

ANNUAL REPORT 2018

# STRENGTHENING THE SAFETY NET

 PAN Foundation



## LETTER FROM **MARTIN BIEBER** CHAIRPERSON

**As I reflect on decades of service in the healthcare industry, access and affordability have risen as two of the most troubling issues facing far too many Americans.**

The work of the PAN Foundation and similar charities illustrates that every day, high out-of-pocket costs for prescription medications have become an insurmountable barrier to access for patients.

A 2019 Kaiser Family Foundation poll of Americans who take prescription drugs discovered that more than a quarter of those surveyed found their medications difficult to afford. Additionally, 1 in 3 people did not take their medications as prescribed due to cost, including skipping doses, cutting pills in half or not filling their prescription at all.

The percentage of Americans who have insurance but who cannot afford their out-of-pocket costs is rising—and it is reducing access and adherence to treatment for the most financially vulnerable among us.

Currently, charitable foundations like PAN are often the only place people can turn for financial assistance so that they can begin and stay on life-saving treatment. This is especially true for Medicare beneficiaries. Providing this important safety net is at the heart of PAN's mission. In the last 15 years, PAN has assisted

nearly one million Americans, who otherwise would not be able to afford their medications.

In 2018, I was proud to collaborate with my fellow board members on developing an ambitious strategic plan for the PAN Foundation. We have set the course for the next three years, focusing our efforts on two vital objectives:

### **1. Expanding the safety net for patients**

As we have done for 15 years, PAN will continue to increase financial assistance and support services for underinsured individuals living with life-threatening, chronic and rare diseases who cannot afford their healthcare out-of-pocket costs.

### **2. Amplifying PAN's advocacy voice on behalf of patients**

PAN will expand its advocacy efforts to educate and drive policy and legislative change to reduce out-of-pocket costs for individuals living with life-threatening, chronic and rare diseases.

While I assumed the role of Chair on January 1, 2019, I have had the honor to serve on the Board for more than four years. In that time, I came to know and admire Don Barone, DO, who recently completed his second three-year term on the Board and served as Chair between 2016 and 2018.

Under his leadership, we completed our recent strategic planning process. As a physician and patient advocate, Dr. Barone truly understands the growing challenges impeding Americans' access to care. On behalf of the entire Board of Directors of the PAN Foundation, we are thankful for his contributions.

In the year ahead, I look forward to working with PAN's leadership team to ensure that we are doing everything we can to meet the growing needs of people with high out-of-pocket costs, and to advocate on their behalf.

With gratitude,

**Martin A. Bieber, Chair**  
PAN Foundation Board of Directors



LETTER FROM  
**DAN KLEIN**  
PRESIDENT AND CEO

**My message for our 2018 annual report is about a drop in the bucket—and the imperative to meet the growing needs of patients across the country.**

Let me explain. First, I'm incredibly proud of and very grateful for the work the PAN Foundation has done to increase access to our safety net programs over the last year. In 2018, thanks to our generous donors, we raised \$530.7 million. That allowed us to help over 180,000 patients with their out-of-pocket costs across 70 disease-specific assistance programs.

All of us at PAN are extremely humbled by our ability to help so many patients. But the stark reality is that even counting the thousands of patients we've served, it's only a drop in the bucket of the millions who need financial assistance in order to afford their critical medications.

High out-of-pocket costs are an insurmountable obstacle for millions of Americans when it comes to paying for their prescription medications. At PAN, we believe out-of-pocket costs should never get in the way of a person's ability to start and stay on treatment.

But we know too well that the continuing rise of out-of-pocket costs—in the form of high-deductible health plans, coinsurance for specialty medications or co-pays—means that paying for prescription drugs forces families to make difficult decisions or forgo treatment altogether.

**Numbers that Alarm Us:**

- People are four times more likely to abandon their prescriptions when faced with out-of-pocket costs of \$50 or more. (Annals of Internal Medicine, 2010)
- The average family of four paid over \$28,000 for their health insurance and out-of-pocket costs in 2018. (Milliman Medical Index)
- The financial burden of high deductibles, coinsurance and co-pays was highest for people who are older or lower-income, and for women. (JP Morgan Chase & Co, 2017)

We urgently need policies that provide patients with relief from out-of-pocket costs and increased access to their critical medications. In the coming year, we'll continue to do everything we can to advocate for lower out-of-pocket costs for patients.

