



Patient Access Network
foundation

2011 ANNUAL REPORT

Providing Hope for Patients, Help for Families

Hope for patients, help for families.

Nothing makes you fully grasp the preciousness of good health until you meet someone without it.

It's an unfortunate but undeniable fact that health insurance doesn't always do everything we wish it would do. Being underinsured means not having the resources to pay rising out-of-pocket costs. The linkage between finances and health is still a harsh reality for many of us.

I've had the opportunity to get to know individuals who are struggling with various forms of cancer, serious illnesses like Multiple Sclerosis and Rheumatoid Arthritis and immune system challenges after a major organ transplant. These men, women and, yes, children are fighting with every fiber of their being to beat their illnesses and rediscover healthy lives.

But, sometimes they need a little help.

That's where the PAN Foundation comes in. Our mission, our entire reason for existence, is to provide hope for patients and help for families.

Since PAN was founded, we've been able to help more than 134,000 patients gain access to high cost, life-saving medications they needed to live and to have hope for a healthier future. I'm so grateful for the generosity of individuals, companies and organizations that, together, have enabled PAN to provide over \$187 million in assistance to patients since 2004.

Every single dollar is critical in ensuring that a patient's journey from illness to a healthy life and encouraging future is not interrupted because of financial need.

As vital as this financial assistance is, I'm particularly proud of the way PAN continues to evolve to better meet the needs of the patients we serve. We strive to make certain that our processes ease the burdens of patients and families.

We continue to improve our application processes to make them simple, quick and easily accessible. We have advanced our online pharmacy and provider portals to enroll patients with less paperwork, enabling us to respond to most grant applications within one business day of receipt. By investing in innovative technologies and increasing efficiencies, we are able to keep our administrative costs low. As a result, 90 cents of every dollar donated to PAN goes directly to patient assistance.

We all dream of a day when there won't be such a degree of need for the assistance we provide, a day when there are cures for the diseases that afflict too many of us.

But, until that day comes, thanks to the benevolence of our supporters and the dedication of our talented staff, PAN will continue to fulfill what I consider to be the most vital mission any organization can have.

With deep gratitude,

A portrait of Kim Schwartz, a woman with blonde hair, wearing a blue blazer, looking directly at the camera.
Kim Schwartz
Kim Schwartz
Chair, PAN Foundation

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ABOUT PAN

Patient Access Network (PAN) Foundation offers help and hope to people with chronic or life-threatening illnesses who otherwise cannot afford breakthrough medical treatments.

It's not just the uninsured who face an inability to pay for essential medical care. The harsh reality is that even those with health insurance face threats to their lives and health for financial reasons.

For many insured patients with severe, chronic diseases, rising deductibles and co-pays stand between them and the care they need. Too often, this means the sickest, most vulnerable patients can't take their medications as prescribed or, even worse, refrain from seeking care altogether. Factor in insurance policies that limit or exclude coverage for various health services, and the problem worsens.

The PAN Foundation was established in 2004 to help underinsured individuals and families access the healthcare they so desperately need. PAN provides the solution for those who need help in the present and deserve hope for the future – a future that will include a normal, productive and fulfilling life.

Since its founding, PAN has served as a vital safety net for more than 134,000 underinsured patients, providing the means to pay the out-of-pocket costs that accompany high-cost, life-saving medications for certain cancers, rare diseases and chronic illnesses. Without PAN – and the generous donations from both public and private sectors that are so critical to the Foundation's work – many of these patients would have few, if any, alternatives.

The PAN Foundation is an independent, national 501(c)(3) organization dedicated to providing underinsured patients with co-payment assistance through more than 40 disease-specific funds, giving patients access to the treatments they need.

But that description doesn't begin to tell the story of how PAN interacts with the patients it serves. Through a quick, streamlined application process for patients and easy-to-navigate portals for specialty pharmacies and providers, PAN makes it simple and convenient for eligible underinsured patients to receive cost-sharing assistance – usually within one business day of submitting an application.

The PAN Foundation's caring, highly-trained staff provides responsive, personal service, guiding patients, providers and advocates through processes, providing support and expertise at every step along the way.



"I could not continue taking the medicine that I need without PAN's help."



"Everything was explained clearly, people ever most compassionate and understanding. Someone cared."

"Courteous and knowledgeable representatives provided needed info to apply for [PAN] assistance. [I] would not have been financially able to get needed treatment otherwise."





2011 PAN DISEASE FUNDS

In 2011, the PAN Foundation operated a total of 35 disease funds, providing co-pay assistance grants to oncology, chronic disease and rare disease patients. In doing so, PAN was able to not only provide co-pay assistance for the high-cost, life-saving drug therapies needed to treat these conditions, but also to lessen the associated burden of illness on patients and their families.

The total, cumulative consequence of suffering from any of PAN's 35 diseases goes far beyond the healthcare costs, or the societal cost of providing services related to the delivery of healthcare, alone. It also includes the personal impact of illness on individuals and their families; the economic, social and psychological costs incurred.

Considering all of the factors associated with suffering from and receiving treatment for cancer, chronic disease or rare disease, it is not surprising that all three areas are often associated with a very high burden of illness. In providing help and hope for patients and their families, PAN strives to lessen this burden so that everyone can look forward to a healthier, happier future.



ONCOLOGY

Anaplastic Large Cell Lymphoma
Chronic Lymphocytic Leukemia
Colorectal Cancer
Cutaneous T-Cell Lymphoma
Hodgkin's Lymphoma
Lung Cancer (Non-Small Cell)
Metastatic Breast Cancer
Multiple Myeloma

Myeloproliferative Neoplasms (MF, PV, ET)
Myelodysplastic Syndrome
Non-Hodgkin's Lymphoma
Pancreatic Cancer
Prostate Cancer
Renal Cell Carcinoma
Well-Differentiated Thyroid Cancer



CHRONIC DISEASES

Ankylosing Spondylitis
Crohn's Disease
Cystic Fibrosis
Cytomegalovirus
Diabetic Foot Ulcers
Growth Hormone Deficiency
Hepatitis B
Hepatitis C

Kidney Transplant Immunosuppressants
Wet Age-Related Macular Degeneration
Multiple Sclerosis
Plaque Psoriasis
Respiratory Syncytial Virus
Rheumatoid Arthritis
Secondary Hyperparathyroidism
Solid Organ Transplant Immunosuppressants



RARE DISEASES

Acromegaly
Gaucher Disease
Retinal Vein Occlusion
Uveitis

The PAN Foundation is constantly working to add additional disease funds and expand the number of patients served. There are now over 40 funds in operation, with more being added all the time. For a list of current disease funds and more information, please visit PANFoundation.org.

