The help you need

2015 Annual Report
I am thrilled to report that 2015 marks a year of continued growth for the Patient Access Network (PAN) Foundation. For 11 years, PAN has been committed to helping people with life-threatening, chronic and rare diseases to get the medications and treatment they need by paying for their out-of-pocket costs and advocating for improved access and affordability.

According to the Commonwealth Fund’s most recent Biennial Health Insurance Survey, more than 31 million people in America were underinsured in 2014, a number that has nearly doubled since 2003. And PAN is all too familiar with this epidemic. People come to PAN because they are struggling to pay for their critical medical treatments, and the PAN team provides them with exemplary service, in a cost-effective manner.

As patients’ insurmountable out-of-pocket costs continue to be a growing issue in our country, PAN’s role in the health care system is becoming more and more crucial.

And in helping people to start and stay on their prescribed therapies, PAN not only enables them to improve their health, we help them to continue doing what they love most.

In the features ahead, you will see a sampling of this work, including how PAN assisted flamenco dancer Juan Talavera with obtaining his life-saving cancer treatment so that he could continue performing, and how PAN makes Patient Financial Coordinator Marie Ealy-King’s job a little easier as she helps her patients access their critical medications. Finally, you will read about one of our most successful alliances to date: our work with the American Lung Association to provide people living with asthma, non-small cell lung cancer and respiratory syncytial virus with the full range of resources they need to best manage their conditions.

As a clinician, I aim to find ways to overcome the barriers that stand between people living with serious diseases and their treatment. That’s why I am proud to serve on the board of an organization that makes eliminating these hurdles a priority. In addition to steadfastly seeking opportunities to open new disease funds to broaden the assistance we offer to patients, PAN continually improves its technology to expedite the application process for patients and providers applying on their behalf. PAN strives to be the stop on patients’ journey that puts them at ease, a place that enables them to stop worrying about paying for their treatment and begin focusing on improving their health. Working together with our donors, health care providers, pharmacists and alliance partners nationwide, we ensure that patients do not miss their window of opportunity to get better.

On behalf of my fellow board members, thank you for all that you do to help our patients.

Donald A. Barone, DO
Chairperson, PAN Foundation Board of Directors
About the PAN Foundation

Overview

Our Mission and Vision

Our Staff and Board of Directors

PAN Foundation :: 2015 Annual Report
Today, more people in the U.S have health insurance than ever before. Yet, increasing numbers of people with health insurance struggle to pay for the out-of-pocket costs required by their health plans. This situation is often referred to as being “underinsured,” and it affects tens of millions of people at nearly all income levels. People with life-threatening, chronic and rare diseases who need specialty medications are especially hard hit by high out-of-pocket costs.

With the generous support of our donors, the tireless efforts of our health care provider and pharmacist colleagues, and the comprehensive services our alliance partners provide, the PAN Foundation provides a vital safety net for underinsured people with life threatening, chronic and rare diseases who cannot afford the out-of-pocket costs of their critical medications.

In 2015, we provided more than $900 million in financial assistance to nearly 230,000 patients. These unprecedented numbers reflect the growing challenge faced by people with life-threatening, chronic and rare diseases to pay for the high deductibles, co-payments and coinsurance that are now commonplace in Medicare and Qualified Health Plans. And we kept our primary focus in the forefront: providing underinsured patients with access to their critical medications. In 2015 alone, we opened or expanded five disease assistance programs for patients living with: arrhythmia with atrial fibrillation or atrial flutter, heart failure, HIV, idiopathic thrombocytopenic purpura and ovarian cancer.

But we know people who apply for assistance from PAN need support beyond co-payment assistance, be it disease-specific information, a link to a compassionate community that can help them deal with the physical and emotional complexities of their disease, educational materials, insurance navigation or case management services. That’s why we have made it our standard practice to partner with leading patient advocacy groups to provide patients with holistic support. In 2015, we launched new alliances with the American Lung Association, the American Liver Foundation and the National Multiple Sclerosis Foundation to ensure we continue to advance that goal.

We are proud of the work PAN accomplished in 2015, but we recognize that we couldn’t have done it alone. On behalf of the entire PAN team, I want to thank our donors and tremendous partners and colleagues in the health care provider, pharmacy and patient advocacy communities. You play an invaluable role in ensuring that people living with life-threatening, chronic and rare diseases are able to begin or continue their medical treatment and focus on what’s most important – their health. We look forward to continuing to work with you in 2016.

