



15 Years of Mission-Driven Progress

PAN FOUNDATION ANNUAL REPORT 2019



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INTRODUCTION

We envision a nation in which everyone can get the healthcare they need.

Since 2004, the PAN Foundation has served nearly 1 million federally and commercially underinsured patients with life-threatening, chronic, and rare diseases in all 50 U.S. states and territories.

We've made a lot of progress.

We've partnered with generous donors, healthcare providers, and pharmacies to provide over \$3 billion in **financial assistance** to patients over the past 15 years. We also work with a large network of other patient-focused organizations to provide additional **support services** and disease-specific education to patients. Our **advocacy work** for improved access and affordability of prescription medications remains a critical component of our mission.

Now, more than ever, we remain committed to our mission.



A message from Board Chair Martin A. Bieber

The spread of COVID-19 has impacted our daily lives as well as every sector of business and the economy.

As the world is dealing with the spiraling public health and economic effects of the COVID-19 pandemic, we need to be mindful of how this is affecting a rising percentage of Americans who can't afford to pay the out-of-pocket costs for the treatment of other life-threatening and debilitating health conditions. What is especially troubling is that those most at risk for COVID-19 are the very same people living with serious illnesses.

Now, more than ever, our neighbors are making difficult decisions about whether they can afford a treatment their doctor recommends or fill their prescriptions at the pharmacy.

Out-of-pocket costs should not prevent individuals with life-threatening, chronic, and rare diseases from obtaining their prescribed medications. But too often, they do. Forty percent of Americans skipped a recommended medical test or treatment in the last 12 months due to cost, according to a [2019 report](#) from the Kaiser Family Foundation.

Solutions are needed now.

Throughout our 15-year history, the PAN Foundation has provided nearly one million underinsured patients with over \$3 billion in financial assistance. The need for patient assistance continues to grow. Given the COVID-19 pandemic is threatening access to affordable healthcare for so many, we at PAN are rising to meet the urgent and expanded need.



LEADERSHIP LETTERS

Although much work remains, I'm encouraged to see the progress PAN has made on its two most important goals:

1. Innovate and expand our safety net programs to meet the increasingly complex needs of economically vulnerable and seriously ill patients.

From help with prescription medication co-pays to transportation to and from medical appointments, PAN's programs are essential for many patients in need—especially for Medicare beneficiaries on fixed incomes. This is truly a pivotal time, as the aging population will continue to grow. Charitable foundations like PAN are often the only place people can turn to for financial assistance, so they can begin and stay on life-saving treatments.

2. Amplify our advocacy efforts to lower out-of-pocket prescription drug costs and give a voice to marginalized patient populations.

In 2019, PAN expanded its efforts to call on policymakers to pursue Medicare Part D reforms that would lower out-of-pocket costs for millions of Americans—just one example of the organization's work on this front. PAN is positioned to make an impact on the legislative and regulatory landscape by urging reforms that would make an enormous difference in health equity, patient access, and affordability in the years ahead.

The year ahead will undoubtedly offer challenges, but our mission remains clear: helping underinsured patients get the medication they need.

On behalf of the Board of Directors, thank you for being on this journey with us and supporting PAN's mission throughout our first 15 years. You've enabled us to continue providing help to thousands of people who, without it, face incredibly difficult choices or give up on treatment altogether.

Together, we will lead change.



With gratitude,

A handwritten signature in black ink that reads "Martin A. Bieber".

Martin A. Bieber

Board Chair, PAN Foundation Board of Directors

A message from President and CEO Dan Klein

Milestone celebrations feel at odds right now with the current climate of the pandemic.

Nevertheless, at PAN, we have been celebrating our 15th anniversary from a distance—humbly reflecting on all that we've accomplished, but also doubling down on our mission to address the new reality of rising treatment costs and reduced access to healthcare for vulnerable patients.

In the coming year, without urgently needed policy reforms, many patients diagnosed with COVID-19 and other life-threatening, chronic, and rare diseases will face challenges getting the care they need due to unaffordable out-of-pocket costs.

The pandemic will continue to take an especially high toll on older, low-income adults. Minority seniors may be among the hardest-hit groups—with reduced access to treatment for their chronic conditions. These are the people who turn to PAN for financial assistance. We take this responsibility seriously and are working hard to ensure our programs are available to help them start and stay on treatment.

Innovative solutions have never been so urgently needed to address our nation's healthcare access and affordability crisis.

Throughout the following pages of our annual report, you'll see examples of how PAN has expanded the help we provide, including the nine new assistance programs added in 2019. To address other critical barriers that prevent patients from accessing treatment, we also helped patients get to and from their medical appointments and pharmacies through our transportation assistance pilot program.

LEADERSHIP LETTERS

PAN is deepening our commitment to expand how we serve and advocate for patients.

Addressing the barriers that prevent patients from starting and staying on treatment is at the heart of our mission. We also remain dedicated to advocating for policy solutions that reduce out-of-pocket healthcare costs for all Americans.

It is truly an honor to do this work.

