



*The help
you
need*

2017 Annual Report

Increasing Access and Preserving the Safety Net



Skipping meals, missing rent or utility payments, taking only half the required dose of critical medication—these scenarios are a reality for thousands of middle-class Americans with life-threatening, chronic and rare diseases, despite having health insurance. These individuals, many of whom are on Medicare, are forced to make impossible financial choices because the out-of-pocket costs for their critical medical treatments are unaffordable.

We know that access to necessary healthcare is critical for successful patient outcomes, but it is often impeded or blocked by out-of-pocket costs—health insurance deductibles, co-pays and coinsurance that must be paid by the patient. High out-of-pocket costs can create barriers between patients and medications, diagnostic tests, office visits, surgeries and other needed services.

And because of benefit designs that penalize the use of expensive medications—even when there are no less-costly alternatives—and place no limits on unreasonably high out-of-pocket costs, the

problem of skyrocketing deductibles and coinsurance falls disproportionately on the most seriously ill patients.

Charitable patient assistance foundations like the Patient Access Network (PAN) Foundation are among the only resources that Medicare beneficiaries can turn to for help in paying for prescription medications. Yet, more and more, these charities are struggling to meet this growing need.

The PAN Foundation proposes three strategies to increase access to treatment for Medicare beneficiaries:

- » Putting a “hard cap” on out-of-pocket costs once beneficiaries reach Medicare Part D’s catastrophic threshold.
- » Spreading out-of-pocket costs more evenly throughout the calendar year.
- » Ensuring that all health conditions have at least one highly effective medication that is not on a specialty tier.

I’ve been practicing medicine for nearly 40 years, and I see firsthand the challenges that many patients face in accessing necessary treatment. I see the personal impact of increased cost sharing, and I am familiar with the difficult conversations that take place between patients and their healthcare providers. But I also see hope, particularly in organizations like the PAN Foundation. PAN’s entire team—from the management and administration side, to dedicated call center representatives—is committed to securing assistance for patients.

As I finish my tenure as Chairperson here at PAN, I am grateful to have worked with such a diligent group of individuals, and I look forward to what the PAN Foundation will surely accomplish in the future.

With deep gratitude,

A handwritten signature in black ink, appearing to read "Donald Barone".

Donald Barone, DO, Chairperson, Board of Directors

See the full list of PAN’s Board of Directors [here](#).

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Chairperson



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ABOUT THE PAN FOUNDATION

Overview

Mission and Vision

Staff and Board

Making Strides to Better Meet Patient Needs

As I look back on 2017, I am proud of what the PAN Foundation accomplished—from the launch of our enhanced portals for patients, providers and pharmacists, to our commitment to compliance and our continued development of disease funds to serve more patients. Indeed, 2017 was a good year for PAN and for thousands of seriously ill patients who needed help accessing their critical medications.

In the past year, PAN received more than \$525 million in donations, and provided assistance to over 262,500 patients, making us again the leader among charitable patient assistance foundations. We also established 11 new disease funds to help people living with a variety of conditions including cancer, chronic and rare diseases.

Regulatory compliance remained a priority in 2017—we adopted a best-in-class compliance

program to ensure we meet all ethical, legal and programmatic requirements. Our program incorporates all seven elements identified by the federal government as necessary for an effective compliance program.

We recognize providers' and pharmacists' work to connect patients to the assistance they need, and we strive to make their jobs easier. So in 2017, we launched updates that make navigating the PAN portals easier. New features include a fund reopen notification system, streamlined enrollment capabilities, easily accessible grant information and more.

In the stories ahead, you will see examples of our work in 2017, including how PAN assistance makes it possible for Harry Schaffner to continue playing tennis with friends, and how Pharmacy Technician Becki Tinder's patients pay it forward after receiving PAN support. You will also read about our alliance with Mended Hearts, an organization that supports people living with heart disease, and about our comprehensive technology enhancements.