Dan Klein, President and CEO
PAN’s Assistance Programs

Acromegaly
Arrhythmia in Patients with Atrial Fibrillation or Atrial Flutter
Asthma
Auto-Immune Diseases
Ankylosing Spondylitis
Plaque Psoriasis
Psoriatic Arthritis
Rheumatoid Arthritis
Basal Cell Carcinoma
Bone Metastases
Chemotherapy-Induced Nausea and Vomiting*
Chronic Iron or Lead Overload
Chronic Lymphocytic Leukemia
Colorectal Cancer
Cushing’s Disease or Syndrome
Cutaneous T-Cell Lymphoma
Diabetic Foot Ulcers

Gaucher Disease
Heart Failure
Hepatitis C
HIV Prevention and Treatment
Homozgyous Familial
Hypercholesterolemia Premium Assistance
Hypercholesterolemia
Hyperkalemia
Idiopathic Thrombocytopenic Purpura
Idiopathic Thrombocytopenic Purpura Co-Pay Assistance
Idiopathic Thrombocytopenic Purpura Travel Assistance
Inflammtory Bowel Disease (Crohn’s Disease and Ulcerative Colitis)
Macular Diseases
Mantle Cell Lymphoma

Melanoma
Metastatic Breast Cancer
Metastatic Prostate Cancer
Metastatic Prostate Cancer Co-Pay Assistance
Metastatic Prostate Cancer - Travel Assistance
Multiple Myeloma
Multiple Sclerosis
Myelodysplastic Syndromes
Myeloproliferative Neoplasms (Myelofibrosis, PV, ET)
Neuroendocrine Tumors of Pancreatic Origin
Neutropenia
Non-Hodgkin’s Lymphoma
Non-Small Cell Lung Cancer
Ovarian Cancer
Parkinson’s Disease

Philadelphia Chromosome Positive Acute Lymphoblastic Leukemia
Postmenopausal Osteoporosis
Renal Cell Carcinoma
Respiratory Syncytial Virus
Secondary Hyperparathyroidism
Short Bowel Syndrome
Short Bowel Syndrome Co-Pay Assistance
Short Bowel Syndrome Premium Assistance
Thyroid Cancer
Tuberous Sclerosis Complex
Uveitis
Venous Leg Ulcers
Wilson Disease

* Opened in 2016
Juan Talavera will never forget the first time he met Shirley MacLaine. It was 1966 and he was dancing at an avant-garde nightclub when the famous actress strutted into the room with actor Herbert Lom.

“She wore a beautiful white dress and her make-up and hair were unbelievable,” Talvera says. “She had tennis shoes under her dress because she did not want to wear high heels.”

“Thank God for the Patient Access Network Foundation—they saved my life.”

At the time, Talavera had a role as a dancer in the Academy Award-nominated film “Gambit,” starring both MacLaine and Lom, and Michael Caine, who regularly asked Talavera to teach him dance moves.

And that’s just one of Talavera’s great stories from his days in tinsel town. His mother put him in flamenco lessons at 13 and he hasn’t stopped dancing since. Talavera has worked over 50 years as a professional flamenco dancer, teacher, choreographer and actor both in films and television series, like “Run for Your Life,” where he was Fernando Lamas’ stunt double.
PATIENT STORY

“I wasn’t supposed to get cancer—it wasn’t in my plans. But, I did. That’s life in the big city.”

“The shoes they gave me to dance in belonged to John Wayne!” he boasts about his time on the series.

Mr. Talavera, a self-described “health freak” says that Flamenco has been a way of life for him. So when he learned in September 2015 that he had colorectal cancer, it came as a shock.

“I wasn’t supposed to get cancer—it wasn’t in my plans,” Talavera says. “But, I did. That’s life in the big city.”

But a dancer always lands on his feet. A month after surgery to remove the cancer, Talavera began rehearsing again.

“I told myself I have to start getting my center back, my rhythm back,” Talavera says.

His only concern was how he would afford the out-of-pocket costs of his multiple prescriptions.

But, when a staff member at his oncology office suggested he reach out to the PAN Foundation, Mr. Talavera decided to take a chance and applied for financial assistance. He was thrilled to find out he was accepted.

“Thank God for the Patient Access Network Foundation—they saved my life,” he says. “Thanks to them, I am able to afford these very expensive chemotherapy pills.”

Mr. Talavera has three sons and seven grandkids, all of whom he says have a great musical ear and rhythm. But it’s his nine-year-old grandson who he thinks might carry on the Flamenco legacy.

“I could see in the mirror that he was watching my feet the whole time I was showing him moves,” Talavera says.

In the meantime, Talavera has plans to star in Hollywood show this summer. The doctors have declared him cancer free.

“Click here to see Talavera in the 1966 film "Gambit."
95% of donations go directly toward helping patients.
When she started as a financial floater at CARTI, Arkansas’ largest private practice, not-for-profit cancer care provider, Marie Ealy-King did not expect to find her dream job. She worked in billing, coding and front office management until the part-time patient financial coordinator transferred to another position. Ms. Ealy-King jumped into that role, and quickly found her passion.

As the patient financial coordinator, she steps in when patients are at their most vulnerable, and helps them decrease the burden of their out-of-pocket costs for their treatment.

“Patients are naturally overwhelmed with emotion when dealing with a cancer diagnosis, and cost is the last thing they should worry about,” Ms. Ealy-King says.

It is a role in which she excels. As the only patient financial coordinator within CARTI, Ms. Ealy-King single-handedly manages all patient assistance needs.

“Many patients are angry or in shock over their diagnosis, and they just need to be heard. So I take extra time to listen to them,” she says.