In the meantime, I want to express my deepest gratitude to our donors, our network of healthcare providers and pharmacists, and our alliance partners. We could not do this critical work without your support—and we look forward to what we will accomplish together in service of patients in the year ahead.

Sincerely,

**Dan Klein**  
President and CEO

# WHO WE SERVED IN 2018

The needs of our patients guide everything we do here at the PAN Foundation. From our daily work, it's clear that the demand for safety net programs continues to grow as the burden of out-of-pocket costs for prescription medications increasingly falls on patients. Here's an overview of the people we assisted across the country in 2018.

## Total patients assisted

**182,615**

## Average grant amount

**\$5,751**

## Gender



**50%**

Male



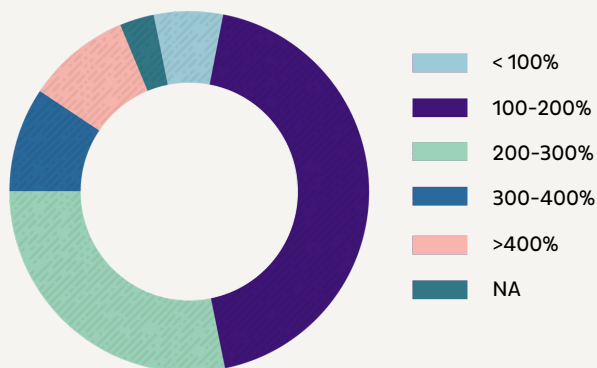
**50%**

Female

## Insurance type

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

Medicare	Commercial	Other
<b>97.1%</b>	<b>2.5%</b>	<b>0.4%</b>



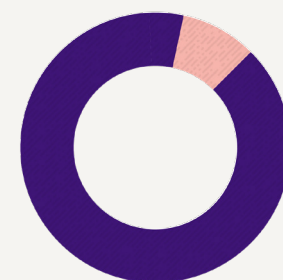
## Patient income by Federal Poverty Level

The people we serve are underinsured—with the majority living under 200% of the Federal Poverty Level, earning less than \$24,280 for a single-person household in 2018.

## Age

Under 65: **17.7%**

Over 65: **82.3%**

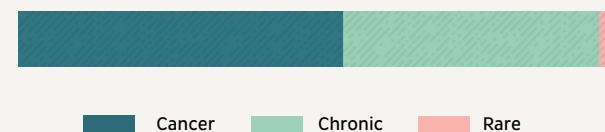


## Patients enrolled by state

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

## 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.





# IMPACT OF PATIENT ASSISTANCE ON ACCESS, MEDICATION ADHERENCE AND QUALITY OF LIFE

In our daily work, we see firsthand the transformative power of patient assistance. Last year, we conducted a survey of 1,459 patients who received PAN Foundation grants to learn more about how patient assistance impacts their healthcare journey.

The most convincing evidence that these programs bolster access to treatment comes directly from patients, their families and their healthcare providers. Here are a few key insights from the results of our survey

## **1. Assistance from charitable foundations helps patients adhere to treatment.**

Without financial support, high out-of-pocket costs frequently prevent people from adhering to medically necessary treatments, especially those with low incomes. Among those who received financial assistance from PAN and had annual incomes less than \$25,000, 54 percent said they had skipped or cut doses of their medication prior to receiving a PAN grant because they couldn't afford to take the full dose.

These results mirror trends seen in published literature investigating patient experiences with out-of-pocket costs related to prescription medications. Research from the Kaiser Family Foundation shows that 21 percent of Americans report that they, or someone in their family, did not fill a prescription because of cost, with that figure rising to 30 percent among people with low incomes and 44 percent among people in poor health. Furthermore, 16 percent of Americans cut pills in half or skipped doses of their medications due to cost, and this rises to 25 percent among

people with low incomes and 35 percent among people in poor health.

