



# The help you need

2016 Annual Report

# Reaching Milestones in Assisting People With Life-Threatening, Chronic and Rare Diseases



It is my pleasure to report that 2016 was a year filled with new successes for the PAN Foundation. Now in its twelfth year, the PAN Foundation continues to soar in its niche industry of charity co-pay assistance organizations. In 2016, we provided more than \$785 million in assistance to nearly 421,500 patients.

We continue to offer nearly 60 disease funds that not only give patients access to necessary medical treatments, but also peace of mind that the out-of-pocket costs of those treatments will be covered. In 2016, we opened three new disease programs: Hyperkalemia, Hypercholesterolemia and Chemotherapy-Induced Nausea and Vomiting.

Read on for stories that highlight the work we do and the partners who help us do it, including alliance partner Catherine L. Ormerod, MSS, MLSP, Vice President, Programs and Partnerships at Living Beyond Breast Cancer, and PAN healthcare provider Lisa Sanford, Specialty Medication Reimbursement Coordinator at the Wichita Urology

Group. We're proud to be able to help patients like Christine Gamrat, the focus of our annual patient story. Christine's perseverance after a double blood cancer diagnosis, and her son's commitment to increasing awareness throughout the community are truly an inspiration.

In 2016, we expanded our network of patient advocacy groups, deepening the support and services we provide to patients. We formed ten new alliances with major organizations from Prevent Blindness to Us TOO International Prostate Cancer Education & Support, the National Parkinson Foundation to the National Kidney Foundation. These partnerships help us connect PAN patients and their families with the holistic support they need to understand their illnesses and treatment options, as well as connect with their peers.

As a practicing clinician for over 35 years, I am aware of the increasing challenges patients face in accessing the treatments they need for chronic, life-threatening and rare diseases. The health

insurance marketplace only grows more complex, and unfortunately the path ahead is unclear. That's why organizations like PAN play an essential role in ensuring a safety net for the millions of Americans who struggle to get the treatment they need.

On behalf of my fellow Board members, thank you to our donors, alliance partners and network of pharmacies and healthcare providers, for your support in 2016. We look forward to more great things in the years ahead.

With deep gratitude,

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

**Donald Barone, DO,**  
**Chairperson, Board of Directors**



# CONTENTS



**2 From the  
Chairperson**



**4 About the PAN  
Foundation**



**5 From the  
President  
and CEO**



**6 Our Assistance  
Programs**



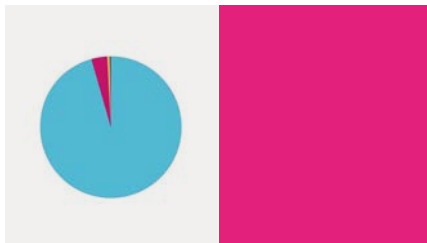
**8 Patient Story:**  
*A Community  
Comes Together  
to Raise Cancer  
Awareness*



**11 Provider Story:**  
*Going the Extra  
Mile for Patients  
in Need*



**14 Advocate  
Story:** *Living  
Beyond Breast  
Cancer*



**17 Expenses and  
Contributions**





Overview



Our Mission and Vision



Our Staff and Board of Directors



# Protecting the Safety Net for Seriously Ill Patients

With the U.S. House of Representative's recent passage of the amended American Health Care Act (AHCA), individuals with life-threatening, chronic and rare diseases are growing increasingly concerned about whether they will have adequate coverage for the specialized care and medications they need. Should the AHCA become law, the Congressional Budget Office estimates that 23 million more Americans will be uninsured by 2026.

Today's health system is far from perfect, but it provides some form of insurance for most Americans. Many people—especially those with serious illnesses—still struggle with access and affordability issues because of limited networks, restricted formularies and high out-of-pocket costs. But Medicaid, Medicare, state exchanges and employer-based health plans generally meet most individuals' needs.

In addition, drug manufacturer-sponsored patient assistance programs and independent charitable foundations provide an important safety net for the uninsured and underinsured. These programs help thousands of seriously ill patients receive the care they need by either providing free medications or by paying for a portion of their out-of-pocket costs. Yet, the uncertainty about what will happen with the healthcare system over the next months and years is making it difficult to predict how many people with serious illnesses will need assistance, and how much support will be available.

The importance of a strong safety net for patients with life-threatening, chronic and rare diseases is not going to diminish any time soon. And high out-of-pocket costs, narrow provider networks and restricted formularies are likely to disproportionately impact these patients under the AHCA—just as they have under the ACA.