Giving Quality to Life: A PAN Patient's Story

Suzanne Wolf has lived a rich life, full of simple yet incredibly meaningful pleasures. She is surrounded by family and friends, treasures her children and grandchildren and makes certain her cats receive tender, loving care. She enjoys her outings to art museums and the theater.

Suzanne had a plan for her life. She is passionate about hiking and appreciating nature, so she dreamt of living out her twilight years in Oregon, making trips to national parks throughout the country.

That dream appeared to be shattered when she was diagnosed with breast cancer in 2005.

There is never a good time to be diagnosed with cancer, but this news came at a particularly bad time. Her limited finances were stretched to the breaking point as she cared for her very ill mother and a daughter who was pregnant and confined to bed rest. Suzanne felt very alone as she looked at a difficult fight against a life-threatening disease.

That solitary feeling disappeared when she received a letter in the mail confirming that she had been approved to receive assistance from the PAN Foundation.

"When I opened that letter, my hands were shaking," she said. "I just felt so lucky. My heart was warmed by it. That warmth just spread through me. I couldn't believe that someone would help me. I felt like I had a mysterious benefactor."

Prior to receiving her grant, Suzanne worried incessantly about how she could afford the medications she needed to treat her cancer while still having money for basic household needs.

"My PAN grant was literally a life-saver. Without it, I would have had to ask myself whether I would eat dinner or afford my cancer meds. I wondered if I would have to depend on free food samples from the deli counter at the grocery store for meals. Do I keep the house at 60 degrees in the winter or do I cut my pills in half? I honestly didn't know how I could make the money stretch," she said.

"My PAN grant was literally a life-saver. Without my grant, it would have been a question of 'Do I go to the deli counter and eat free food samples for dinner or do I buy my cancer meds? Do I keep the house at 60 degrees all winter or do I cut my pills in half?'"

Thanks to the assistance she received from PAN, Suzanne was able to afford her medications and all of her food and shelter necessities. For that, she could not be more thankful.

"PAN made it possible for me to have a life. I wish I could thank all of the people who have helped me. I couldn't have done it without each and every one who made that grant possible," she said.

Today, she is paying the generosity forward, working with a disability attorney and helping to shepherd clients through the process of applying for and obtaining social service program benefits. She was inspired by the kindness and generosity of the PAN Foundation and its donors to find a job that would allow her to give back to others in need. As she puts it, "Receiving my PAN grant made me a stronger person. It made me more aware of the importance of charity and giving back to my community."

In fact, receiving the assistance from PAN that enabled her to regain her health and resurrect her dreams has inspired Suzanne to begin making her own financial donations.

"After seeing what a difference someone's generosity made in my life, now I always try to give something, even when I don't have much to spare."



Suzanne Wolf

PAN Patient



Stacy Morton

Medication Assistance Program Coordinator at the Wexner Medical Center at the Ohio State University Department of Pharmacy and the Solid Organ Transplant Program

Every day, I face the challenge of working with underinsured patients to provide needed funding for medication co-payments. I've known individuals whose health could have rapidly deteriorated if not for the help provided by PAN.

My role as a Medication Assistance Program Coordinator is to help patients access financial resources for the medications related to their transplants of solid organs. Transplant patients require lifetime immunosuppressive therapy to prevent rejection of their transplanted organs. These medications are very costly. Even with an insurance paying 80 percent of the cost of immunosuppressive medications, the 20 percent co-pay for the patient is anywhere between \$300 and \$800 a month.

The Priceless Value of Health & Quality of Life: A Provider's Perspective on PAN Services

To say that cost-sharing foundations like PAN are vital is a great understatement.

One patient with a \$5,000 insurance deductible had maxed out her credit cards trying to afford her transplant medications. She took a second job to try to cover the expenses and even contemplated bankruptcy. The stress was taking a terrible toll on her health and she even told her doctor during one clinic visit that she didn't think she could continue her medications.

This patient hadn't applied for any assistance because she thought she made too much money to qualify. I helped her apply for a PAN grant and she received \$4,500 in support through the Solid Organ Transplant Immunosuppression (SOTI) fund. This grant allowed her to meet her insurance deductible and afford her medications and transplant care. *Because of PAN's assistance, she saw a marked improvement in her physical, financial and emotional health.*

I see this type of story often. The PAN Foundation's SOTI and Kidney Transplant Immunosuppression (KTI) grants fill a huge need, allowing our underinsured patients to meet their co-pays and deductibles and avoid an interruption in their post-transplant therapy. Patients frequently tell me how the help they received from PAN has reduced their stress, improved their health and given them a better quality of life. Without these grants, I can tell you that many of our patients would be unable to afford the medications they need.

There has been a significant change in recent years in the profile of patients needing assistance. Four or five years ago, most of the people we helped were those with Medicare plans. Recently, though, we're seeing more patients with non-Medicare insurance needing financial help.

These patients once had very manageable prescription drug co-pay requirements in their insurance plans, but now face extremely large deductibles – sometimes as high as \$5,000 – before insurance will pay a penny toward their medications. People with modest incomes simply can't afford these costs.

That is where PAN comes in. I utilize the PAN Foundation literally on a daily basis to help patients find help through the SOTI and KTI funds. PAN's processes are extremely patient-friendly. Determinations are usually made within one or two days after an application is submitted, and PAN often allows temporary approval for patients who need more time to gather their financial documentation. This quick access is critical for patients who need immediate assistance.

PAN's streamlined and easy-to-use Provider Portal allows providers to send messages and documentation easily, enables tracking and management of patient applications and alerts providers when patients are due to renew their grants. This ensures that patients don't have delays or gaps in their therapy. PAN reimbursement counselors are always professional and responsive in assisting our patients through the application process. This isn't an impersonal operation. The PAN counselors genuinely care about patients, and they go above and beyond to help them.

PAN's assistance is enormously valuable to each patient. A \$4,500 grant allows a patient access not only to the immunosuppressive medications they need, but also offers hope for improved health and quality of life. *This lifeline isn't only priceless for the patients involved, but those of us on the provider side are incredibly grateful to see our patients regain their health and well-being.*

FINANCIALS

In 2011, the PAN Foundation experienced a dramatic 135 percent increase in total contributions, compared to the prior year. These donations accounted for 95 percent of the \$88 million in total support and revenue reported.

The contributions reported in 2011 allowed PAN to increase the number of patients that could be helped through each fund and to expand the number of disease funds that PAN operates. Contributions, including unconditional promises, which are recognized as revenue in the period made, are reported as temporarily restricted if the funds are restricted for future periods. A major portion is set aside and earmarked for each grant for future claims.