As we reflect upon the past year and anticipate what's ahead, I want to acknowledge the dedication, commitment, and creativity of all the people and organizations with whom we collaborate: our generous donors; alliance partners; network of healthcare providers and pharmacies; and our Board of Directors and staff who continue to support PAN's mission and connect patients to treatment.

And a special thank you to our patients for putting your trust in the PAN Foundation: you are the reason why we won't rest until everyone can access the healthcare they need.



Sincerely,

A handwritten signature in black ink that reads "Dan Klein".

Dan Klein
President and CEO



How we help



“When I was diagnosed with early stage Parkinson’s disease, I was started on a drug that caused my hands and neck to tremor. My doctor recommended a new treatment that would stop the tremors, but I couldn’t afford it.

With the support of PAN, I was able to take the new medication and continue enjoying each day with my family.”

James Yuan, age 66, Texas, Parkinson’s disease grant recipient





When high out-of-pocket costs keep patients from getting and staying on critical treatment, **PAN is there to help.**

We are dedicated to providing direct financial assistance to help patients with nearly 70 life-threatening, chronic, and rare diseases. [It's easy to apply.](#) In 2019, we provided 187,000 patients with a 12-month grant to help cover their out-of-pocket costs.

Through our transportation assistance pilot program in 2019, nearly 250 of our grant recipients received [subsidized rideshares](#) to get to and from doctor's appointments or pharmacies. The success of the program is evidence that there is a tremendous need for travel expenses and we remain committed to further developing the transportation assistance we provide.

How we help



When patients and providers need more support navigating diseases, **PAN is there to help.**

We connect patients and their healthcare teams with additional sources of support through our network of 19 dedicated [alliance partners](#) who provide disease-specific education, resources, and support. In 2019, more than 34,000 patients received **referrals to patient support organizations**.

FundFinder, our free web app, alerts patients, caregivers, healthcare providers, and pharmacists when financial assistance becomes available for a specific disease state. [Anyone can sign up](#) for email or text message notifications to learn when financial assistance becomes available for a specific diagnosis at any of nine foundations—eliminating the need to manually monitor their websites. In 2019, more than 16,000 people were using FundFinder.





“FundFinder is amazing! It is nice to receive the information about open funds in real time. I work in a small community clinic and wear many hats, so this has helped me to streamline patient support. Thanks so much for making my job easier!”

Laura Muller, BSN, RN, CPUI, OCN

Director of Oncology & 1 South Clinics, Magruder Hospital, Port Clinton, Ohio



When patients need advocates and a voice in the fight to lower out-of-pocket costs and improve healthcare access, **PAN is there to help.**

We create [advocacy resources](#) to break down complex aspects of the healthcare system—and help others become informed advocates. There are still millions of people who cannot afford the treatment they need. From joining **patient advocacy coalitions** to publishing **reports and responses to government policies**, we continue to push for long-term solutions to lower out-of-pocket costs and improve healthcare access.

In 2019, PAN published **11 guiding position statements** on access to healthcare and key policy strategies that will lower out-of-pocket costs for patients, several new **issue briefs** presenting research for policymakers on key topics relating to healthcare access and affordability, and **six policy letters** signed and submitted to Congress and the Trump administration.