We know that financial assistance is just one element of the support that seriously ill patients need to maximize their health and quality of life. That is why in 2017, we launched four exciting **alliances** with leading patient advocacy groups to provide additional support to PAN patients. Our new alliances with MPN Advocacy & Education International, Multiple Sclerosis Association of America, ThyCa: Thyroid Cancer Survivors' Association and Us TOO, mean that PAN patients have access to more support than ever.

PAN continues to play an essential role in ensuring that hundreds of thousands of patients get the care they need. We could not have done it without the support of our generous donors, and fantastic healthcare provider, pharmacy and patient advocacy partners. In 2018, we will continue to fight to ensure excessive out-of-pocket costs do not prevent anyone from accessing necessary treatments.


Dan Klein, President and CEO



Our Assistance Programs

Acromegaly
Acute Myeloid Leukemia
Ankylosing Spondylitis
Arrhythmia in Patients with Atrial Fibrillation or Atrial Flutter
Asthma
Atopic Dermatitis
Basal Cell Carcinoma
Bladder Cancer*
Bone Metastases
Chemotherapy-Induced Nausea and Vomiting
Chronic Iron or Lead Overload
Chronic Lymphocytic Leukemia
Colorectal Cancer
Cushing's Disease or Cushing's Syndrome
Cutaneous T-Cell Lymphoma
Diabetic Foot Ulcers

Exocrine Pancreatic Insufficiency
Gaucher Disease
Glioblastoma Multiforme
Heart Failure
Hemophilia
Hemophilia Premium
Hepatitis C
HIV Treatment and Prevention
Homozygous Familial
Hypercholesterolemia Premium
Hypercholesterolemia
Hyperkalemia
Idiopathic Pulmonary Fibrosis
Immune Thrombocytopenic Purpura
Immune Thrombocytopenic Purpura Travel
Inflammatory Bowel Disease (Crohn's Disease and Ulcerative Colitis)
Inherited Retinal Disease

Inherited Retinal Disease Premium
Inherited Retinal Disease Travel
Macular Diseases
Mantle Cell Lymphoma
Melanoma
Metastatic Breast Cancer
Multiple Myeloma
Multiple Sclerosis
Myelodysplastic Syndromes
Neuroendocrine Tumors of Pancreatic Origin
Neutropenia
Non-Hodgkin's Lymphoma
Non-Small Cell Lung Cancer
Ovarian Cancer
Parkinson's Disease
Philadelphia Chromosome Negative Myeloproliferative Neoplasms
Plaque Psoriasis

Postmenopausal Osteoporosis
Prostate Cancer
Prostate Cancer Travel
Psoriatic Arthritis
Pulmonary Hypertension
Renal Cell Carcinoma
Respiratory Syncytial Virus
Retinal Vein Occlusion
Rheumatoid Arthritis
Secondary Hyperparathyroidism
Short Bowel Syndrome
Short Bowel Syndrome Premium
Systemic Lupus Erythematosus*
Thyroid Cancer
Tuberous Sclerosis Complex
Uveitis
Venous Leg Ulcers
Wilson Disease

* Opened in 2018





With over 60 disease funds in 2017, PAN helped patients and families manage treatment costs so they can keep doing what they love.



Rising to the Challenge and Spreading the Word

*Harry Schaffner,
Grant Recipient*

Harry Schaffner is one of those rare people who seems to have done everything right in life. Growing up in a working-class family in Chicago, he worked hard and made good decisions.

“I think of myself as the embodiment of the American dream. I was the first person in my family to graduate from high school, the first to graduate from college, and the first to go to graduate school.”

Schaffner, 75, describes his younger self as streetwise and an excellent student. From a young age, he knew he wanted to be an attorney.

“When I was in high school, I used to ditch school and go watch famous court cases that were going on in Chicago,” he says. “I’d be sitting in the back with old retired men watching trials.”