Temporary restrictions, which were placed on 97 percent of the contributions reported in 2011, were released during the year to fund the cost-sharing support that was provided by the 35 disease funds PAN operated last year. Of the total support and revenue reported in 2011, 58 percent was allocated to patient grants awarded in 2011. These funds will be released in 2012 to meet the cost-sharing needs of both existing and new patients. The remaining 42 percent of total support

Support & Revenue	2010	2011	% Change
Contributions	\$35,551,233	\$83,632,322	135%
Investment Income	\$3,883,846	\$4,368,396	12%
TOTAL SUPPORT & REVENUE	\$39,435,079	\$88,000,718	123%

and revenue includes \$30.5 million in unrestricted funds that were released during the year in order to meet the cost-sharing obligations that PAN had previously made to patients.

In 2011, investment income increased by 12 percent to \$4.3 million. For the past two years, PAN was able to leverage the investment income to fund several initiatives and innovative technologies that helped us to improve the quality and efficiency of the services that we provide to patients and the providers that serve them. *The online specialty pharmacy portal is an example of the types of improvements that changed how we work with providers as we administer the cost-sharing assistance program.*

We have made changes to improve how patients interact with the PAN Foundation, from their initial call for help and throughout the time that PAN is providing cost-sharing assistance on their behalf.

For individuals receiving chronic therapies, the need for cost-sharing is likely to follow the typical 30- or 90- day dispensing pattern and to continue throughout the year. In contrast, for individuals who require physician-administered medications, such as those used to treat cancer, the cost-sharing needs may be more variable and for shorter durations.



(Allocated to co-pay assistance and other expenses in 2011.)



(Reserved for forthcoming grants.)



2011 In Numbers



35 TOTAL FUNDS IN 2011.

7 NEW FUNDS ADDED IN 2011.

\$83.6M

RECEIVED FROM DONORS, A 135% INCREASE OVER 2010.

23,832

NUMBER OF PATIENTS SERVED IN 2011.

GROWTH

100%

FOR HIGH COST PATIENTS WITH OUT-OF-POCKET COSTS FOR PRESCRIPTION DRUGS AT THE 90TH PERCENTILE, ALL COSTS WOULD BE COVERED BY THE AVERAGE LEVEL OF PAN SUPPORT.

GENEROSITY



90 DAYS A 'LOOK BACK' PERIOD FOR ELIGIBLE CLAIMS OF PAN PATIENTS.

1 DAY THE NUMBER OF BUSINESS DAYS IT USUALLY TAKES FOR PAN TO MAKE A DECISION AFTER RECEIVING A REQUEST FOR HELP.

PATIENT & FAMILY SUPPORT



90¢ OF EACH DONATED DOLLAR WAS DIRECTLY USED IN THE TREATMENT AND CARE OF PATIENTS.

31 SPECIALTY PHARMACIES PARTNERED WITH PAN.

143,000 CALLS WERE RECEIVED FROM PATIENTS IN 2011. IN MANY INSTANCES WE PROVIDED ADVICE AND GUIDANCE WHEN THE PATIENT DID NOT QUALIFY FOR PAN ASSISTANCE.



ADMINISTRATIVE EFFICIENCY



THE UNDERINSURED

The PAN Foundation was created specifically to help people who cannot afford the cost-sharing obligations associated with critical biologic and drug therapies that have been prescribed to treat a serious illness such as cancer, a rare disease or a chronic condition. In other words, the PAN Foundation assists the underinsured – individuals with high out-of-pocket drug costs associated with their health plan's deductible, co-payment or co-insurance requirements. The number of underinsured is much higher than the commonly presumed 29 million adults which have

The underinsured:

<i>14,000,000</i>	<i>children</i>
<i>≈ 29,000,000</i>	<i>adults under 65</i>
<i>4,000,000</i>	<i>Medicare beneficiaries</i>
<i>≈ 47,000,000</i>	<i>underinsured patients</i>

been described in many press reports. Another 14 million are children and four million are Medicare beneficiaries who do not have supplemental coverage. The likelihood of being classified as underinsured depends on the relationship between annual household income and out-of-pocket medical expenses, which is expressed as a threshold percentage of household income.

There is confusion because there are three thresholds. The first threshold is based on the deductible, while the second and third thresholds are based on all out-of-pocket medical expenses and needs.

WHO ARE THE UNDERINSURED?

Threshold 1: Underinsured because the deductible amount equals five percent or more of annual income.

An estimated five million adults under age 65 are underinsured for this reason.

- » **A family of four with an annual household income of \$77,300 would be underinsured if they had to pay for the first \$3,865 in healthcare costs, i.e. the average deductible for HDHP coverage.**
- » **The family household income is 350 percent of the FPL.**

Threshold 2: Underinsured because of low income and high out-of-pocket medical expenses.

This group includes the almost two-thirds of the underinsured adults who have a household income less than twice the federal poverty rate, five percent of which is used to pay out-of-pocket healthcare costs.

- » **A Medicare beneficiary living alone with annual household income of \$22,278 would be underinsured, even if her out-of-pocket medical costs were less than \$100 per month.**
- » **The household income is 200 percent of the FPL.**

Threshold 3: Underinsured because of high out-of-pocket medical expenses relative to income.

This group includes individuals with household income greater than twice the poverty rate, 10 percent of which is used to pay out-of-pocket medical expenses.

- » **An only child living with both parents with an annual household income of \$34,748 would be underinsured if the annual out-of-pocket costs exceeded \$1,737.40, or \$145 per month.**
- » **The family household income is 200 percent of the FPL.**

COST-SHARING TRENDS IMPACT UNDERINSURANCE

The likelihood of being underinsured has been increasing as the variety and design of benefit plans have been changing, thus inflating the cost-sharing obligation, a situation common to individuals who are helped by PAN.

Average 2011 Deductible for ESI Plans

Single Coverage: » **\$2,149** for most plans
 » **\$2,033** HDHP with HSA

Family Coverage: » **\$2,149** for most plans
 » **\$3,865** HDHP with HSA

The average amount of the annual deductible has been increasing. In addition, employers are more frequently applying separate deductibles for the policy holder and the dependents covered as a family.

Consumer protections, such as a maximum limit on out-of-pocket spending, have also been weakened as employer-sponsored insurance (ESI) plans began to exclude cost-sharing paid for specific types of covered services, including pharmacy. Moreover, some employers have begun to apply separate spending limits for the policy holder and the dependents, rather than an aggregate amount for family coverage. *The benefit design changes impacting higher cost specialty drugs result in higher co-payment amounts and the increased use of higher co-insurance for drugs in the third or fourth tier of a plan’s formulary.* The average co-insurance percentage for specialty drugs dispensed in mail-service pharmacies is 39 percent.

