, and media mentions, including Morning Consult, Fortune, The Hill, Kaiser Health News

17

issue briefs breaking down complex topics for policymakers



3

advocacy coalitions with Medicare Access Patients Rx, All Copays Count Coalition, and the Coalition to Improve Access to Cancer Care



MORNING CONSULT

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# Research highlights

## Potential impact of policies to modify Medicare Part D

A University of Pennsylvania research team completed an analysis in 2020 to evaluate policy solutions to lower Medicare Part D out-of-pocket costs. Specifically, they assessed the impact on the out-of-pocket cost burden and access to specialty drugs necessary for Medicare patients with serious chronic conditions.

This research was conducted by Jalpa A. Doshi, PhD; Pengxiang Li, PhD; Amy Pettit, PhD; and Vrushabh P. Ladage, MHCI at the University of Pennsylvania Perelman School of Medicine and Leonard Davis Institute of Health Economics, and presented at the AcademyHealth 2021 Annual Research Meeting (June 15, 2021). The research was made possible by a grant from the PAN Foundation.

## Key findings and recommendations

- Under the existing 2020 Medicare Part D benefit, Medicare beneficiaries face prohibitive annual out-of-pocket costs, especially early in the year, which likely leads to high rates of abandonment of critical specialty drugs, estimated at 53.9 percent.<sup>1</sup>
- An annual out-of-pocket cost cap alone, whether \$2,000 or \$3,100, will not alleviate the high financial burden faced by patients early in the year, nor reduce their likelihood of abandoning needed specialty drugs.
- Smoothing annual out-of-pocket costs uniformly across the year (i.e., monthly out-of-pocket costs) is a more effective solution than just having an annual cap. Smoothing addresses the burden of high out-of-pocket costs early in the year and improves access to specialty drugs. The abandonment rate of specialty drugs drops significantly when smoothing is implemented with an annual cost cap.
- The most effective and equitable policy option applies different annual cost caps based on a patient's income and smooths these costs evenly over 12 months. This solution reduces the out-of-pocket cost burden while lowering abandonment rates for critical specialty drugs, especially for lower-income Medicare patients who do not qualify for cost sharing subsidies under Part D.

<sup>1</sup>Doshi et al. "Association of Patient Out-of-Pocket Costs with Prescription Abandonment and Delay in Fills of Novel Oral Anticancer Agents." *Journal of Clinical Oncology* 36(5):476-482, 2018.

# Our grassroots advocacy



California, Florida, and Texas  
states with the most advocates



“As a senior, I want cost predictability. I don’t want to stay up at night wondering if my next prescription is going to cost \$800 out of pocket.”

## George Valentine

### Grant recipient

George Valentine was diagnosed with chronic lymphocytic leukemia (CLL) in 2002, toward the end of his more than 40-year career in IT. After his CLL treatment began, he started reaching his out-of-pocket maximum for prescription medications every year. But when George reached retirement, that limit disappeared.

“Now under Medicare, there is no fixed limit to out-of-pocket medication costs. CLL treatment is costly. You don’t know what the next drug is going to be, so you don’t know what the next drug is going to cost. But my income is fixed,” he said.

We share George’s concerns about high out-of-pocket costs and predictability. In September 2020, we invited our community to ask Congress to place an annual cap on out-of-pocket costs and distribute those costs evenly through the year for Medicare patients.

Through our advocacy action center, people who are concerned about high out-of-pocket costs and healthcare affordability can directly contact their representatives and ask them to take action. To date, supporters have sent more than 7,000 emails to members of Congress representing nearly every state. Our grassroots efforts will continue until legislation eases the burden on George and every patient we serve.

“Only when we all collectively act will things change,” he said.

# OUR FINANCIALS



# 2020 financials

In 2020, the PAN Foundation reported contributions of \$439 million.

We supported 170,814 patients with \$454 million in financial assistance for their out-of-pocket treatment costs.