Until there is a systemic fix to the problem of underinsurance, we must continue to work together to ensure that patient assistance programs, in particular those operated by charitable foundations,

can continue to assist patients struggling with high out-of-pocket costs. Since 2004, the U.S. Department of Health and Human Services Office of Inspector General has authorized independent charitable co-payment foundations to provide patients with assistance and has allowed pharmaceutical manufacturers to provide such organizations with financial support, in compliance with strict federal regulations. Without the safety net provided by charitable foundations, each year, hundreds of thousands of seriously ill patients would not be able to get the care they need.

We are proud of the strides PAN made in 2016. And we know that our work would not have been possible without the support of our generous donors and remarkable healthcare provider, pharmacy and patient advocacy partners. But our job is far from done. We look forward to continuing to work with you in 2017 to ensure that—together—we are doing everything we can to preserve the safety net for the patients who need it most.



Dan Klein, President and CEO



# PAN's Assistance Programs

Acromegaly	Gaucher Disease	Melanoma	Philadelphia Chromosome
Arrhythmia in Patients with Atrial Fibrillation or Atrial Flutter	Heart Failure	Metastatic Breast Cancer	Positive Acute Lymphoblastic Leukemia
Asthma	Hepatitis C	Metastatic Prostate Cancer	Postmenopausal Osteoporosis
Auto-Immune Diseases	HIV Prevention and Treatment	Metastatic Prostate Cancer Co-Pay Assistance	Renal Cell Carcinoma
Ankylosing Spondylitis	Homozygous Familial	Metastatic Prostate Cancer - Travel Assistance	Respiratory Syncytial Virus
Plaque Psoriasis	Hypercholesterolemia Premium Assistance		Retinal Vein Occlusion
Psoriatic Arthritis	Hypercholesterolemia*		Secondary Hyperparathyroidism
Rheumatoid Arthritis	Hyperkalemia*		Short Bowel Syndrome
Basal Cell Carcinoma	Idiopathic Thrombocytopenic Purpura	Multiple Myeloma	Short Bowel Syndrome Co-Pay Assistance
Bone Metastases	Idiopathic Thrombocytopenic Purpura Co-Pay Assistance	Multiple Sclerosis	Short Bowel Syndrome Premium Assistance
Chemotherapy-Induced Nausea and Vomiting*	Idiopathic Thrombocytopenic Purpura Travel Assistance	Myelodysplastic Syndromes	Thyroid Cancer
Chronic Iron or Lead Overload	Inflammatory Bowel Disease (Crohn's Disease and Ulcerative Colitis)	Myeloproliferative Neoplasms (Myelofibrosis, PV, ET)	Tuberous Sclerosis Complex
Chronic Lymphocytic Leukemia		Neuroendocrine Tumors of Pancreatic Origin	Uveitis
Colorectal Cancer		Neutropenia	Venous Leg Ulcers
Cushing's Disease or Syndrome		Non-Hodgkin's Lymphoma	Wilson Disease
Cutaneous T-Cell Lymphoma	Macular Diseases	Non-Small Cell Lung Cancer	
Diabetic Foot Ulcers	Mantle Cell Lymphoma	Ovarian Cancer	
		Parkinson's Disease	



\* Opened in 2016





Every day, the PAN Foundation helps thousands of people living with life-threatening, chronic and rare diseases who have health insurance, but are unable to afford the out-of-pocket costs associated with their critical medical treatments.



# Christine Gamrat

*Grantee*

## A Community Comes Together to Raise Cancer Awareness

**A**s the game finished and the sun began to set on a warm September evening in 2012, Coach Widdows walked to center field and introduced this year's Sterling Heights High School Cancer Awareness Football Game honoree, and presented her with a jersey with her name on it: Christine Gamrat, his mother.

Gamrat, of Oakland Township, MI, was diagnosed with multiple myeloma in April 2011. The following year, as she prepared for her autologous stem cell transplant, she received another shocking blow—a second blood cancer diagnosis, chronic myeloid leukemia. Stunned, Gamrat and her family quickly adjusted to their new reality, and her doctors adapted her treatment plan. No longer a candidate for the autologous transplant, Gamrat received an allogeneic transplant, which put her chronic myeloid leukemia into remission.