PATIENTS SERVED BY THE PAN FOUNDATION

The PAN Foundation helps the underinsured when a high annual deductible amount has made their drug therapy unaffordable or

they are unable to pay higher cost-sharing amounts such as the co-insurance rates which approach the upper limit of 40 percent. High deductibles can be particularly difficult for patients as the patient is fully responsible for all of the drug costs until the first-dollar amount has been reached. This is similar to being in the original Part D doughnut hole, when the Medicare beneficiary was responsible for 100 percent of the drug costs during the coverage gap period.

In 2011, the PAN Foundation provided cost-sharing assistance to underinsured patients who come from a diverse range of households including Medicare beneficiaries from the three eligibility groups (i.e. age 65, a disability or End Stage Renal Disease (ESRD)). *In order to respond to the unique needs of patients reflecting a diverse group of households, payers and levels of supplemental coverage, PAN is flexible and sensitive to individual patient situations.*

PROFILE OF PAN’S ASSISTANCE BY SIZE OF HOUSEHOLD

Among the patients receiving assistance from PAN, 44 percent live alone. Another 37 percent live in a two-person household and 19 percent live in households of three or more. *The disproportionate number of single households reflects an older demographic of Medicare beneficiaries for whom drug costs are burdensome.* [see chart below]

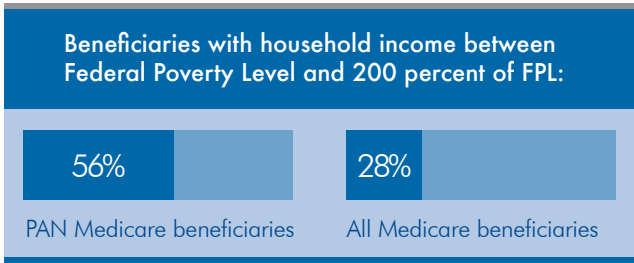
EFFECTS OF UNDERINSURANCE: <i>Faced with unaffordable cost-sharing amounts, underinsured individuals are more likely to forgo a particular therapy or to avoid healthcare all together. They are also more likely to have medical debt which they are paying off over time, and many have had to change their way of life in order to do so.</i>	
Living Alone: On average, PAN paid \$2,520 of their 2011 pharmacy cost-sharing obligations.	<ul style="list-style-type: none">» Almost half of PAN’s patients live alone vs. 28 percent in the US.» 55 percent are age 65 or older vs. 23 percent in the US.» The majority of PAN patients are women, similar to the national profile.
Two-Person Households: On average, PAN paid \$2,836 of their 2011 pharmacy cost-sharing obligations.	<ul style="list-style-type: none">» More than one-third of PAN’s patients live in two-person households vs. 33 percent in the US.» A much higher proportion, 62 percent, is age 65 or older vs. 28 percent in the US.
Larger Households with Children: On average, PAN paid \$2,083 of their 2011 pharmacy cost-sharing obligations.	<ul style="list-style-type: none">» 20 percent of PAN’s patients live in households with three or more people vs. 39 percent in the US.» 40 percent are under age 18 vs. 39 percent in the US.» 91 percent are under age 65 vs. three percent in the US.

ASSISTANCE TO MEDICARE BENEFICIARIES

PAN helps Medicare beneficiaries meet the out-of-pocket costs of biologic and drug therapy, which are either a Part B-covered service or a Part D drug benefit. Part B drugs are usually administered by injection or infusion in clinics or hospitals. Beneficiaries have the option of obtaining Part D drug coverage from a stand-alone prescription drug plan (PDP) or the drug plan affiliated with their Medicare Advantage plan. Part D drugs are generally purchased at pharmacies and can be self-administered. The fastest growing use of innovative medications is oral medications and consequently Part D cost-sharing is becoming more important.

MEDICARE BENEFICIARIES: Almost half (48 percent) of the individuals receiving support from the PAN Foundation are age 65 or older. For most of them, Medicare is their primary source of coverage, as it is for those who are helped by PAN and are eligible for Medicare because of a disability or ESRD.

PAN COMPARED TO MEDICARE



Compared to all Medicare beneficiaries, those supported by the PAN Foundation are much less likely to have supplemental coverage, only 56 percent compared to 90 percent. On average, PAN provided \$2,573 of the 2011 cost-sharing obligations for individuals with

Medicare as their primary source of coverage.

The purpose for bona fide charitable foundations is to offer assistance to the financially needy. Cost-sharing support is provided to twice as many low income beneficiaries as might be expected based on the income distribution of the entire Medicare population. In contrast, only one percent of the beneficiaries helped by the PAN Foundation have income which is more than four times the poverty level whereas 25 percent of all Medicare beneficiaries are in this income range. PAN assistance is directed to a less affluent subpopulation of Medicare beneficiaries who need assistance the most.

MEDICARE COMPARISON

MEDICARE ADVANTAGE (MA)	ORIGINAL MEDICARE (OM)
» 53% of PAN's Medicare patients were enrolled in a MA plan.	» 47% of PAN's Medicare patients were covered by OM.
» All MA plans provide some level of supplemental coverage.	» Only seven percent of these patients had supplemental coverage.
Medicare Only (without supplemental)	
On average, PAN paid \$2,492 of the 2011 cost-sharing obligations for this group of Medicare beneficiaries.	» 44% of Medicare beneficiaries helped by PAN rely on Medicare entirely. » Only 10% of all Medicare beneficiaries have Medicare coverage only. For the PAN patient population, the percentage is four times greater. » The majority of PAN patients are women, similar to the national profile.
Medicare With Supplemental Coverage	
On average, PAN paid a higher subsidy, \$2,806 of the 2011 cost-sharing obligations to this group of Medicare beneficiaries.	» 94% are MA enrollees. » 6% are OM beneficiaries.
Medicare as Secondary Payer	
On average, PAN paid \$2,420 of the cost-sharing obligations for this small group of 123 Medicare beneficiaries.	» For those below the poverty line, the average award was \$4,388.

THE PAN FOUNDATION REACHES THE UNDERINSURED

PAN support greatly exceeds the amount usually spent out-of-pocket by individuals with incomes at or below 200 percent of the FPL. The average support provided to individuals who live alone, with incomes near the poverty rate, is 3.8 times higher than the underinsured out-of-pocket expenditure threshold.

POLICY ISSUES & FURTHER IMPLICATIONS

The Affordable Care Act (ACA) has a significant potential to change the nature of underinsurance, probably impacting the scope and level of cost-sharing assistance that the charitable co-pay foundations will need to provide. Several of the provisions implemented in 2010 and 2011 have already begun to improve the level of health coverage among those with insurance, including Medicare beneficiaries enrolled in a Part D drug plan and privately insured individuals that had annual or lifetime limits on their coverage. The early improvements include the changes to the Part D drug benefit by shrinking the donut hole, the elimination of lifetime limits and the first round of restrictions in annual cost-sharing limits.