Our survey also revealed the significant impact of patient assistance on treatment initiation and adherence. After receiving financial assistance from PAN, 93 percent of patients said they were much more likely to take their medications as prescribed. Healthcare providers and pharmacists agreed with their patients: more than 80 percent said that financial assistance makes it more likely that patients will take their medications as prescribed and improve their health.

## **2. Financial support reduces stress and offers hope to patients and their families.**

Charitable assistance has positive ripple effects. Nine out of ten patients who received support from PAN said that it decreased stress for the entire family. A significant body of research confirms these findings—reduced financial stress improves the quality of life for patients and their families.

Additionally, 84 percent of patients surveyed reported that financial assistance increased their ability to manage other expenses. Patients also expressed that the support they received from PAN provided them with hope that their health would improve.

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## **3. The need for patient assistance is urgent and ongoing.**

Even with financial support from charitable foundations, patients continue to face challenges paying for critical medical treatment. We discovered that 83 percent of grant recipients had ongoing concerns about finances and 40 percent were worried about keeping their job while managing their illness. Four out of five patients said even after receiving financial assistance, their out-of-pocket medical expenses were higher than expected and only 10 percent of patients were confident that they would be able to cover the cost of their treatment.

Studies from the Commonwealth Fund and the National Council on Aging have assessed the extent of economic insecurity among older adults and how healthcare costs impact the underinsured. This research contextualizes the growing need for patient assistance programs to ensure that individuals with inadequate insurance coverage can access needed prescription medications.

Until policies are enacted that ensure access to needed

# PATIENT SPOTLIGHT: AN ARTIST LIVING WITH METASTATIC BREAST CANCER

For decades, 83-year-old Phyllis lived an excitingly nomadic and creative life. Born in Hong Kong to missionaries and having spent her childhood in China, India, Burma, and England, Phyllis quickly became a citizen of the world.

She eventually settled into a career working as a human relations specialist and manager for a Fortune 500 company in the United States, and married and became a mother to four children.

Now in retirement, Phyllis spends her days as a professional artist working in oils, acrylics and collage, and supporting her local art gallery. During this time in October 2012, she was surprised after years of “amazingly good health,” when she was diagnosed with stage 4 breast cancer.

At first, Phyllis’s health insurance plan covered almost all her out-of-pocket costs. However, as stronger medications were recommended, Phyllis could not afford the expensive co-pays. The stress became overwhelming.

“I had visions, when all this happened, of losing our home and not knowing how to survive elsewhere,” she says. Phyllis was also worried about her husband and how their financial stress might affect his health. She feared that they would be unable to keep their car for travel to her medical appointments, and she didn’t know what to do about her beloved rescue dogs.

Eventually, Phyllis reached out to her hospital’s patient relations manager to learn about what financial options were available. “He eased my fears by referring me to a patient financial advocate, a lovely lady who immediately contacted my oncologist and together, they called PAN,” she recalls.

The application process was painless, and when Phyllis learned she was approved for a grant that would cover a year of co-pays for her treatment, she was overwhelmed with emotion.

**“I cried with relief, and slept well for the first night in ages. In my heart I blessed all the wonderful donors who have given to this organization. Once PAN stepped in, it was like being reborn.”**

Today, Phyllis credits PAN with saving her life. “I could not have afforded these expensive pills without giving up our home,” she says. With the continued support of a PAN grant, Phyllis is still on treatment and her artwork



remains at the center of her life. She continues to maintain her art studio and sell her art. Her doctor even encouraged her to focus on her art during treatment because it reduced stress and brought her joy. “He followed my website, and he and his wife even bought some of my paintings for their home,” she said.

She shares her sense of hope and the importance of going forward with newly-diagnosed cancer patients she meets.

“Never give up,” she says. *“Hope is the engine that drives the soul.”*

# PROVIDER SPOTLIGHT: NAVIGATING HOPE ON THE CANCER JOURNEY

We are proud to partner with healthcare providers and pharmacists who are dedicated to improving the health of their patients and who share our concern about how high out-of-pocket costs impact a patient's ability to best manage their condition.

By connecting patients with charitable assistance, the providers and pharmacists we work with help remove financial barriers to care, ensuring that patients can access the medications they need and adhere to their course of treatment as prescribed.

In our ongoing spotlight series, we interview providers and pharmacists from around the country to better understand their experiences and how we can best support their work.