And for Schaffner, the research paid off. He got into law school at the age of 20 through a special program that let him start a year early.

Schaffner enjoyed a 35-year career as a successful attorney and litigator, all the while doing a stint in the Marine Corps, marrying his soulmate and raising three daughters.

At 60, Schaffner decided it was time to retire.

“Everything about my retirement plan was correct and I had sufficient money to do it,” he says.

HARRY'S STORY

After enjoying a comfortable retirement for over 10 years, Schaffner and his wife began to face a number of trials, including losing half their savings in the dot-com bubble, dealing with the damage to their flooded home after a freak desert storm, and draining their remaining savings by paying for round-the-clock care for Schaffner's ill mother.

"For the first time since I was 30, I was having to keep track of money and how I spent it," he says. "I am not complaining. It's part of my life and I was honored to help my mother."

Then, at the age of 71, he was diagnosed with asthma. Despite having suffered allergies all his life, the diagnosis was unexpected for Schaffner, an avid tennis player and a self-described "athletic and healthy guy."

"With asthma medications, people go without drugs, they skip doses, they're doing all kinds of things to make ends meet."

"I did not have asthma attacks, I had asthma symptoms, which was the feeling of someone choking me," he says.

Adding insult to injury, Schaffner soon learned about the high cost of his asthma medication, another hit to his already-dwindling life savings. After doing some research, he discovered that many other Medicare-aged asthma patients had similar stories.

"With asthma medications, people go without drugs, they skip doses, they're doing all kinds of things to make ends meet," Schaffner says.

He began to research financial assistance, and was thrilled when he found the PAN Foundation. "I made the fateful telephone call and I was qualified in minutes," Schaffner says. "I would be able to avoid the costs of my drugs for several years. I slept well for the first time in months with the comfort I felt from the friendly and knowledgeable people I talked to at PAN."

After his success with the PAN Foundation, Schaffner made it his mission to share his story

with others to help them defray the cost of their medication.

"I slept well for the first time in months with the comfort I felt from the friendly and knowledgeable people I talked to at PAN."

"In my work life, I always felt I could help people with what I knew, and I felt the same way about PAN—I know things that could help other people, so I've become a proselytizer, a bishop, if you will, for the PAN Foundation."



Harry, with his wife and daughters on a recent hike.

[Click to read more about Harry.](#)



Thousands of Thank Yous

In 2017, PAN received thousands of thank you notes from the patients and families we've helped. We cherish each word—those messages are the best reward and acknowledgment of our work.

Paying It Forward

Becki Tinder, Pharmacy Technician

For Becki Tinder, her work is personal. As a Certified Pharmacy Technician at the Ghosh Center for Oncology & Hematology in Cedar Rapids, Iowa, Ms. Tinder manages the medication dispensary, inventory and supplies, and oversees the mixing of chemotherapy. She also purchases the medications and knows exactly how much a particular medication will cost a patient.

“I get to see the big picture—it makes it much more personal when you see what the final cost is for the patient,” Ms. Tinder says. “It really makes it a mission to help these patients as much as possible.”

Ms. Tinder works toward this mission by seeking out financial assistance for her patients, the majority of whom are over 65.



At the Ghosh Center, about 75 percent of patients need some sort of financial assistance, and the protocol is both simple and patient-centric: patients are not alerted to the cost of their treatment until financial assistance has been secured.

“We are proactive—we spell out treatment costs, factor in insurance and determine the patient’s responsibility,” Ms. Tinder says. “The next time they come in, we tell them about the treatment, inform them how much their insurance covers and tell them about the financial assistance we’ve secured. The last thing we want patients to worry about is what it is going to cost them.”



“There are patients who absolutely would have denied getting treatment because they couldn’t afford it.”

“We are proactive—we spell out treatment costs, factor in insurance and determine the patient’s responsibility.”