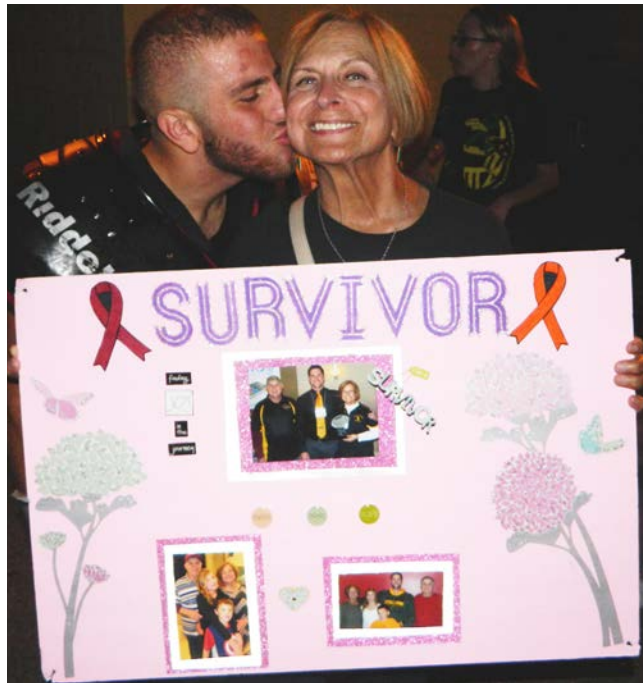
**“It’s amazing to know that you can get your medications and work on staying as healthy as possible, and not have to worry about selling things off.”**

Managing her multiple myeloma proved very difficult once Gamrat switched from her husband’s insurance to Medicare.





PATIENT STORY



“We couldn’t believe how little insurance would cover. There was no way we could pay that month after month,” says Gamrat. “I was very anxious, but my husband assured me that we would find a way.”

Gamrat’s local Gilda’s Club referred her to the Patient Access Network Foundation. Once enrolled, Gamrat and her family felt that a weight had been lifted. “It was a relief, physically and emotionally. It’s amazing to know that you can get your medications and work on staying as healthy

as possible, and not have to worry about selling things off,” Gamrat says. “It helps the body heal better.”

Family and friends rallied around Gamrat, and she leaned on them for support. Her son, Sterling Heights High School football coach Brent Widdows, felt a drive to increase cancer awareness by honoring both his mother, and football player Brian Thomas.

Team captain and starting quarterback Brian Thomas was diagnosed with oligodendroglioma, cancer of the upper spine, in his junior year. He lost his battle a year later. To honor his memory, Coach Widdows retired Thomas’ jersey number, 6, except for one game every season. Each year for the Cancer Awareness Football Game, Coach Widdows selects a player who has demonstrated leadership and community involvement to wear Thomas’ number. The Thomas family and most of the Sterling Heights community attend the game, and proceeds go to cancer-focused organizations like Alex’s Lemonade Stand.

With the leadership of Coach Widdows and support from the Sterling Heights community, the game has evolved over the years. Each player honors an individual in the community affected by cancer—a current cancer fighter, a survivor or

someone who lost their battle—by wearing a jersey with their name on it, and presenting it to the individual or family after the game.

The Cancer Awareness Football Game has raised over \$10,000 for cancer research and family support services. It is now the biggest game of the season at Sterling Heights High School.

Though her multiple myeloma never went into full remission, these days Gamrat is feeling good and staying busy. When she’s not spending time with her grandchildren, 10-year-old Ella and seven-year-old Caleb, or playing euchre with friends from high school, she can be found outside. “I love working in the yard—weeding, gardening, cutting grass, all of it. That’s my true passion, being outside,” she says.

And every fall, Gamrat adds another activity to her busy schedule—working with Brian’s mother to organize the annual Cancer Awareness Football Game, now in its seventh year.





A close-up photograph of a man with a beard and short dark hair, wearing a white shirt, kissing a young child on the cheek. The child has dark skin, curly hair with a small white bow, and is wearing a green button-down shirt. The child is looking towards the camera with an open mouth, appearing happy. The background is a soft-focus green, suggesting an outdoor setting. The image is framed with a white curved border at the bottom.

# 95%

of each donated  
dollar goes  
directly toward  
helping patients



# Lisa Sanford

*Specialty Medication  
Reimbursement Coordinator*

## Going the Extra Mile for Patients in Need

Crisis can be defined as a lot of different things, but when patients are diagnosed with cancer, that is very hard to process,” says Lisa Sanford, Specialty Medication Reimbursement Coordinator at the Wichita Urology Group in Wichita, Kansas. “Any bit of relief we can provide helps patients through their treatment plan.”