One of our most memorable interviews from 2018 featured two phenomenal providers from the Green Bay Oncology team in Green Bay, Wisconsin.

We spoke with Lori Schneider, an office business manager, and Jacqueline Heroux, a financial navigator. Both Ms. Schneider and Ms. Heroux watched loved ones live with cancer and shared with us how assistance from PAN brings hope to patients on their cancer journey.

## What is your position—and what is most rewarding about your job?

Jacqueline Heroux (**JH**): I am one of the financial navigators with Green Bay Oncology. Patients come to me with their financial concerns and I assist them in reducing or preventing financial toxicity. It is greatly rewarding to form personal connections with patients.

Lori Schneider (**LS**): I am the business office manager. I feel lucky to lead a wonderful financial team. The most rewarding part of my job is watching my team

help patients and seeing how the patients touch their lives. Our oncology patients are so kind, caring and appreciative. I also enjoy being able to speak nationally about the wonderful program that our team has developed and the services we provide.

## Why did you choose to become a provider?

**JH**: My grandfather was a patient at Green Bay Oncology, and he shared stories about how great the clinic was. It's truly rewarding to be a part of this team. I love being able to meet with patients and help them find all the options available to them.

**LS**: I went into oncology because I watched my mother, father and sister-in-law struggle through their cancer journey. I wanted to make a difference for other people in similar situations. My main goal was to help others, so they wouldn't have to struggle.

## How do you implement the mission of Green Bay Oncology into your daily practice?

**JH**: Our team truly leans on each other to explore all possible options for patient assistance. We strive to build empathetic relationships with patients and assure them that we're there for them and will work tirelessly to reduce their financial toxicity. We want them to leave the search for financial assistance to us so they can focus on getting better.

**LS**: Our financial counseling program has been trademarked with the name of Navigating Hope. It is our intention to be able to expend our resources locally, but

to also go to other cancer centers throughout the U.S. to help them set programs up that can be customized to fit their needs.

## How has the PAN Foundation impacted your patients?

**JH**: I once worked with a patient whose co-pay was thousands of dollars. The patient said there was absolutely no way they would be able to start treatment. I let the patient know that the PAN Foundation had available funding. We applied for assistance and their application was approved. When I told the patient that their entire co-pay would be covered, they started crying and gave me a big hug saying, "You don't know how much this means to me."

**LS**: We regularly see patients that would not be able to get the treatment they need if not for the help of charitable foundations. The help that PAN provides offers patients hope because they know that otherwise they wouldn't be able to afford treatment.

## Working in healthcare is all about tending to the needs of patients. How do you practice self-care when you're off the clock?

**JH**: I like to spend as much time as possible with family and friends. I also like to binge watch Netflix when I get some alone time.

**LS**: When I'm off the clock, my family is number one. When I have alone time, I like to relax with a good book.



# INCREASING ACCESS TO TREATMENT THROUGH TECHNOLOGY

One of the keys to delivering on our mission of providing patient assistance is through leveraging technology.

From patient applications and enrollment to grant management, technology is critical to our work and we're dedicated to advancing our systems to provide exceptional service that is efficient, safe and secure.

## Helping Patients, Quickly and Seamlessly

We know too well the healthcare system is often fraught with paperwork and delays. But when faced with a critical diagnosis, helping patients immediately access their treatment is our highest priority.

Our enrollment processes and grant management system are designed to help patients, or their healthcare team, apply for and receive financial assistance fast and seamlessly. We also have several other systems in place to ensure high quality services and to accurately forecast patient need:

- Our self-service portals allow patients, healthcare providers and pharmacists to enroll in minutes and manage grants online.
- We offer instant, online financial eligibility verification in order to minimize the paperwork burden on applicants.
- Our integrated financial system and customer relationship management platform provide enhanced fund- and grant-level reporting.
- Our advanced data analytics help us accurately forecast demand and grant availability, ensuring that we're addressing patient needs.

"I think the PAN application portal is one of the easiest to navigate. Everything is straightforward and useful. I prefer to enroll patients online instead of over the phone because it is more time-efficient. I also like how all the information about the patient's grant is readily available for reference, if needed. Keep up the great work! It makes my job as a patient advocate much easier!"