## Income and assets

Total income

\$450,368,794

Net investment income

\$11,247,150

Total end-of-year net assets

\$437,009,810

Since PAN was established in 2004, contributions have consistently represented more than 90 percent of the PAN Foundation's total support and revenue.

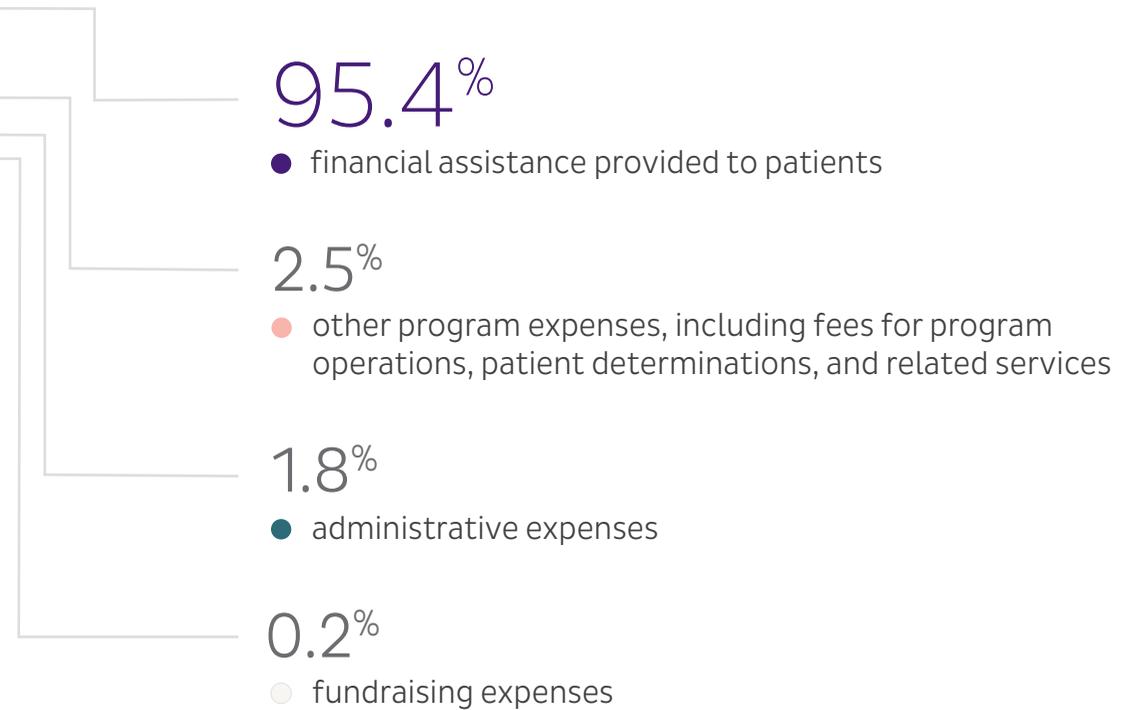
These contributions enabled the PAN Foundation to provide financial assistance to more than 170,000 patients through nearly 70 assistance programs in 2020.

For more detailed information and to view our 990 tax return and financial statements in their entirety, visit [panfoundation.org/about-pan/annual-reports](https://panfoundation.org/about-pan/annual-reports).



## Expenses

In 2020, the PAN Foundation recorded total expenses of \$476 million. For the last 11 years, less than one penny of each dollar contributed to the PAN Foundation has been spent on fundraising.



Note: Administrative expenses include investment management fees, which are netted against investment income in audited financial statements.

# Our supporters

Thank you. Your generosity was a lifeline and a chance at a healthier tomorrow for 170,000 people this year. All supporters listed contributed \$150 or more in 2020.



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“It was a huge stress reliever to know PAN had my back and that I would continue to live.”

**Debi Wilson**  
Grant recipient

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**Toni Ryan**

Grant recipient and supporter



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The PAN Foundation helps underinsured people with life-threatening, chronic, and rare diseases get the medications and treatments they need by assisting with their out-of-pocket costs and advocating for improved access and affordability.

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