ABOUT US

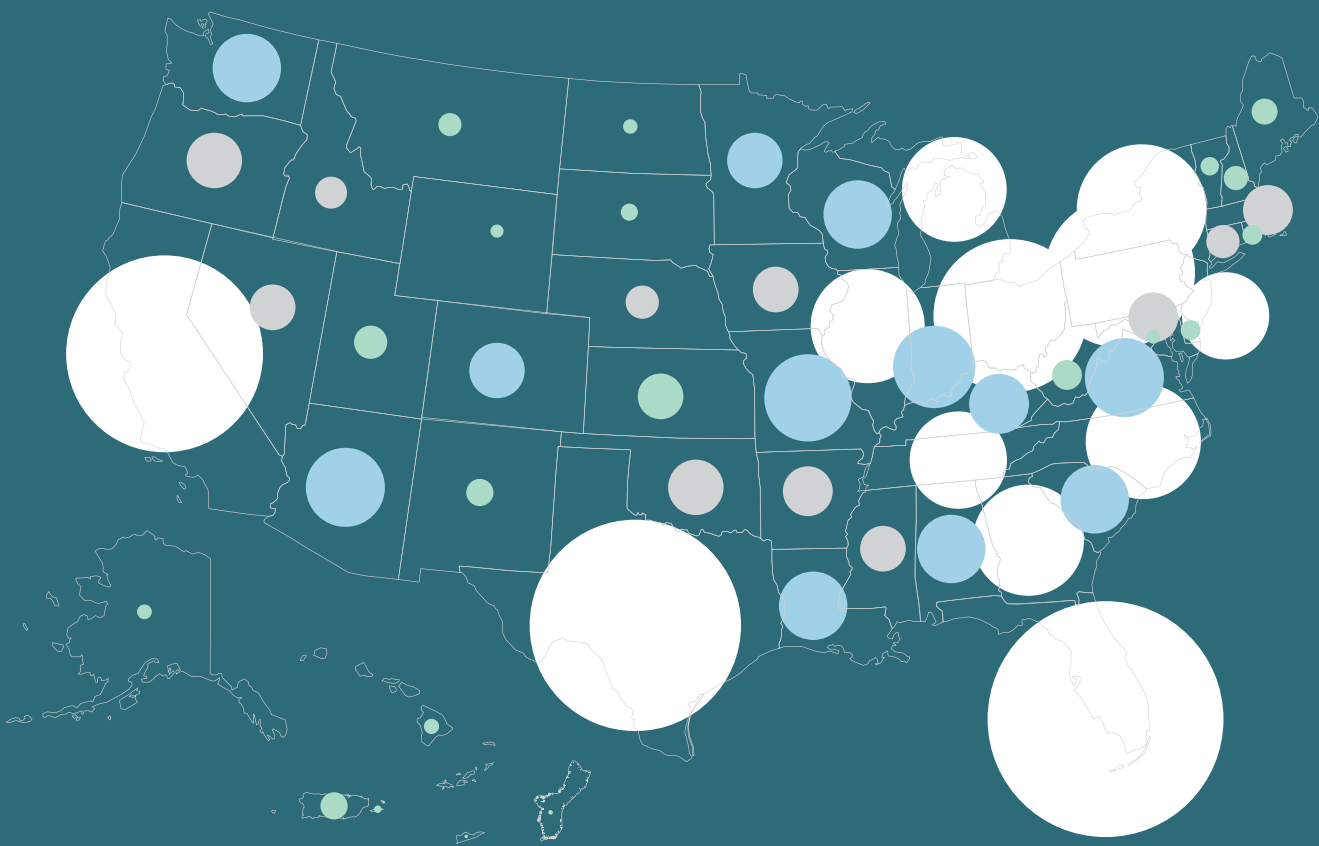
Who we serve

We serve economically vulnerable patients with life-threatening, chronic, and serious illnesses who face high out-of-pocket costs for their treatment.

Without direct financial assistance to pay for their prescription medications, many of the patients we help would forgo treatment altogether. The demand for safety net programs continues to grow as the burden of out-of-pocket costs for treatment increasingly falls on patients.

Patient enrollment by state

We serve patients across all 50 U.S. states and overseas territories.



AK 131	DE 588	IN 4,652	MN 2,605	NH 681	PA 9,360	VA 4,352
AL 3,452	FL 18,544	KS 1,804	MO 4,744	NJ 4,995	PR 922	VI 45
AR 2,287	GA 5,957	KY 3,160	MP 4	NM 947	RI 618	VT 249
AZ 4,402	GU 25	LA 3,642	MS 1,907	NV 1,804	SC 3,663	WA 3,681
CA 12,481	HI 377	MA 2,238	MT 657	NY 8,446	SD 430	WI 3,458
CO 2,629	IA 1,838	MD 2,236	NC 7,820	OH 9,613	TN 5,253	WV 1,084
CT 1,679	ID 1,205	ME 829	ND 364	OK 2,317	TX 15,062	WY 252
DC 107	IL 6,324	MI 5,838	NE 1,369	OR 2,558	UT 1,360	

ABOUT US

Gender

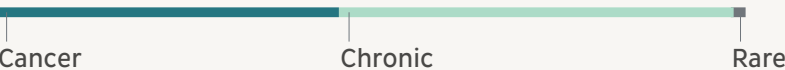


Age



Type of illness

Patients with life-threatening, chronic, and rare diseases often require expensive specialty medications that can be challenging, if not impossible, to afford.

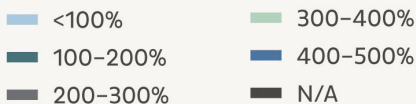


Patient income by Federal Poverty Level

The people we serve are underinsured—with the majority living under 200% of the Federal Poverty Level, earning less than \$24,980 for a single-person household in 2019.

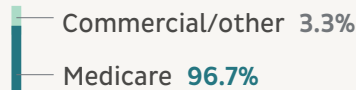


Percentage under the Federal Poverty Level



Insurance type

Our nearly 70 assistance programs offer grants for those with Medicare or commercial insurance.



Our impact



A strong safety net

ASSISTED

187,056 patients

PROVIDED

\$366 million

in co-pay assistance to patients

AVERAGE PATIENT GRANT AMOUNT

\$5,243

PATIENT SATISFACTION SCORE

9.5 / 10

ANSWERED

365,546 calls

SERVED CALLERS IN

25 languages

PROCESSED

985,115 claims

on behalf of patients





Patient-centered customer service

Every year, we enhance our programs to provide empathetic, patient-focused service to make obtaining financial assistance for out-of-pocket costs as easy as possible so that instead of finances, patients can focus on their health. Here are just a few improvements we made this year:



Strengthened customer service tools to provide callers with timely, accurate information.



Streamlined medical claims processing for healthcare providers to allow for faster payment.



Reduced application completion time for renewal grants.



Upgraded to a new phone system with expanded self-service to help callers receive answers quickly and to check their grant balance.