—Jennifer, medical oncology and blood disorders patient advocate

## Efficient Grant Operations

Our instant enrollment process means that patients can be approved for a grant within minutes and quickly access their prescription medications. When patients receive a grant from PAN, their first claim is usually submitted in less than one week—and often on the first day. For many of our assistance programs, if a patient needs more financial support during their grant eligibility period, we also offer second grants when funding is available.

In addition, we have a new process in place to monitor patients' grant use—if we find they are not using their grant, we reach out to them to determine if they still need it. This new approach cycles unused funds into new grants daily and keeps our assistance programs open longer to help more patients.

"I am so blessed to be able to renew my multiple sclerosis drug grant for another year. Your notification process of grant funding availability is outstanding. As soon as I received the email, I

went online to the patient portal and applied. I updated my income information and was instantly approved. What an incredible feeling of relief and hope.

—Mary, a PAN Heart Failure grant recipient

## Putting Patients First

We're committed to connecting patients with financial assistance so they can start treatment. When we're unable to provide a grant, we always refer patients to other patient assistance programs, regardless of whether they enroll via our call center or online application portals. In addition, we are a source for patient support, caregiver resources and more.

We also encourage patients to sign up for FundFinder, a new web app powered by the PAN Foundation, so they can receive notifications when an assistance program for their diagnosis opens at any of the eight charitable foundations. FundFinder is the first free app available to all types of users that sends automated alerts for financial assistance, ensuring that anyone with a life-threatening, chronic or rare disease can easily monitor available patient assistance programs.

## Technology That Works for All of Us

Our systems allow us to help more patients all the time, creating efficiencies, enabling real-time data analysis, saving administrative costs and ultimately, offering a seamless patient experience when receiving assistance from the PAN Foundation so they can start and stay on treatment.



# SIMPLIFYING THE SEARCH FOR ASSISTANCE WITH FUNDFINDER

Thousands of people living with life-threatening, chronic and rare diseases depend on financial assistance from charitable foundations to start and stay on treatment.

While charitable foundations provide a critical safety net, we often hear from patients and their healthcare teams that the road to financial assistance is difficult to navigate.

Until recently, people looking for charitable assistance had to manually monitor the status of disease funds across multiple organizations to find an available program. This placed an additional burden on patients, their families, providers and pharmacists.

## Streamlining the Search for Patient Assistance

To ease this burden, we spent 2018 developing FundFinder, a web-based app that is designed to help underinsured and economically vulnerable patients quickly find financial assistance from PAN and seven other charitable foundations.

FundFinder simplifies the search for financial assistance by instantly notifying users when the funding they need becomes available. It's also the first free app of its kind to serve the general public.

In addition to providing information on available patient assistance from the PAN Foundation, FundFinder tracks program availability from seven other charitable foundations: CancerCare, Good Days, HealthWell, Leukemia and Lymphoma Society, Patient Advocate Foundation, Patient Services, Inc. and The Assistance Fund.

On the day FundFinder launched, over 1,200 users signed up for the app—demonstrating the demand for a tool of this kind.

## Signing up for Real-Time Alerts

After creating an account, users can subscribe to email or text message notifications and select specific disease funds to follow. When a followed fund opens, users receive an alert indicating which foundation has available funding. The app is updated hourly, and users can access the free app from any web browser, tablet or smartphone by visiting [fundfinder.panfoundation.org](http://fundfinder.panfoundation.org).

Since its launch in December 2018 into the first quarter of 2019, FundFinder sent 25,847 email and 8,808 text message alerts of available patient assistance to over 7,500 users.

At PAN, our daily work is devoted to ensuring that we can offer some form of support to all who come to us for assistance—whether through a PAN grant or referral to another organization that may be able to help. For our team, FundFinder is a vital part of our mission, allowing us to make strides toward our vision of a nation where everyone can access the healthcare they need.

We're committed to developing new resources to streamline the workflow of healthcare providers and pharmacists so that they can more efficiently connect their patients with the care they need. Most importantly, we're humbled to help patients simplify their own search for financial assistance so that they can worry less about the cost of treatment and focus more on improving their health and well-being.