Ms. Tinder came to the Ghosh Center seven years ago, after spending nearly two decades working as a Pharmacy Technician in both retail and hospital settings. In those positions, she was familiar with co-pay cards and some assistance programs, but the Medicare patients she sees at the Ghosh Center presented a new challenge. She credits an online search and NeedyMeds for finding the PAN Foundation. After securing PAN assistance for the first time, she knew she had found a valuable resource for her patients.

For many years, Ms. Tinder was the only business office employee at the Ghosh Center, but now a colleague manages chemotherapy while she oversees the oral medication side. Their team has been extremely successful—in the last three and a half years, they have helped patients save more than \$6.5 million.

According to Ms. Tinder, patient assistance organizations like PAN have made cancer care more affordable.

“There are patients who absolutely would have denied getting treatment because they couldn’t afford it,” she recalls. “It has given these patients time to spend with their loved ones doing things that they would not be able to do otherwise.”

Ms. Tinder says that when she tells patients they will receive financial assistance, there are hugs and tears. One patient who has received assistance with a life-saving drug for several years brings her home-baked treats on a weekly basis.

But perhaps the most remarkable display of gratitude is the desire to pay it forward. For many patients, financial support inspires them to help others.

“Sometimes they can’t believe there are foundations and programs to help them, and sometimes they find they have a little extra money, so they feel inspired to help somebody else,” Ms. Tinder says. “It has a domino effect in our community. They say, ‘What can we do to pay it back?’”



Amy, Ethan and Carson Blesie at the 2017 Blesie Tree Walk, an event to show support for local cancer patients and raise money for the Blesie Tree Foundation.

Prior photo: Dr. Chirantan Ghosh embraces a participant at the Blesie Tree Walk.



In **2017**, thanks to
PAN donors, we provided
\$347.9 million in
assistance to more
than **262,500** patients.

Sharing Experiences, Knowledge and Strength

Mended Hearts, Alliance Partner

Andrea Baer knows what it feels like to be on the receiving end of a heart disease diagnosis. However, the diagnosis—a congenital heart defect—was not for herself, but for her newborn son.

“The day he was born, I was told he would have open heart surgery,” Baer says.

Baer says she never felt more alone than when she received the news. After posting about her son’s diagnosis on social media, a friend reached out to tell her that her son had recently received the same diagnosis and offered to talk. Baer’s friend also told her about Mended Hearts.

“Just getting the information that I am not alone in this was so comforting,” Baer says. “When someone gets a heart disease diagnosis, most

of the time what they need is reassurance that there’s a way through the disease, that it’s not a death sentence.”

Baer immediately got involved with Mended Hearts, first starting the local chapter of the national board and then becoming a staff member. She is currently the Director of Program Management at Mended Hearts and Mended *Little* Hearts, which helps families of children with congenital heart disease.

Andrea’s story mirrors those of the rest of the Mended Hearts team. “It’s one heart patient talking to another heart patient,” says Dr. Fredonia Williams, Assistant Southern Regional Director and Visiting Chair. “We say we’re the largest peer support group in the world.”



Jessica Rogers, heart transplant survivor, leads a YOUNG Mended Hearts roundtable discussion.

Since the two organizations aligned in July 2016, PAN has referred more than **2,500** patients to Mended Hearts.

MENDED HEARTS' STORY

As the largest heart patient support network in the world—with 20,000 members and 300 chapters—Mended Hearts is the perfect alliance partner for the PAN Foundation. Recognized for its role in facilitating a positive patient-care experience, Mended Hearts partners with hospitals and cardiac rehab clinics to offer support through visiting programs, group meetings and educational forums.

Since the two organizations aligned in July 2016, PAN has referred more than 2,500 patients to Mended Hearts. Patients living with heart failure and hypercholesterolemia who apply for financial support from the PAN Foundation, are offered the opportunity to get peer-to-peer support from Mended Hearts.