Our impact



9 new assistance programs

Atopic dermatitis

Amyloidosis

Bladder cancer

Carcinoid syndrome

Fabry disease

Fabry disease premium

Glioblastoma multiforme

Neurotrophic keratitis

Waldenstrom macroglobulinemia



Alliance partners

19 partnerships

with leading patient support organizations

34,581 patients referred

to alliance partners for additional patient support and education resources

ABOUT US



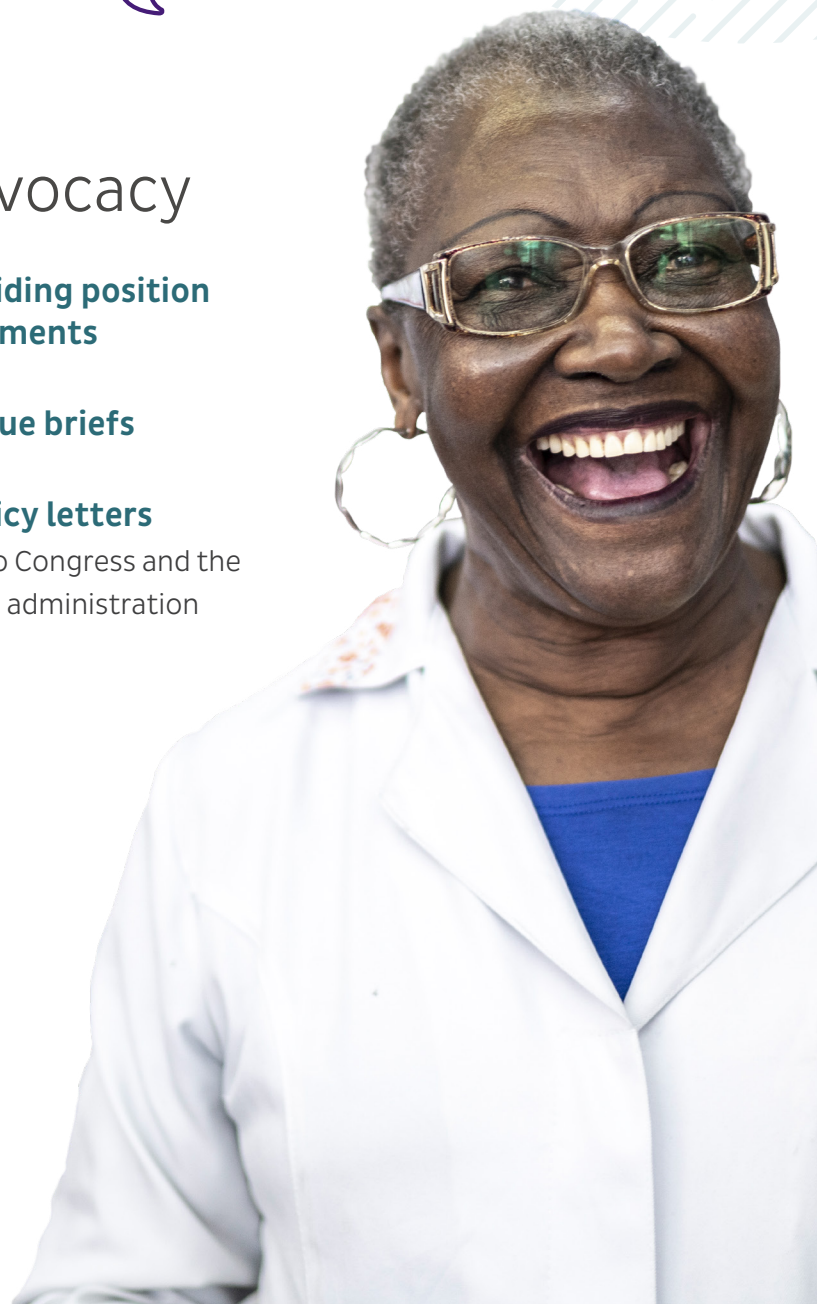
Advocacy

11 guiding position statements

13 issue briefs

6 policy letters

sent to Congress and the Trump administration



15 years
of impact

TOTAL PATIENTS ASSISTED

nearly
1 million

AMOUNT OF CO-PAY
ASSISTANCE GRANTED

\$3 billion

ASSISTANCE PROGRAMS
COVERING LIFE-THREATENING,
CHRONIC, AND RARE DISEASES

nearly **70**

HEALTHCARE PROVIDERS AND
PHARMACISTS IN OUR NETWORK

32,400

CALLS ANSWERED AT OUR
CALL CENTER

3.7 million

CLAIMS PAID ON BEHALF OF
PATIENTS SINCE 2011

7.3 million




HIGHLIGHTS

Life-saving medication assistance

At age 50, Kentucky native Robin Lancaster was diagnosed with primary myelofibrosis, a rare blood cancer that affects over 13,000 people in the U.S. “I quickly went to Google—nothing but horrible news,” she said. “The only thing ringing through my head was ‘I’ll never know my grandchildren.’”