According to Sanford, helping patients who are in a medical crisis is the most rewarding part of her job.

At Wichita Urology Group, Sanford is responsible for authorizing the oncology medication that comes through the office, and helping patients find financial assistance for the out-of-pocket costs of their



treatment. Most of her patients are on Medicare with a fixed income. Sanford is committed to helping patients, and she says PAN has been her go-to resource from the beginning because she wants patients to focus on their medical health and not financial health.

“One patient with prostate cancer who also has memory loss frequently asks if he is responsible for any out-of-pocket cost for his medication,” says Sanford. “He is always thrilled when I tell him he does not owe anything and that his PAN grant has covered the cost.”

“Any bit of relief we can provide helps patients through their treatment plan.”

In a 2016 survey, 99% of patients reported being satisfied with PAN.

Sanford goes the extra mile to help her patients in any way that she can, often completing their application paperwork to ensure they get the help they need.

**“Crisis can be defined as a lot of different things, but when patients are diagnosed with cancer, that is very hard to process.”**

“I do pretty much 99% of the legwork on that end, and then the patients receive co-pay assistance letters and updates,” she says. “We don’t want them to have to worry about enrolling—we are going to take care of that for them.”

With multiple patients who could not afford the out-of-pocket costs of their oral oncology medications without PAN funding, Sanford says that one

of the toughest parts of her job is what she calls “having to be the bad guy.”

“I hope that funding remains available for PAN because we have so many patients in need and the hardest part of my job is telling them there is no more funding and we can’t provide that service, that we have to look elsewhere or that they have to pay out-of-pocket,” she says. “It is just a huge need.”

Sanford says working with PAN allows her and her team at Wichita Urology Group the opportunity to provide their patients with the best treatment available so they can have a better quality of life.

“The better the patients feel, the more active they are, the healthier their mental state is, which in turn reflects their physical state, and it just wouldn’t be possible for some of these patients without the PAN funding.”





Since its founding in 2004, PAN has provided more than **\$2.5 billion** in financial assistance.





# Living Beyond Breast Cancer

## *Alliance Partner*

### Connecting Metastatic Breast Cancer Patients to Resources, Services and Each Other

A breast cancer diagnosis can be overwhelming for both patients and their caregivers. And learning about the disease, treatment and side effects is just the beginning. Offering programs ranging from a peer-to-peer support helpline to Breast Cancer 360s—panel discussions with both web and live audiences—from national conferences to community outreach programs, the team at Living Beyond Breast Cancer (LBBC) has spent the past 26 years helping people living with breast cancer navigate this journey.

“We have a robust offering of programs for people living with breast cancer, their caregivers and loved ones, as well as healthcare providers,” says Catherine L. Ormerod, MSS, MLSP, Vice President,



Programs and Partnerships at LBBC. “We serve people living with breast cancer of all ages and all stages.”

Since the launch of its alliance with PAN in January 2016, LBBC has connected with even more patients, particularly those living with metastatic breast cancer, a disease that affects more than 150,000 people living in the United States. Of the 3,263 patients enrolled in PAN’s Metastatic Breast Cancer Fund through PAN’s call center, 961 patients—approximately one-third—were referred to LBBC for education and support.



“We have information tailored to meet almost every need you can imagine.”



## ADVOCATE STORY



Attendees at a recent LBBC annual Metastatic Breast Cancer Conference.

**In 2016, PAN referred more than 950 patients to LBBC for education and support services.**

“We reach out to people PAN serves and offer our programmatic menu of activities,” says Ormerod. “We provide information and support to help people living with metastatic breast cancer better understand their treatments, and educate them on how to be better engaged with their healthcare provider so they know what questions to ask and feel more confident in doing so.”

Metastatic breast cancer is a particularly complex disease and Ormerod says that people have a wide variety of questions.

“Some people are going through a particularly difficult treatment and want to know more about it and about the side effects; others have emotional or sexuality issues because of treatments,” says Ormerod. “We have information tailored to meet almost every need you can imagine.”

In addition to providing patients with a variety of resources, LBBC gives people living with breast cancer the opportunity to become resources themselves by offering training to participate in its peer-to-peer helpline.