“We reach out to patients through our telephone visitors, who work every day,” says Baer. “We usually refer them to a local chapter, send information or direct them to our website. We love that we can reach those people who might not have found Mended Hearts if it weren't for PAN.”

First and foremost, the phone visitors tell the patients that they will need support with their diagnosis.

“Family is fine, but you benefit from talking with people who have had similar experiences to yours, which is why I went to Mended Hearts,”

says Dr. Williams. “I had questions about my medicine that the doctors couldn't answer. You learn about side effects and what works for others, and then you can go back to your doctor and say, ‘I have friends where this works, would you mind if we try this?’”

Dr. Williams says that she has been impressed by how excited and eager to talk patients have been. Their questions range from how soon they can get back on their feet, to what kind of lifestyle changes they need to make, to concerns about their medication. “They're so excited to find out that they can continue to do the things they love and that someone else has been down the same path and can ‘amen’ what they are doing,” she says.

“The fact that PAN is working with Mended Hearts and we are able to reach out to these patients is a plus, because it gives them one more support system,” Dr. Williams says.

As for Baer's son, he's nine and thriving now.

“Just knowing that I wasn't alone changed the way I saw things. That's why I love to do what I do, because I've been there,” Baer says. “Some of the people I've supported are now empowered and helping other people—that's the most rewarding thing.”