# EDUCATING AND ENGAGING NEW SUPPORTERS

In 2018, we took community-building efforts to the next level.

To reach new supporters and engage a larger community around the issue of underinsurance, we launched an educational and awareness campaign about the adverse impacts of out-of-pocket costs on patients and families, reaching over 100,000 people—many of whom were learning about the PAN Foundation's mission for the first time.

## You Decide: Fair or Unfair?

To propel awareness and education around the issue of underinsurance and access to healthcare, we launched an online quiz in October 2018 that asked people to read the facts about the impact of cost sharing on families and decide—is it fair or unfair?

Each question illustrates how common it is for people to struggle with the financial burden of the medications prescribed for treatment. For example, after learning that 50 percent of cancer survivors did not adhere to their prescription medication due to the cost, quiz takers had to decide whether it was fair or not. We invite you to take the quiz and decide for yourself.

Through the quiz, we started cultivating a community of people around the country with concerns about and interest in helping those impacted by the tremendous financial challenges from accessing medical treatment.

## Real Stories

We also invited people to both share their own experiences and read the accounts of others who have faced the financial hardship of a life-threatening, chronic or rare disease on our online message wall. More than 4,000 people shared their personal stories and how PAN impacted their lives. Here is just a sample of the thousands we received:

"I have idiopathic pulmonary arterial hypertension and one of the drugs prescribed to manage this condition costs about \$10,000 per month. Even with Medicare Part D, I would never be able to afford the monthly co-pay without assistance from the PAN Foundation. With great medical care and the PAN Foundation, I can avoid frequent hospitalizations and live a normal life."

**—Jackie, a PAN grant recipient living with pulmonary arterial hypertension**

"I could not afford the inhalers to treat my asthma even with my company's insurance. Thank god for PAN! They helped me get the inhalers I need so I can breathe easier and not miss any work. Thank you for all the help you do for those that need it."

**—Maria, a full-time caregiver and PAN grant recipient living with asthma**

"My job is to make sure patients are able to obtain the oral chemotherapy they desperately need. Usually the first thing they say is, 'If it's too expensive, I'll just have to go without it.' With the vital help of PAN Foundation grants, I have seen patient after patient be able to take the chemotherapy medicine. They see their children marry or their grand kids graduate. They celebrate birthdays and anniversaries. They get to live with cancer, not die with cancer. Thank you for making this possible!"

**—Diane, a pharmacy technician in an oncology practice**

We were overwhelmed by the outpouring of stories about these key issues and are grateful for this new coalition of supporters who are truly concerned for the people affected.

Our vision is to bring these issues to life, demonstrate the consequences for everyday people throughout our country, and activate those who are ready to make a difference. In the year ahead, we'll continue to find new ways to engage and educate the public and develop support for the millions of people who find themselves underinsured and in need of patient assistance.

# BOLSTERING OUR BEST-IN-CLASS COMPLIANCE PROGRAM

Thoughtful and strict adherence to legal and regulatory guidelines is vital to our mission.

The PAN Foundation's commitment to compliance allows us to continue connecting thousands of people with the healthcare they need, while demonstrating program integrity and effectiveness in a variety of ways, including:

- Providing assurance to enforcement and regulatory agencies that we are committed to preventing improper and unethical behavior and have sufficient safeguards in place.
- Demonstrating to our donors, partners and the public that our culture is one of integrity, ethics and good corporate citizenship.
- Providing necessary information to our Board of Directors so that they can exercise their oversight responsibilities.

## Compliance Overview

Over the past year, PAN has enhanced its compliance program. Our ongoing compliance initiatives are intended to support an ethical culture, promote effectiveness and ensure that we meet all legal requirements and specifications set forth in PAN's original Advisory Opinion and subsequent modifications, issued by the Office of Inspector General in the U.S. Department of Health and Human Services.

PAN's compliance program incorporates all seven elements identified by the government as necessary for a comprehensive and effective program. As directed and overseen by the Audit, Risk Oversight and Compliance Committee of PAN's Board of Directors, these elements include:

- Compliance program organizational structure and oversight
- Written compliance guidance
- Compliance education and training
- Lines of communication\*
- Disciplinary and enforcement standards
- Auditing and monitoring
- Investigation of complaints, response to detected offenses and corrective actions

\*Includes PAN's compliance hotline (1-866-580-6442), where complaints can be made, and issues raised on a confidential and anonymous basis.