FACTOR BY WHICH PAN’S AVERAGE SUPPORT EXCEEDS THE OOP SPENDING UNDERINSURED THRESHOLD

Household Size	≈ 100% of FPL	Between 100% and 200% of FPL
One	3.8x higher	2.3x higher
Two	3.0x higher	2.0x higher
Three+	2.0x higher	1.2x higher

2010	2011 to 2013		2014
Lifetime Limits Eliminated for 105 Million People	LIMIT MUST BE ≥ TO:	FOR PLAN YEARS:	Lifetime Limits Eliminated for Additional 18 Million People
	\$750,000	9/26/2010– 9/25/2011	
	\$1.25 million	9/26/2011–9/25/2012	
	\$2.0 million	9/26/2012-9/31/2013	

MEDICARE PART D REFORM OF COVERAGE GAP

The value of the Medicare Part D benefit is being enhanced as the coverage gap, known as the “donut hole”, is eventually closed. In 2011, Part D cost-sharing was reduced for drugs purchased during donut hole period, either in the form of a 50 percent discount from the manufacturer of a brand-name drug or a federal subsidy for generic co-pays. PAN observed a reduction in the size of patient needs in 2011. In 2020, when the donut hole is closed, patients will still face out-of-pocket obligations as the enrollee will be responsible for 25 percent of the average cost of the Part D benefit.

PRIVATE INSURANCE REFORM OF COVERAGE LIMITS

Annual or lifetime coverage limits have traditionally been used by health plans to limit the insurance risk of high cost cases. The

coverage limit is set based on a specific dollar amount and no healthcare services beyond the dollar amount are covered. The adverse effect of lifetime coverage limits was greatest for individuals with higher than average health costs due to their need for ongoing treatment for chronic conditions. The elimination of lifetime coverage limits in September 2010, improved the value of health insurance coverage for the 105 million Americans with health insurance provided by an employer or purchased in the individual market. Restrictions on annual limits will improve coverage for 18 million after they are eliminated in 2014 after three years when services must be covered up to the dollar limit in the chart above.

Before the ACA, Medicare beneficiaries were likely to look for help from the PAN Foundation during the donut hole coverage gap, when they were responsible for the full cost of a drug. Future PAN-eligible patients are likely to need a comparatively lower level of cost-sharing support for a drug therapy covered by one of the PAN Foundation disease funds. The underinsured population, on the other hand, is expected to expand significantly.

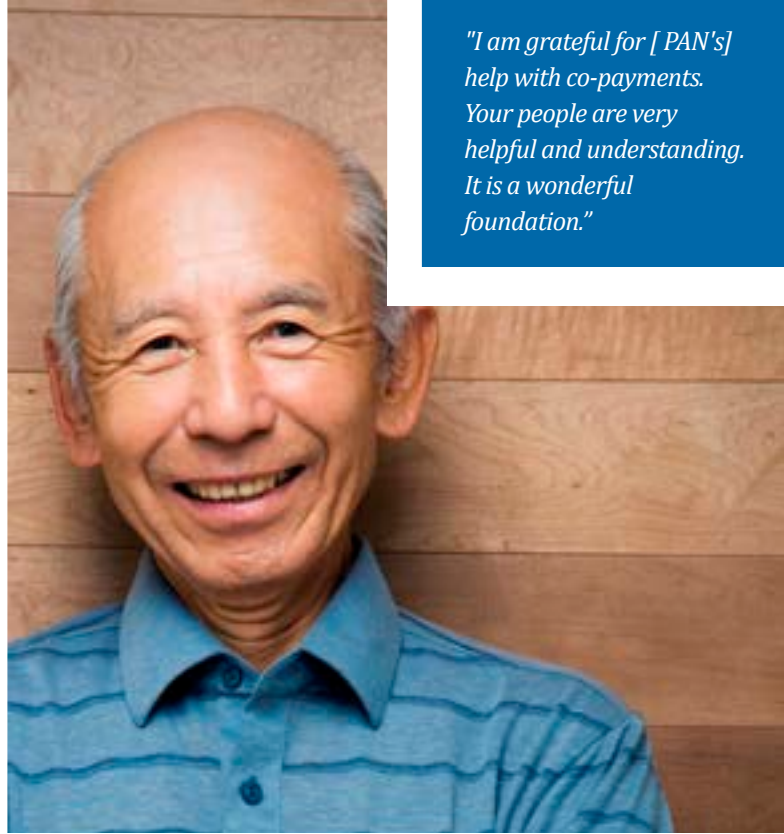
FUTURE COVERAGE EXPANSION

Although the major expansion of health coverage starts in 2014, the ACA has already expanded coverage for a limited number of groups, including dependents younger than 26 and those with pre-existing conditions. The likelihood of either group becoming underinsured depends on the affordability of their cost-sharing requirements. Dependents under age 26 will be influenced by ESI benefit design changes whereas individuals covered through the Pre-Existing Condition Insurance Plan (PCIP) Program will be impacted by two new ACA features – a plan with an actuarial value set at 65 percent and \$5,950 out-of-pocket spending limit. Unlike the coverage that will be available from a qualified health plan (QHP) purchased inside a Health Insurance Exchange, there is no direct federal subsidy for the PCIP premiums or cost-sharing support. The good news for these patients is that they continue to be covered, but the bad news is there are no provisions for help with out-of-pocket liabilities. PAN expects to help more patients as a result of PCIP and similar ACA reforms that have already begun.

Among the newly covered in 2014, two groups are less likely to be underinsured as a result of the benefit design. They include the Medicaid expansion population in participating states and newly insured who enroll in a qualified health plan inside an exchange and qualify for the federal subsidy which will lower the cost-sharing requirements, on a sliding scale basis, for income up to 250 percent of the FPL. For low-income individuals in these two groups, the relatively minimal cost-sharing requirements may be, nonetheless, unaffordable. Cost-sharing requirements could also be a challenge for those who are not eligible for the federal cost-sharing subsidy, particularly for individuals who enroll in a bronze level plan which has a coverage level which is comparable to PCIP. PAN recognizes this new need and is working to design funds that meet this lower but still unaffordable cost-sharing.

As coverage expands, PAN expects that the underinsured population will increase and become even more diverse. Therefore, we are continuing to evaluate our plans and processes so that we can accommodate the anticipated newly eligible, but possibly underinsured, patient population.

"I am grateful for [PAN's] help with co-payments. Your people are very helpful and understanding. It is a wonderful foundation."