A diagnosis of a serious medical condition can be scary. But for many patients the more terrifying question becomes,

“How will I afford my treatment?”

The cancer diagnosis left Robin and her husband, Rick, unprepared and overwhelmed for the challenges of what would be their “new normal.”

Myelofibrosis can cause anemia, enlargement of the spleen and liver, impaired kidney function, extreme fatigue, and other problems. In some patients, it can progress to an aggressive type of leukemia.

Specialty life-extending medications to address the progressive symptoms of Robin’s cancer would be incredibly costly. But what good would they be if she couldn’t afford them?

For years, the couple relied on co-pay assistance cards from the drug manufacturers to afford the medication. But things took an unexpected turn at the pharmacy counter when they were told they owed \$10,000 out-of-pocket for Robin’s prescription medications. Was this a mistake? Unfortunately not.

In January 2019, Rick’s company switched to a high-deductible insurance plan that would not allow co-pay assistance to count towards the deductible.

Employers often adopt these programs as a cost-savings strategy without truly understanding the negative impact it could have on their employees.

In a high-deductible health plan the monthly premium is usually lower, but patients pay more healthcare costs out of their own pocket before the insurance company starts to contribute. [High front-end deductibles](#) can create barriers to

HIGHLIGHTS

treatment for people who need it most, making prescription medications more expensive and unaffordable for many people like Robin, who was still on a feeding tube and slowly working toward getting back to a normal diet at the time of the \$10,000 bill.

“Co-pay accumulators,” as they are called, are a relatively new and harmful practice that [some health plans](#) use to stop counting drug manufacturer co-pay assistance toward a person’s deductible or out-of-pocket maximum.

“Between our health savings account and our now empty personal savings account, we were no longer able to cover the cost of my treatment,” Robin said. “That’s when a counselor at my pharmacy told me about the PAN Foundation.”

Out-of-pocket costs should not prevent people with life-threatening, chronic, and rare diseases from getting the critical treatment they need.

Some states have taken action to protect their residents from this harmful practice, recognizing the importance of patient assistance. Arizona, Illinois, Virginia, and West Virginia enacted state laws in 2019 requiring insurers to accept third-party payments, including drug manufacturer assistance, made on behalf of an insured person to count towards their deductible and out-of-pocket costs.

Robin’s home state of Kentucky has not taken any action. But PAN was there to help.

Through a grant from PAN’s Philadelphia chromosome negative myeloproliferative neoplasms program, Robin was able to pay for her January medication refill. She sends in receipts from her prescriptions and receives a check to cover the cost.

“I can’t describe what PAN has done for our family,” she said. “There are still lots of smaller billing and insurance issues we have to deal with throughout the year, but coming up with a whopping sum for deductibles every January is not a worry on the list anymore.”

The PAN Foundation urges policymakers to prohibit programs like co-pay accumulators that increase out-of-pocket costs for those with serious health conditions.



HIGHLIGHTS

Look for the helpers

Interview with Nicole Kearney, Noble Health Services

Every day, healthcare providers and pharmacists are on the front lines of helping patients in need connect with financial assistance to start and stay on treatment.

“I recently met with a patient at risk of going an entire month without their HIV medication because they could not afford the co-pay,” said Nicole Kearney, who works for Noble Health Services, a specialty pharmacy in Syracuse, New York. Luckily, that same day, she applied for and received a PAN grant for her patient—before any prescription doses were missed.

“The most rewarding aspect of my job is being able to reduce patient stress—especially if they are newly diagnosed with a complex, chronic disease. Seeing patients access grants quickly is a great feeling.”

As a Process Improvement Supervisor, Nicole manages the onboarding and training of employees who staff Noble’s 24/7/365 call center. She also oversees their free overnight medication delivery program and co-pay assistance services. It’s a big job, but she is passionate about helping those with complex and chronic conditions.

HIGHLIGHTS

In 2019, PAN provided grants to 8,446 patients in New York.

COVID-19 is only going to deepen existing health disparities across the U.S., especially in states hit hard by the virus. Nicole said more of her patients will be applying for assistance. “We’re looking to set our patients up for success so that they can continue their treatment without being burdened by the cost of care.”

She uses PAN’s website in her day-to-day work.

Not long ago, she was helping a new pharmacy patient apply online for a PAN grant. “We received a message to call PAN and were informed that he actually previously enrolled,” Nicole recalled.

Her call was one of the 365,546 calls PAN answered in 2019. What impressed her the most as the manager of a patient call center? How promptly PAN’s representatives helped her patient renew his funding. “They even provided needed processing information to our pharmacy—that makes my job easier.”

It takes a village to provide quality patient care.

Financial concerns are often just one part of the challenge. “Patients often request injection training resources, sharps container disposal, and travel kits for refrigerated medications,” Nicole said. “They need more than just co-pay assistance.”

Pharmacists and staff are also in a great position to fill in those missing patient education gaps related to specialty medications.

Through PAN’s network of [alliance partners](#), which includes 19 partnerships with leading patient support organizations, 34,581 patients received additional patient support and education resources in 2019.