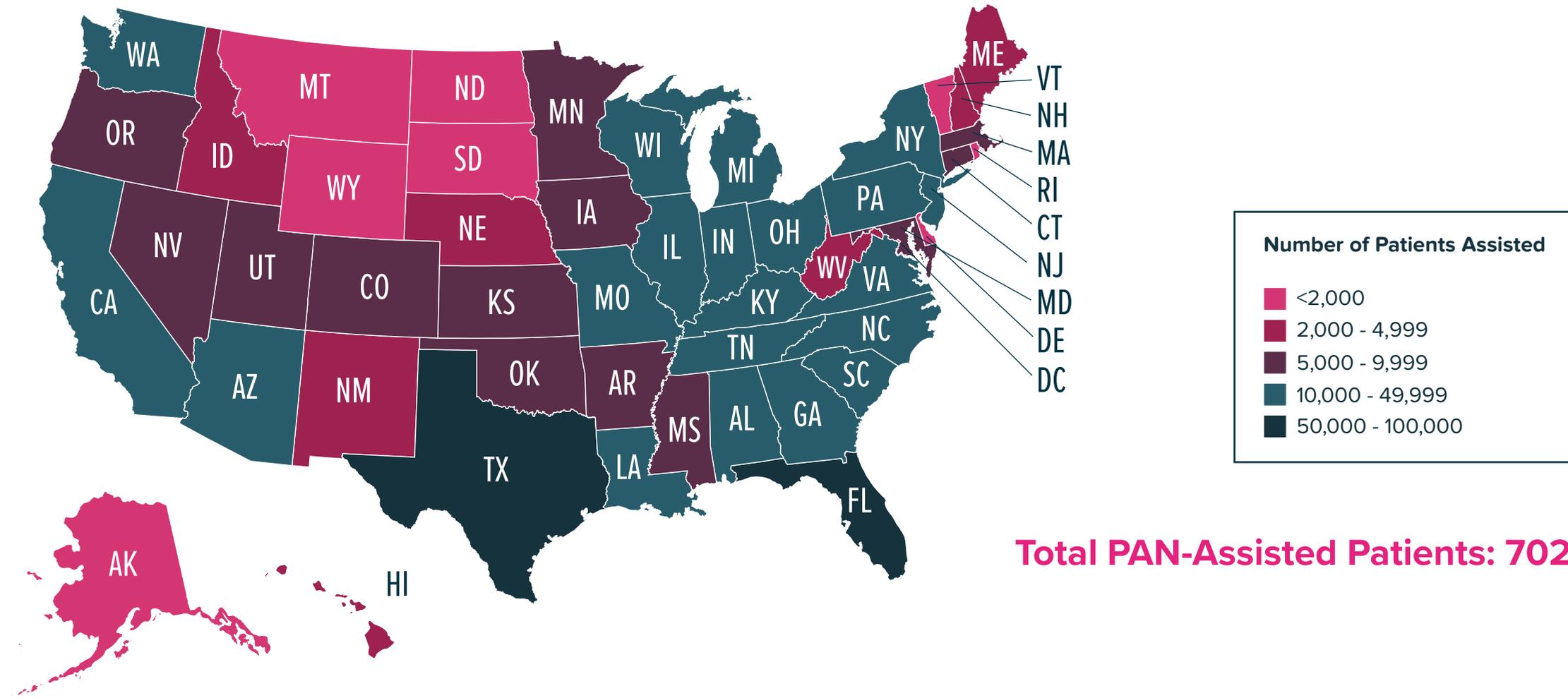


Lynn Berringer, Southwestern Regional Director for Mended Hearts, and his wife Kathy, at the Annual Educational and Training Conference.

“When someone gets a heart disease diagnosis, most of the time what they need is reassurance that there's a way through the disease, that it's not a death sentence.”

Map of PAN-Assisted Patients

January 1, 2012 to December 31, 2017



Total PAN-Assisted Patients: 702,008

Reinventing Our Technology for Superior Service

As the leader among patient assistance organizations, PAN continues to advance its best-in-class technology for patients, providers, pharmacists and donors. In 2017, we launched enhanced portals for all users, and reached new levels of performance in our financial management and technology platforms.

PAN's portals offer unrivaled technology, making it simpler for providers and pharmacists to enroll patients and view their grant and claims information. With our enhanced knowledgebase, patients, providers and pharmacists who contact the call center receive up-to-the-minute information about grants. Users can sign up for our fund reopen notification program which alerts them when a fund reopens. With automatic notifications, healthcare providers and pharmacists no longer need to call PAN or monitor our website to check a fund status, freeing up more time for patient care. And, patients can count on PAN to notify them when funds reopen.

Additionally, PAN's tightly integrated financial and customer relationship management systems allow for real-time data analysis and improved accuracy in enrollment projections, ultimately maximizing our ability to help the greatest possible number of patients.

Provider and Pharmacy Portal Features

PAN's updated portals allow users to:

- » Quickly enroll new and returning patients;
- » Update patient demographic information;
- » Check the status of claims and payment information;
- » Check grant balances;
- » Enroll patients for second grants;
- » Add and manage multiple portal users;
- » Receive email notifications when disease funds open;
- » Receive referrals to other funding sources if a PAN disease fund is closed.

Patient Portal Features

PAN Patient Portal updates make it easier for patients to:

- » Apply for and renew grants;
- » Determine which medications are covered;
- » Apply for a second grant;
- » Find out when a closed disease fund has reopened;
- » Obtain referrals for other patient assistance programs;
- » Connect with disease-specific education and support services through PAN alliance partners;
- » Update personal information.



“Your portals are phenomenal, streamlined and just easier to work with. I’ve said it a million times—you have set the bar high.”

—Certified Pharmacy Technician, oncology practice



Other Notable Enhancements

Several significant data system and technology updates give PAN even greater visibility and control of patient and program information, ultimately reducing program administration fees.

In 2017, we:

- » Integrated PAN's financial system with its customer relationship management platform, allowing for better fund- and grant-level reporting;
- » Boosted in-house analytics capabilities, increasing data visibility and maximizing data integrity;
- » Developed analytic reports and dashboards with real-time access to patient- and fund-level information, increasing enrollment and out-of-funding projection accuracy and helping us learn more about our patients.

“The enhancements have made the portals even more user-friendly. You get instant approvals, which we love, and it’s easy to see what is available. It’s one of our advocates’ favorite portals because it is one of the simplest and most self-explanatory.”