"Financial assistance from PAN was like lifting a great weight off of my shoulders. PAN's support has been such a blessing in my life. Thank you so much, PAN, for all the wonderful help you've provided me with!"



"Because of assistance from PAN, I get the treatment I need and I feel better."



CONTRIBUTING FACTORS OF UNDERINSURANCE

HEALTH STATUS		HOUSEHOLD INCOME	LIKELIHOOD OF BEING UNDERINSURED	BENEFIT DESIGN
RARE DISEASE	ONE OR MORE CHRONIC CONDITIONS	<p>≤200% of FPL</p> <p>≈\$23k for a single-person household</p> <p>≈\$46k for a four-person household</p>	<p>HIGHLY LIKELY, except for:</p> <p>Medicare beneficiaries with secondary coverage through Medigap or Medicaid</p> <p>Most Medicaid enrollees</p> <p>High-cost enrollees in a retiree plan that capped annual drug benefits discontinued drug therapy at a higher rate than comparable patients in an uncapped plan.</p>	<p>No Out-of-Pocket Maximum</p>
		<p>≈300% of FPL</p> <p>≈\$34.5k for a single-person household</p> <p>≈\$69k for a four-person household</p>	<p>MORE LIKELY for:</p> <p>54% of individuals with family coverage from employers and an out-of-pocket maximum of \$5,000 or higher</p> <p>Privately insured patients who use specialty drugs as part of their treatment plan for cancer, kidney disease, RA or MS reduced their use rate by 1-21% in response to greater cost sharing.</p>	<p>Out-of-Pocket Maximum >\$5,000</p>
		<p>≈400% of FPL</p> <p>≈\$46k for a single-person household</p> <p>≈\$92k for a four-person household</p>	<p>MORE LIKELY for:</p> <p>84% with employer PPO coverage for whom prescription cost-sharing does not count toward the OOP maximum, or</p> <p>21% with employer coverage who have separate OOP maximums for each family member</p> <p>4.5% of individuals with health insurance and income 400+ percent of FPL said that they were unable to afford the costs of their prescription drugs, which went unmet.</p>	<p>Deductible & Pharmacy Cost-sharing Excluded from OOP Maximum</p>
		<p>≥500% of FPL</p> <p>≈\$57.5k for a single-person household</p> <p>≈\$115k for a four-person household</p>	<p>LESS LIKELY, except for Medicare beneficiaries with multiple chronic conditions who are covered by:</p> <p>Original Medicare with no supplemental coverage</p> <p>Medicare Advantage with the \$6,700 annual OOP maximum</p>	<p>Out-of-Pocket Maximum >\$2,500</p>
CANCER				

On average, an orphan drug is likely to be covered by 77% of non-national Part D plans and 86% of national Part D plans. When covered, they are likely to be placed on high cost sharing tiers and require prior authorization.

A recent study of oral oncolytics showed that Medicare patients were more likely to have cost-sharing of \$500 or more and also had a higher abandonment rate than those covered by a commercial plan; 15.5% vs. 8%.

Access problems were greater for the 14.4% of insured individuals with one chronic condition and the 20.1% of insured individuals with two chronic conditions.

THANK YOU.

Thanks to the generous support of our donors, the PAN Foundation was able to offer help and hope to over 23,800 underinsured patients with chronic or life-threatening illnesses last year, providing over \$31 million in cost-sharing assistance in total. These patients might have had to go without their life-saving, high-value medications, were it not for PAN and grants that were made possible by the generous support of our donors.

The support the PAN Foundation received in 2011 enabled PAN to provide underinsured patients around the country with help and hope in the form of not only cost-sharing assistance, but also:

- » Responding to almost 143,000 patient phone calls, in many cases providing advice and assistance
- » Adding seven new disease funds
- » Approving patients generally within one business day
- » Partnering with 31 Specialty Pharmacies

2011 was a record breaking fundraising year for the PAN Foundation. The generous support received in 2011 will allow PAN to grow and provide assistance to over 50,000 patients in 2012. We are extremely grateful to our donors for their continued support. We cannot wait to continue breaking records and providing help and hope to patients and their families. We could not have accomplished any of this without each and every one of our donors.



*“PAN is my
lifeline.”*

Offering Help and Hope for a Healthy Tomorrow

The challenge of the underinsured is bigger than commonly perceived. The number of underinsured patients approaches 47 million when patients under 18 and older than 64 are included. This is a higher number of underinsured than commonly quoted--29 million. Currently, we are seeing how policy changes, such as those related to closing the Part D donut hole, reduce some of the heavier need for cost-sharing support but will eventually expose a larger number of patients to the status of underinsured. The 50% discount legislated and implemented in 2010 is having a positive impact on financial burden, but cost-sharing obligations remain.

As a result of new regulations, healthcare coverage will become more standardized and out-of-pocket spending more regulated. The profile of the underinsured will change as more of the newly eligible patients receive cost-sharing subsidies based on a sliding income scale, but probably end up opting for high deductible plans with lower premiums. Understanding these intricacies comports with PAN's unique approach and specific focus on patients with hardships who would not initiate or would have a higher probability of abandoning treatment. While smaller, the financial barrier can be sufficient to preclude the adoption of treatment.

As you can see in our performance statistics, 2011 was a year of great success for PAN. Donations increased by 135 percent, positioning PAN to allocate over 50 thousand patient grants in 2012, almost doubling the number of patients we currently assist and grants we award. We expect to field well over 200 thousand calls and assist an additional 10 thousand to 20 thousand patients who do not qualify for PAN assistance, but need help finding other sources of support. Our patient grants are sufficient to cover costs for the course of treatment or 12 months, giving comfort to the patient and caregivers.

Finally, we remain vigilant and aware of evolving government regulations, assuring that every standard of confidentiality is observed and respected, and in conducting assessments of the changing healthcare landscape, continually working to respond and redesign funds when necessary.

I'm confident there is a bigger need than currently realized and cost-sharing is here to stay. With the support of generous donors, we'll respond accordingly.

Sincerely,



Patrick McKercher, PhD
President, PAN Foundation



PAN BOARD OF DIRECTORS



Kim Schwartz, CPA (Chair) has spent most of her career as a financial executive in the areas of healthcare, working with nonprofit organizations that focus on assistance to the underserved both domestically and internationally. She is currently the CFO for Population Services International (PSI), the world's largest NGO delivering social

marketing, behavioral change and product delivery to over 65 countries. Prior to her role with PSI, Ms. Schwartz held leadership positions with the American Red Cross, the American Lung Association, Gannett Corporation, Ernst & Young and Inova Health System.