How PAN supports providers and pharmacists



Online provider and pharmacist portals

to enroll patients and manage grants 24/7.



Comprehensive information about our programs

on our website, including eligibility criteria, medications covered, and diagnosis codes.



Referrals to open patient assistance programs at other charitable foundations

when a PAN program is closed on our website, enrollment portals, and through FundFinder.



Tailored resources, education, and training

on how to enroll patients, submit medical and pharmacy claims, and manage grants on our website, so providers and pharmacists can enroll patients and receive reimbursements quickly.



Dedicated support team at PAN

including an in-house pharmacist and provider relations specialist.



Regular communications and opportunities to provide PAN feedback

including an annual survey, quarterly newsletters with program updates, and training and education resources.



HIGHLIGHTS

Solving transportation barriers for patients

Accessing treatment goes beyond the inability to afford out-of-pocket costs for prescription medications.



Let's say you are one of the 59 million Americans who live in a rural area—where only 5.5 percent of physicians practice. You're diagnosed with cancer and live 75 miles away from the nearest oncologist. Do you have the resources to get there? A working car, money for gas, or public transportation? Can you afford it on a fixed income? Who will take you if you're too sick to get there on your own?

It's a big commitment to get up and drive a couple of hours to see the physician, get your labs drawn, receive treatment, and then drive home. And depending on your health, you may not be able to drive yourself at all.

Transportation challenges are often overlooked when it comes to helping seriously ill patients start and stay on treatment.

More than 70% of U.S. counties [analyzed](#) by the American Society of Clinical Oncology had no medical oncologists. Alaska, South Dakota,

and Wyoming have the fewest number of oncologists, whereas Nevada, Idaho, and Hawaii have the lowest oncologist density, with fewer than ten oncologists per 100,000 residents age 55 years and older.

But it's not just patients living with cancer. Approximately 3.6 million Americans miss or delay medical care because they lack appropriate transportation to their medical appointments, according to [research](#) by the National Academies of Sciences, Engineering, and Medicine.

In 2019, the PAN Foundation ran a pilot transportation program to meet this growing need with grants for Lyft rides to medical appointments and pharmacies.

Through the program, 249 patients with various life-threatening, chronic, and rare diseases were able to book up to 10 rideshares with a \$14 subsidy per ride to get to and from their medical



"I often cancel medical appointments since I am unable to drive myself and can't find an available driver."

Miriam Gordon

age 55, North Carolina, living with asthma, atopic dermatitis, and heart failure

HIGHLIGHTS

appointments or pharmacy. Many patients reached out to express an even greater need for transportation assistance and that they need more flexibility to choose how they get to and from medical appointments.

The need for transportation programs to support vulnerable patients has never been greater.

Many immune-compromised patients with conditions like cancer, multiple sclerosis, Parkinson's disease, heart disease, asthma, and more are at a greater risk for COVID-19. For them, practicing social distancing also involves avoiding public transit and people they would call for rides. But even without the risk of a pandemic, getting to and from treatment centers can be challenging and expensive.

PAN looks forward to expanding transportation assistance to patients in the near future.

"We must do everything we can to protect and support vulnerable patients with life-threatening, chronic, and rare diseases," said Dan Klein, PAN President and CEO. "Telehealth is not an option for many of the patients we serve. They have enough to worry about—especially during the pandemic. They shouldn't have to worry about how they will pay for transportation to medical appointments and the pharmacy."

2019 Patient transportation needs survey

We surveyed 4,460 older adults with serious and chronic conditions to better understand how access to transportation impacts their ability to receive care from a physician or pick up medications from pharmacies. **HERE'S WHAT WE FOUND:**



61%

had trouble getting to their doctor's office.

Two-thirds relied on family members or friends to get to their appointments. Others cited being late to or missing appointments due to unreliable transportation, not being able to afford transportation, and limited availability of transportation options for people with accessibility issues.



21%

reported that physical disabilities, vision problems, or mobility limitations prevented them from getting to their doctor's office or pharmacy.

Finding safe, accessible, and reliable transportation is hard. 86% surveyed were ambulatory or used a cane, crutches, or a walker.



14%

could not afford transportation to get to their medical appointments.

Costs can be high when a patient does not live near their treatment center. Most patients reported traveling more than 10 miles to get treatment.



HIGHLIGHTS

Connecting patients with financial help: FundFinder

FundFinder connects patients with open assistance programs to start and stay on treatment.

Digital health innovation usually starts at the top—solving problems for small groups of people who already have the means to address them. What would happen, however, if innovation started at the bottom, solving complex challenges like helping patients afford their needed medical treatments?

Through conversations with thousands of low-income patients, their family members, healthcare providers, and pharmacists,



HIGHLIGHTS

PAN learned that searching for financial assistance for their treatment was time consuming and frustrating. People spent day after day monitoring websites for available funding with no guarantees they would find assistance.

For thousands of patients with a serious illness, a closed patient assistance program means they might delay or forgo their treatment because they cannot afford the out-of-pocket costs.