Read more about these program elements in our Compliance Program Summary.

## Compliance Leadership and Communications

In September 2018, PAN's President and CEO Dan Klein and Chief Compliance Officer Tom Herrmann led a discussion on best compliance practices for independent charity patient assistance programs. The session was part of CBI's Patient Assistance Program Legal Update Conference.

Speaking to pharmaceutical company representatives, pharmacy benefit managers, patient assistance advocates and legal experts, Mr. Klein and Mr. Herrmann discussed how independent patient assistance programs can develop and implement an effective compliance structure.

"PAN is committed to helping as many patients as

possible get access to the care they need, while at the same time providing a safe harbor for our donors in adherence to all legal and regulatory guidelines," President and CEO Dan Klein said to participants.

PAN's compliance efforts were also nationally recognized in an article written by Mr. Herrmann and published in Compliance Today in November 2018 titled, "Effective Compliance for an Independent Charity Patient Assistance Program." An excerpt:

"A compliance program needs to be responsive to the mission, structure and culture of an organization while also addressing the seven core elements referenced by the Federal Government. In addition, it should address the identified risk areas and be responsive to the needs of all stakeholders (e.g., government, donors, patients, physicians, pharmacists, contractors). ...there is 'no one size that fits all organizations.' However, a compliance program should address the seven core elements and 'foster a culture of compliance that begins at the executive level and permeates throughout the organization.'"

## Culture of Compliance

PAN's comprehensive program is intended to ensure compliance with all applicable laws, regulations and government guidelines, as well as adherence to the specifications set forth in the OIG Advisory Opinion 07-18 (as modified). Relevant to all stakeholders—donors, patients, providers, pharmacies, Board members, employees and contractors—it's designed to foster a culture of compliance that begins at the executive level and permeates throughout the organization.

# ADVOCATING ON BEHALF OF PATIENTS

**Being insured does not guarantee access  
to affordable healthcare.**

That is the reality for millions of patients today who face high out-of-pocket costs for their prescription medications. High-deductible health plans and the Medicare prescription Part D benefit design force people to pay thousands of dollars before they can fill their prescriptions and begin treatment.

While the safety net provided by the PAN Foundation and similar charities serves a critical need today, long-term, we believe there are strategies that can significantly help patients lower their out-of-pocket prescription medication costs.

That is why a vital part of our mission is to advocate on behalf of patients for legislative and regulatory change that will lower these costs and help people access their treatment without delay.

## Our Guiding Positions

The following position statements guide our work in advocating for increased access to healthcare for underinsured patients.

- Out-of-pocket costs should not prevent individuals with life-threatening, chronic and rare diseases from obtaining their prescribed medications.

- Out-of-pocket costs for prescription medications should be spread more evenly throughout the benefit year.
- Out-of-pocket costs for prescription medications should be capped through the use of monthly and/or annual limits.
- Value-based insurance designs that increase access to treatment for individuals living with life-threatening, chronic and rare diseases should be encouraged.
- All conditions should have at least one highly-effective innovator drug on a fixed co-payment tier.
- High front-end deductibles create barriers that can prevent access to treatment for many individuals with life-threatening, chronic and rare diseases.
- Co-pay accumulators or similar programs lead to greater out-of-pocket costs for individuals with life-threatening, chronic and rare diseases and should be prohibited.

## Advocacy Highlights

In 2018, PAN collaborated with stakeholder groups to explore the impact of out-of-pocket costs on patients and to discuss potential policy solutions. Additionally, we took new steps to educate people about the impact of these costs, while providing tips on how to better manage and plan for them.

## Cost-Sharing Roundtable

We hosted the third annual Cost-Sharing Roundtable in collaboration with the American Journal of Managed Care. The day-long event brought together thought leaders from the private and public sectors to discuss policy solutions and resulted in a final report. Read the Executive Summary and access the full report [here](#).