—Regional Financial Counseling Supervisor,
medical practice





The PAN Foundation
ranked **#23** on Forbes'
*"100 Largest U.S.
Charities"* list in 2017.

2017 FINANCIAL STATEMENT

CONTRIBUTIONS

In 2017, the PAN Foundation reported contributions of **\$525.4 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 assistance to more than **262,500 patients** through over 60 disease-specific assistance programs during the course of 2017.

For more detailed information and to view the Foundation's 990 tax return and financial statements in their entirety, please visit panfoundation.org.

EXPENSES

In 2017, the PAN Foundation recorded total expenses of \$360,293,029.* Here is a detailed breakdown of the PAN Foundation's 2017 expenses:

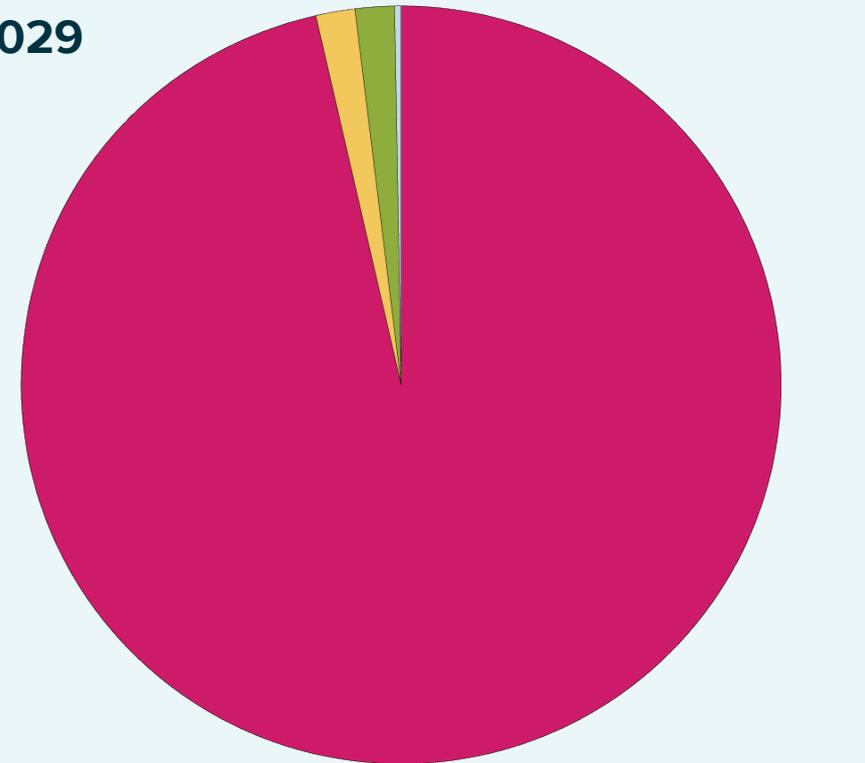
- » **96.6 percent, or \$347.9 million**, of these expenses is associated with co-pay assistance
- » **1.8 percent** is associated with other program expenses, including fees for program operations, patient determinations and related services
- » Administrative and fundraising expenses accounted for **1.5 percent*** and **0.2 percent** of total expenses, respectively
- » For the last eight years, **less than one penny** of each dollar contributed to the PAN Foundation has been spent on fundraising

* Includes investment management fees, which are netted against investment income in audited financial statements.

2017 Financials

TOTAL EXPENSES (\$)

\$360,293,029



96.6%
Co-pay Assistance
\$347,865,265

1.8%
Other Program Expenses
\$6,413,822

1.5%
Administrative
\$5,324,765

0.2%
Fundraising
\$689,177

In 2017, the PAN Foundation's end-of-year net assets totaled \$253,229,871.

Thank you

To our donors and hardworking network of providers and pharmacists: without your help, hundreds of thousands of patients each year couldn't access the treatment they need. Thank you for your continued collaboration and support.



PAN Foundation

panfoundation.org