To address the obstacles to locating financial assistance, the PAN Foundation launched FundFinder in December 2018, the first free web app to track the status of more than 200 assistance programs offered by nine foundations all in one place. Any user can

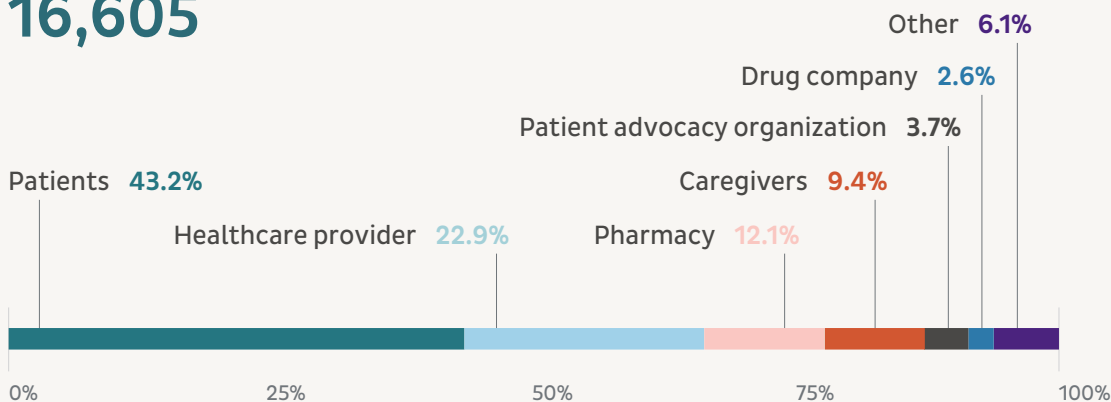
check the status of or sign up for email or text message alerts when funding opens for a specific condition. In its first year, 16,000 users signed up and over 180,000 email and text message notifications have been sent out about available funding.

Dean Bumgardner, whose wife has multiple sclerosis, said FundFinder's text messaging capability was the reason they didn't miss out on an opportunity for patient assistance —even while out of town. "My wife was getting close to running out of her medication when we were out of town for a family event," he said. "We received a text message from FundFinder that patient assistance for multiple sclerosis was available. Without it, we could have possibly lost out on the funding we needed to pay for her medications."

FundFinder users

NUMBER OF USERS

16,605



HIGHLIGHTS

In the short time since its launch, hundreds of other patients, healthcare providers, and pharmacists have reached out to let PAN know how FundFinder has changed their ability to connect with financial assistance.

Crystal Condo, a patient financial advocate at Northern Maine Medical Center, said FundFinder eliminates her having to search through every foundation website for grant opportunities. “I can easily monitor funds to better assist my patients,” she said. “It’s an amazing tool. Our patients are truly grateful for it, too.”

This user response in such a short time is evidence that FundFinder is providing a pivotal service for people who require financial support to access their medications and the healthcare professionals who support them.



“It’s an amazing tool.
Our patients are truly
grateful for it, too.”

Crystal Condo

Patient Financial Advocate, Northern Maine
Medical Center

Data from FundFinder illustrates conditions with the greatest need.

The most followed disease areas on FundFinder closely reflect the conditions that require patients to spend thousands of dollars in out-of-pocket costs for their treatment.

In 2019, the five most followed diseases on the app include: multiple sclerosis, prostate cancer, breast cancer, non-small cell lung cancer, and colorectal cancer.

Medicare beneficiaries with multiple sclerosis know this all too well: a [2019 report](#) from the Kaiser Family Foundation estimated that they pay on average between \$6,500 and \$7,400 out-of-pocket annually for their medications.

In the last year, patient assistance programs for multiple sclerosis opened 27 different times across all charitable foundations. Thanks to FundFinder, when these programs opened, 19,994 notifications were sent to 1,123 people about available assistance.

“Our goal is to quickly connect patients with available funding for their out-of-pocket treatment costs so they can start and stay on treatment without delay,” said Ayesha Azam, Vice President of Medical Affairs at PAN. “We know that FundFinder is just one piece of the puzzle in ensuring that patients can access their critical medical treatment.”

HIGHLIGHTS

2019 FundFinder highlights

MOST FOLLOWED DISEASES ON THE APP

**Multiple
sclerosis**

Prostate cancer

Breast cancer

**Non-small cell
lung cancer**

**Colorectal
cancer**

SPOTLIGHT ON MULTIPLE SCLEROSIS

Patient assistance programs
for multiple sclerosis opened

27 times

resulting in

1,123 people

receiving notifications about available
assistance for multiple sclerosis across
all charitable foundations



HIGHLIGHTS

Advocating for policy solutions to lower out-of-pocket costs

Rising premiums, deductibles, co-pays, and coinsurance are leaving more Americans than ever underinsured and unable to afford treatment.

Patients with serious illnesses who face high out-of-pocket costs are less likely to fill their prescriptions, take longer to start their treatment, and experience increased interruptions and gaps in treatment.

Now more than ever, we need smart policy solutions to address the access and affordability crisis and put patients first in our healthcare system.