Allan Goldstein, MD, MPH, FACP (Vice Chair) has a clinical background in internal medicine and consults in the areas of consumerism, patient advocacy, provider performance measurement and development of innovative primary care delivery systems. He obtained his medical training at the Albert Einstein College of Medicine and received

his MPH from Columbia University. Dr. Goldstein is board certified in internal medicine and a fellow of the American College of Physicians.



Stephen F. Loebs, PhD (Treasurer) is Professor Emeritus with the Division of Health Services Management and Policy, School of Public Health at The Ohio State University. Dr. Loebs has served in numerous faculty and administrative appointments in hospital and health services, public health, health policy and hospital administration. He

has been involved with 65 healthcare-related research projects, reports and publications and is the recipient of various international and research fellowships.



Anita Plotinsky, PhD (Secretary) brings to PAN more than 20 years of experience in the nonprofit sector. She was affiliated for many years with the Indiana University Center on Philanthropy, where she developed academic programs and taught courses in nonprofit management and philanthropic studies. Currently a consultant

to nonprofit organizations in Washington, D.C., Dr. Plotinsky has served as Executive Director of the Association for Research on Nonprofit Organizations and Voluntary Action (ARNOVA) and Director of the Foundation Center in DC.



Lyn Boockock-Taylor is the Vice President of Competitive Grants at Geisinger Health System, a physician-led healthcare system, dedicated to healthcare, education, research and service spanning 43 counties of 20,000 square miles, serving 2.6 million people. Prior to her role at Geisinger, she served as Vice President of Development at Albert

Einstein Healthcare Network and President of the Arthritis Foundation of Eastern Pennsylvania. Ms. Boockock-Taylor has worked in the advancement field for 30 years, raising millions of dollars for projects in the Philadelphia area.



Michael Gerald, PhD is a Professor of Pharmacy at the School of Pharmacy, University of Connecticut and has served as the Dean of the school. Dr. Gerald's past professional appointments have included Professor of Pharmacology and Associate Dean for Professional Programs at the College of Pharmacy, The Ohio State University, and

as a consultant at the World Health Organization in Geneva. He has authored over 100 publications and five books.



Michael O'Grady, PhD is the President of the West Health Policy Center whose mission is to lower healthcare costs by developing innovative solutions to the current unsustainable growth in healthcare spending. The Center conducts independent, non-partisan research and analysis, convening and communicating with stakeholders,

and advancing practical and actionable health policy options. Dr. O'Grady is a health policy expert with 24 years of experience working with Congress and the Department of Health and Human Services. Throughout his career, he has helped shape significant healthcare legislation on a broad spectrum of issues. He has been instrumental in the development of key federal policies and programs tackling some of the most complex and controversial health issues facing the country.



Fred Schnell, MD is a medical oncologist in private practice with Central Georgia Cancer Care, PC. He is also a clinical Assistant Professor in the Department of Medicine at the Mercer University School of Medicine in Macon, Georgia. Dr. Schnell is active in research to improve patient outcomes. He led the development of the

Georgia Center for Oncology Research and Education, an independent, nonprofit organization working to improve cancer care in Georgia by strengthening clinical research throughout the state. His personal research interests include medical oncology and breast, lung and gastrointestinal cancer. He is a past president of The Georgia Society of Clinical Oncology, chair of the Community Oncology Alliance and a recipient of the American Society of Clinical Oncology's community research award.



Ian D. Spatz, JD, MPA is a healthcare policy consultant working for a range of for profit and nonprofit clients. He is a senior advisor to Manatt Health Solutions. In addition, Mr. Spatz founded his own firm, the Rock Creek Policy Group. He is also a faculty member in the Department of Health Policy of The George Washington

University School of Public Health and Health Services. Previously, he served as Vice President for Global Health Policy for Merck & Co., Inc. and has also worked in the government and nonprofit sectors. Mr. Spatz has degrees from the New York University School of Law and the Woodrow Wilson School of Public and International Affairs of Princeton University.

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*"I appreciate
the program
more than
words can say."*



*"PAN is an
agency with
efficiency,
effectiveness
and courtesy."*



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"I've been given a chance in life to feel "good" again; I can enjoy doing things with my 5 grandkids again; I live with less pain and can move easier."



"I was able to go through the treatment successfully and I am cured."



"PAN helped me make the impossible possible."





Glossary

"Before receiving PAN it was difficult to cover other expenses and keep good credit rating and peace of mind."



"PAN enables us to avoid spiraling debt due to expensive medication."



ACA Affordable Care Act

The ACA, or health reform law, refers to the Patient Protection and Affordable Care Act (PPACA), as amended by the Health Care and Education Reconciliation Act (HCERA) of 2010.

Donut hole

Also known as the Medicare Part D coverage gap, the term refers to the period of time after a Part D enrollee's drug spending exceeds the initial coverage limit (ICL) and before the enrollee's out-of-pocket expenses reach the TrOOP limit, when catastrophic coverage begins. CMS sets the dollar amount for the ICL and TrOOP annually.

ESI Employer-sponsored insurance

ESI is the most common source of health insurance. Sometimes referred to as "group health insurance", ESI covers about 150 million nonelderly people in the US.

ESRD End Stage Renal Disease

The Medicare ESRD Program is a national health insurance program for people with permanent kidney failure requiring dialysis or a kidney transplant and who meet the relevant eligibility criteria.

FPL Federal poverty level

This term is frequently used to administer programs based on eligibility and refers to poverty guidelines developed by the Department of Health and Human Services. It is used in this report to refer to the poverty thresholds calculated by the US Bureau of the Census.

HDHP High deductible health plans

This type of health plan features higher deductibles than traditional insurance plans. HDHPs can be combined with a health savings account (HSA) or a health reimbursement arrangement (HRA) which can be used to pay for qualified out-of-pocket medical expenses on a pre-tax basis.

HSA Health savings account

This is a medical savings account which is available to taxpayers who are enrolled in a HDHP. The funds contributed to the account are not subject to federal income tax at the time of deposit.

MA Medicare Advantage

The MA Program, which is also known as Medicare Part C, allows managed care companies or health plans to contract Medicare in order to provide all Medicare Part A and Part B benefits to Medicare beneficiaries who choose to enroll in a MA plan.

MAPD Medicare Advantage Prescription Drug Plan

This type of drug plan is offered by an MA plan which is able to manage the Part D drug benefit with Part A and Part B benefits as a single plan.

OM Original Medicare

Original Medicare refers to fee-for-service coverage for Part A and/or Part B benefits. Healthcare providers are paid directly by the federal government through a Medicare administrative contractor.

PCIP Pre-Existing Condition Insurance Plan

The ACA established the PCIP program as a means of providing a health coverage option for individuals with a pre-existing condition who have been uninsured for at least six months and have been denied coverage by a private insurance company or have been offered insurance without coverage of the pre-existing condition. In 2014, individuals with PCIP coverage will have access to coverage through an Exchange and all health plans will be prohibited from discriminating on the basis of a pre-existing condition.