“Talking to someone who is going through the same experience is especially meaningful to the metastatic population, because they will be in treatment for the rest of their lives,” says Ormerod.

Another program, “Hear My Voice,” trains women and men with metastatic breast cancer to take information back to their communities and educate

the public about living with the disease. During the nine-month program, which is held in conjunction with LBBC’s annual metastatic breast cancer conference, participants receive training in the landscape of metastatic breast cancer, different kinds of advocacy in which they can engage, scientific research and clinical trials. Ormerod says LBBC trained more than 50 people in the first year and expects to have trained another 50 by the end of 2017.

**“Talking to someone who is going through the same experience is especially meaningful to the metastatic population, because they will be in treatment for the rest of their lives.”**

Joining forces with LBBC has allowed PAN to link people living with metastatic breast cancer to a wide range of resources and a supportive community.



A photograph of an elderly couple embracing outdoors. The woman, on the left, has short brown hair and is wearing a light gray cardigan over a dark top. She is smiling broadly, showing her teeth. The man, on the right, has white hair and is wearing a blue button-down shirt. He is also smiling and looking towards the woman. They are standing in front of a green lawn and trees, with a soft, warm light suggesting late afternoon or early morning. The image is partially covered by a large orange curved shape at the bottom.

The PAN Foundation  
ranked #16 on  
Forbes' "50 Largest  
U.S. Charities  
For 2016" list.



CONTRIBUTIONS

In 2016, the PAN Foundation reported contributions of \$582.54 million. Since PAN was established in 2004, contributions have consistently represented more than 90 percent of the PAN Foundation’s total support and revenue. Continuing this trend, in 2016, contributions represented 100 percent of this total.

These contributions enabled the PAN Foundation to provide assistance to close to 421,500 patients through nearly 60 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 financial statements in their entirety, please visit [panfoundation.org](http://panfoundation.org).

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

EXPENSES

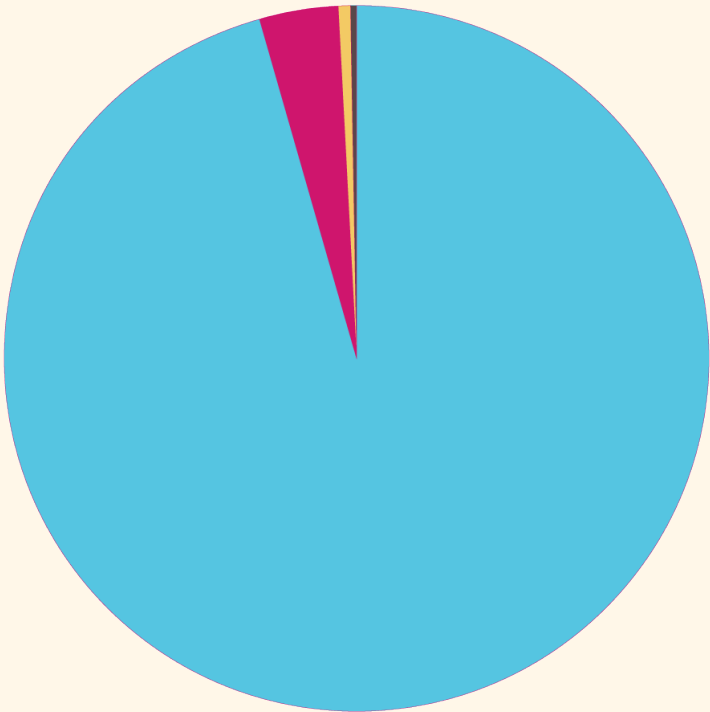
In 2016, the PAN Foundation recorded total expenses of \$820,225,956.\* Below is a more detailed breakdown of the PAN Foundation’s 2016 expenses:

- » 95.7 percent, or \$785 million, of these expenses is associated with co-pay assistance
- » 3.5 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
- » For the last eight years, less than one penny of each dollar contributed to the PAN Foundation has been spent on fundraising

2016 Financials

TOTAL EXPENSES (\$) 2016

\$820,225,956



95.7%  
Co-pay Assistance  
\$784,840,353

3.5%  
Other Program Expenses  
\$20,595,174

0.6%  
Administrative  
\$5,111,177

0.1%  
Fundraising  
\$1,194,500



In **2016**, thanks to contributions from our generous donors, we provided assistance to close to **421,500** patients through nearly **60** disease-specific assistance programs.



# PAN Foundation