“The Heart at the Other End of the Phone

“PAN is the most reliable patient assistance organization. It’s the first place I go when I’m trying to help my patients.”
She manages patients’ needs with ease and warmth, earning her the nickname “the heart at the other end of the phone” from coworkers.

CARTI offers state-of-the-art cancer treatment for more than 22,000 patients each year throughout Arkansas. The practice is growing, and with it is the number of underinsured patients. Ealy-King estimates that almost half of the patients at CARTI are underinsured.

“Many times patients are speechless. They are amazed that such a program exists, and they can’t believe someone will help them,” she says. “On a few occasions I’ve had patients call me back just to make sure that this was real. They honestly didn’t believe it could be true.”

On one occasion, Ms. Ealy-King called a patient recently diagnosed with Non-Hodgkin’s Lymphoma to inform her that she would receive PAN assistance.

“When I spoke to her, she was on the other line with her doctor saying that she couldn’t get treatment because she couldn’t afford it,” she recalls. “She felt she had no other alternative, and at that very moment she was informing her doctor that she had to refuse the therapy she needed. Needless to say, she was elated when I told her PAN could help.”

“Simply put, PAN makes my job easier,” Ms. Ealy-King says. “The portal is quick and easy to use. But most importantly, PAN is the most reliable patient assistance organization I’ve come across. It’s the first place I go when I’m trying to help my patients.”
We helped nearly 230,000 patients get the medical treatment they need.

We opened 5 new assistance funds.

We provided $940,459,500 in co-pay assistance.
The team at the American Lung Association (ALA) National HelpLine knows that patients need more than medical treatment for their conditions—sometimes, they just need to talk.

When the National HelpLine was created in 1999, it was staffed by just two registered nurses and a respiratory therapist.

Today, a team of 21 specialists run the HelpLine, which serves as a free resource for lung health information, prevention guidance, tobacco cessation, lung disease control and outcomes and more. The information from this trusted resource is valuable, but HelpLine specialists say many callers just need someone to listen.

“Some patients or caregivers call because they may not have outside support, and they just want to talk with someone who understands what they are going through.”

Other callers have questions about their prognosis, or the financial implications of their treatment.

“Patients are bombarded with so much information at their doctor’s office. They walk out feeling overwhelmed, and they’ve heard maybe 40% of the discussion,” Davis says.

She and her colleagues at the HelpLine work to fill in the gaps and help patients by answering any questions they may have.

“We assure the patients and caregivers that we’re here—they can call us anytime, and I think that means a lot.”

Cheryl Davis

R.N. and HelpLine Specialist

Care Beyond the Doctor’s Office

The team at the American Lung Association (ALA) National HelpLine knows that patients need more than medical treatment for their conditions—sometimes, they just need to talk.
While ALA launches many short-term projects, the alliance with the PAN Foundation is here to stay.

“We assure the patients and caregivers that we’re here—they can call us anytime, and I think that means a lot,” she says.

In partnering with the PAN Foundation, ALA has connected even more patients and caregivers with these important resources.

“Within the first nine months of our partnership, we had served 3,770 patients referred directly by PAN,” says Cherylee Bridges, registered nurse and Operations Manager at HelpLine. “About 30% of these callers wanted additional disease information, and about 7% wanted other support regarding their illness.”

Many of the patients referred to the HelpLine from PAN are living with lung cancer, and want to better understand why their doctor chose a particular treatment, or learn what side effects they should expect from that treatment.

“Most of the callers are incredibly grateful that we have followed up with them. They are happy to know that there is another resource available, and a place they can turn if they walk out of a doctor’s visit and forget to ask a question,” Davis says.

While ALA and PAN were separate entities, we may have received a referral or two by chance,” says Michael Mark, Senior Vice President of HelpLine services. “The marriage of these two organizations has created a larger, more comprehensive network of services for the patients who need them most. In managing and treating lung disease, the financial aspects can be just as important as the medical side. Our alliance brings these trusted services together for patients.”

“Within the first nine months of our partnership, we had served 3,770 patients referred directly by PAN.”

“We assure the patients and caregivers that we’re here—they can call us anytime, and I think that means a lot,” she says.
The PAN Foundation ranked #18 on Forbes’ 50 Largest U.S. Charities 2015 list.

We created alliances with six large patient advocacy organizations to ensure patients get more holistic care.

Together with AJMC, we launched our inaugural call for papers, “The PAN Challenge: Improving Patient Access to Critical Therapies.”
In 2015, the PAN Foundation reported contributions of $801 million, an increase of 22 percent over its 2014 total.

These contributions enabled the PAN Foundation to provide assistance to nearly 230,000 patients through more than 50 disease-specific assistance programs during the course of the past year.

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

In 2015, the PAN Foundation recorded total expenses of $967,928,679*, an 89.3 percent increase over the previous year. Looking closer at the PAN Foundation’s 2015 expenses:

- 97.2 percent, or $940 million, 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 0.6 percent* and 0.1 percent of total expenses, respectively; and
- 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.
Contributions made it possible for the PAN Foundation to provide assistance to nearly 230,000 patients through more than 50 disease-specific assistance programs during the course of 2015.