PDP Prescription drug plan

This term typically refers to a stand-alone Medicare Part D drug plan that offers the outpatient prescription drug benefit to beneficiaries who choose to stay in the Original Medicare program.

HOW YOU CAN HELP

The PAN Foundation is committed to providing hope for patients and help for families through co-pay assistance grants. Many PAN Foundation patients say that with PAN's help, they no longer have to forego life-saving treatments they previously could not afford. You can be a part of helping the underinsured get the financial assistance they need by making a donation.

GIVE ONLINE OR BY MAIL

Through our online donation process with Network for Good (accessible through PANFoundation.org), you can set up monthly donations, donate in memory or in honor of someone you love or designate your donation for a specific disease fund. You can also download a donation form at PANFoundation.org and mail it to PAN Foundation at: 1331 F Street, NW, Suite 975, Washington, DC 20004.

It is easy to give in other ways too, through corporate gifts, gifts of stock, real estate, personal property, retirement assets or life insurance. To make a gift or for more information on making a donation, please contact us at 202-347-9272.



*To date, **PAN has helped 134,000 patients with over \$187 million** in co-payment assistance. Patients trust PAN to provide personal and compassionate assistance that eases their financial and emotional burdens. With PAN's help, they no longer have to choose between their medications and keeping a roof over their head.*

A 2011 PAN survey found that 99 percent of those receiving PAN assistance were satisfied with PAN's help.



PAN is an independent public charity established in 2004. Through a simple application process, PAN provides co-payment assistance to patients who have insurance, but lack the means to pay for out-of-pocket costs for their medications or infusions.



*Every day, the PAN Foundation helps thousands of patients who have insurance but lack the means to pay for out-of-pocket costs of medications for cancer or chronic illness. Depending on their illness, **insured patients can receive between \$1,500 to \$10,000 a year in co-payment assistance that can often mean the difference between life and death.***



*PAN's professional, compassionate case managers help patients throughout the United States and U.S. territories receive needed treatments for **more than 40 specific diseases.***



Headquartered in Washington, D.C., with a call center in Charlotte, NC, PAN is governed by a nine-member board of directors who are nationally recognized experts in medicine, public health, pharmaceuticals, healthcare administration, finances and nonprofit management.

*Find out more by calling us at:
202-347-9272
or visiting our website at:
PANFoundation.org*

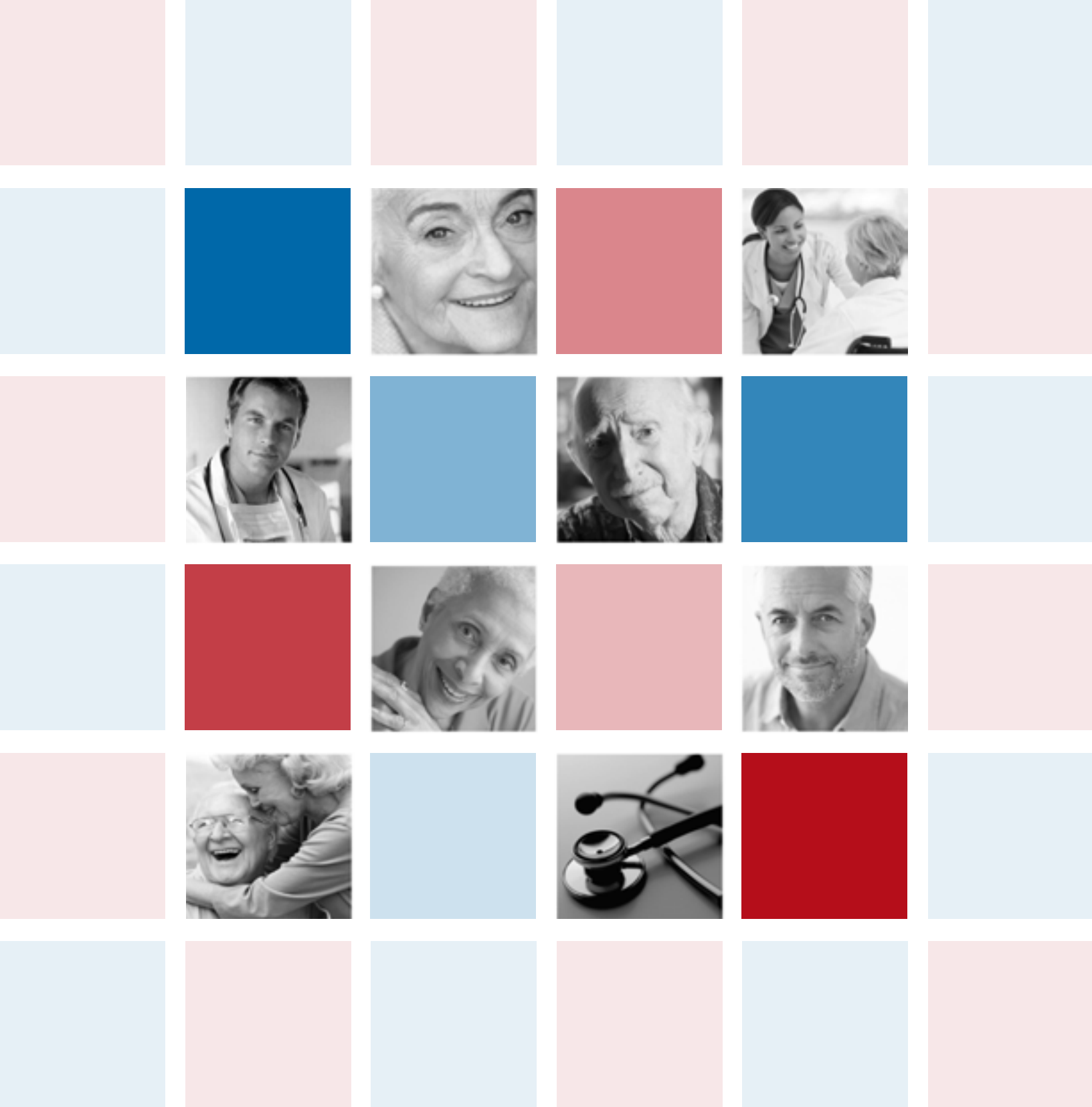


PAN is supported by a wide range of donors, including private companies, medically related organizations, individuals and foundations.



*For PAN patients and the other estimated **47 million Americans** who are underinsured, coming up with required out-of-pocket costs can be daunting. PAN lets patients focus on their health, not on their pocketbooks.*





Patient Access Network
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