HIGHLIGHTS

We give patients a voice by:

Calling for policy reforms to achieve needed legislative and regulatory change for patients.

PAN sent six letters to Congress and the Trump administration to advocate for reforms that would lower out-of-pocket costs for patients.

In July, we joined the Alliance for Aging Research along with 12 other organizations in submitting comments to the U.S. Senate Finance Committee and House Committee on Ways and Means supporting Medicare Part D affordability reform and advocating for policies to ensure seniors can access the care they need.

In the same month, we joined the Medicare Access for Patients Rx (MAPRx) Coalition to urge the U.S. Senate Finance Committee to [strengthen the cap on out-of-pocket costs](#) in Medicare Part D included in the Prescription Drug Pricing Reduction Act. The letter, which PAN signed with 27 other patient groups, also recommended a monthly cap that would allow total out-of-pocket costs to be distributed more evenly throughout the year.

We also signed on to a MAPRx Coalition letter with 55 other patient advocacy organizations in October 2019 to call on Congress to [pursue Medicare Part D reforms](#), including implementing a cap on out-of-pocket prescription drug costs.

Polling of Americans on issues related to out-of-pocket healthcare costs.

A national poll conducted by Morning Consult for the Alliance for Aging Research in July 2019, with support from the PAN Foundation, [surveyed 2,203 adults](#) over the age of 60 with health insurance about their ability to pay for healthcare and to gauge support for capping what seniors pay out-of-pocket for prescription drugs under Medicare Part D.

OVERALL POLL FINDINGS REVEALED

1 in 5 older adults

with chronic conditions are forgoing their medications due to cost.

A majority of adults over 60

support a cap on out-of-pocket costs for prescription drugs in Medicare Part D, with a preference for a monthly cap.

More than half of adults over the age of 65

would be willing to pay a few dollars more each month for their Medicare premiums to allow a cap on out-of-pocket costs.

HIGHLIGHTS

Developing resources that educate policymakers on key issues relating to healthcare access and affordability.

PAN has published a [guiding set of position statements](#) and [13 issue briefs](#) to help policymakers and advocates understand key topics impacting patient access to healthcare.

“[Medicare’s Low-Income Subsidy Program](#),” for example, provides an overview of the federal subsidy program and the need to expand the eligibility criteria so that more economically vulnerable patients can qualify for the benefit. “[Healthcare Access and Affordability](#)” explores how the lack of affordable healthcare can create insurmountable barriers between economically vulnerable patients and necessary healthcare services, medications, and procedures.

Our commitment

We remain committed to bolstering our advocacy efforts and collaboration with coalitions and patient advocacy groups to ensure patients can access the medications they need and to express the urgency with which policymakers need to lower out-of-pocket costs for Americans.

Amplifying awareness and understanding of the issues

Media highlights

Our message around lowering out-of-pocket costs for patients resonated nationally, resulting in placements in major news outlets, including [NPR](#), [Morning Consult](#), [Kiplinger](#), and [the Wharton Business Radio Dollars and Change show](#).



MORNING CONSULT

Kiplinger



Health literacy education

Healthcare, prescription medication, and insurance terminology are complicated and difficult to grasp for all Americans, regardless of insurance status and education level.

PAN commemorated [Health Literacy Month](#) in October 2019 by creating new resources for patients on navigating Medicare Open Enrollment, including key things to know about choosing a plan and what to know after enrolling in a Part D plan. We also published resources on other topics such as co-pay accumulators, high-deductible health plans, and more.

HIGHLIGHTS

“One thing that worries me is that Congress is very focused on lowering prescription drug prices. That’s a good goal, but it’s meaningless in an environment where patients still can’t access care or medications because of their deductibles.”

Dan Klein, PAN President and CEO, NPR, April 2019



In 2019, we assisted **187,056 patients** with **\$366 million** in co-pay assistance.

Expenses

In 2019, the PAN Foundation recorded total expenses of \$413 million.

For the last ten years, less than one penny of each dollar contributed to the PAN Foundation has been spent on fundraising.

HERE IS A TOTAL BREAKDOWN OF 2019 EXPENSES

95.2%

of these expenses are associated with co-pay assistance.

2.2%

is associated with other program expenses, including fees for program operations, patient determinations, and related services.

Administrative and fundraising expenses accounted for

2.4% and 0.2%

of total expenses, respectively.

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



Reported contributions

In 2019, the PAN Foundation reported contributions of \$434 million. 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 over **187,000 patients** through nearly 70 disease-specific assistance programs in 2019.

Income and assets

Total income: \$451,209,012

Net investment income: \$17,173,579

Total end-of-year net assets: \$462,673,779

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



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Without the generosity of our donors, PAN would not have been able to help thousands of seriously ill patients access their treatment over the past 15 years.

All supporters contributed \$100 or more in 2019.

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- See if your employer will match your gift
- Plan a future gift in your will
- Make a tax-free gift from your IRA
- Shop with AmazonSmile and select the PAN Foundation as your charity of choice
- Fundraise on Facebook

Learn more about [ways to give](#).

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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