## Response to the Administration's Blueprint to Lower Drug Prices

In June 2018, with support from 52 patient advocacy groups, PAN submitted a letter to the U.S. Department of Health and Human Services in response to its Blueprint to Lower Drug Prices and Reduce Out-of-Pocket Costs Request for Information.

Collectively, we agreed that far too many people abandon prescriptions at the pharmacy after learning what they owe out-of-pocket. Our letter asserted that until all patients have affordable access to necessary therapies, patient assistance programs must continue the critical work of providing needed financial support to those who require costly medications to maintain or regain their health, well-being and quality of life. See the press release and full letter [here](#).



# ADVOCATING ON BEHALF OF PATIENTS *(cont.)*

Being insured does not guarantee access  
to affordable healthcare.

## Issue Briefs

PAN published a series of issue briefs—in-depth explainers on timely topics related to out-of-pocket costs—to serve as a resource for advocacy groups and thought leaders. From challenges surrounding access to specialty medications to introducing a cap for Medicare Part D beneficiaries' out-of-pocket costs, these briefs break down complex issues in cost sharing and benefit design. Access the issue brief series [here](#).

## Patient Resources

Our healthcare system is complicated and difficult to navigate. Far too often, patients, caregivers and family members are at a loss understanding terminology, insurance design and even where to turn for help. In 2018, PAN took several steps to help fill this information gap:

- We developed factsheets to help patients understand complex aspects of the healthcare system, exploring topics like the structure of high-deductible health plans and co-pay accumulator programs and providing resources to learn more.
- We collaborated with the National Council on Aging to provide information about navigating Medicare Open Enrollment. The article was published by more than 1,000 local and national media outlets, reaching 161 million people.

- President and CEO Dan Klein participated in an extensive media tour sharing tips on how to manage out-of-pocket costs for prescription medicines in 30 radio interviews on stations around the U.S.

## Our Commitment to Solutions for Patients

In 2018, we saw increased attention from policymakers on the need to lower drug prices and reduce out-of-pocket costs for patients, especially those needing access to specialty medications. This attention has highlighted the urgency with which policymakers need to address these complex problems of our healthcare system.

We will continue our work with stakeholder groups to ensure patients can access the medications they need and ultimately, experience lower out-of-pocket costs at the pharmacy counter.



# FINANCIALS

Thoughtful and strict adherence to legal and regulatory guidelines is vital to our mission.

In 2018, the PAN Foundation reported

**\$530.7**million

in contributions and assisted

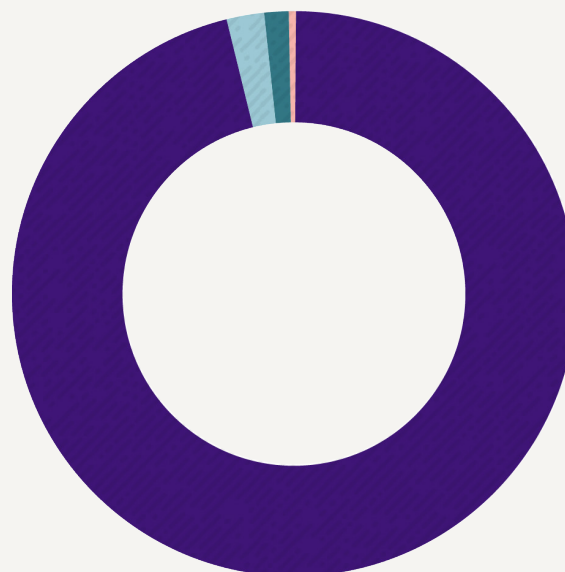
**182,615**  
patients

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 180,000 patients through nearly 70 disease-specific assistance programs during 2018.

For more detailed information and to view our 990 tax return and financial statements in their entirety, visit our financials on the PAN website.

Total 2018 Expenses



- Fundraising: **0.2%**
- Administrative: **1.5%**
- Other program expenses: **2.1%**
- Co-pay expenses: **96.2%**

In 2018, the PAN Foundation recorded total expenses of \$364.6 million. Here is a total breakdown of our 2018 expenses:

- 96.2 percent of these expenses is associated with co-pay assistance.
- 2.1 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 nine 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.

 PAN Foundation