



2012 ANNUAL REPORT
A Source of Help and Hope



Patient Access Network
foundation

Help & Hope For a Healthy Tomorrow



We take great pride in knowing that we are here to provide help and hope to as many patients and families as we can. Living with a life-threatening or chronic disease can take a huge toll on patients and their families, their dreams and futures. Whether those we serve have just been diagnosed or have been fighting to regain their health for any number of years, the Patient Access Network (PAN) Foundation is here to help patients and families afford their specialty medications today, so they have hope for a healthier tomorrow.

Last year was a banner year for the PAN Foundation, and I am proud to say that because of our fundraising success, we were able to provide help to more patients and hope to more families than ever before. In 2012, we operated more than 40 assistance programs, through which we assisted nearly 60,000 patients who were either beginning or continuing specialty therapy for certain cancers, chronic illnesses and rare diseases. Almost 50,000 of the patients we served in 2012 were new to the PAN Foundation – nearly three times as many new patients as we served in 2011.

With almost a decade of experience serving and supporting critically and chronically ill patients across the country, the PAN Foundation understands the physical, emotional and financial challenges these individuals and their

families face. Since 2004, we have provided more than \$350 million in patient assistance through more than 50 assistance programs, awarding more than 200,000 patient grants and helping more than 160,000 patients.

With each year come new obstacles to overcome and opportunities to embrace, and 2012 was no exception. With changes in health insurance and population demographics, the profile of the underinsured is changing. As needs change and treatments are more personalized and diversified, the PAN Foundation remains a resource for underinsured critically and chronically ill patients, helping to reduce the financial burden these patients and their families face, so they can focus on managing their health needs.

Through all of these changes and transitions, the PAN Foundation has remained a steadfast source of help and hope. You will read later in this report about how we have been there for patients like Emma and Glen and their families when they had nowhere else to turn, when they needed support the most. We are delighted to be able to share these patients' stories with you, so you too can relish their triumphs and lament their setbacks. Hearing from patients like Emma and Glen reminds us every day that a little bit of help goes a long way. They serve as an inspiration to us as well as to the many other patients and families who face the long road to recovery and healthy futures.

It is also our great pleasure to spotlight committed provider partners such as Florida Cancer Specialists and Tennessee Oncology. We are honored to be able to unite with such exceptional organizations, who work with us to heal patients and nurture good health and well-being. We are so grateful to be able to continue expanding our reach and fostering partnerships with so many dedicated physicians, pharmacists, nurses, social workers and others across the country. Together, we do make a difference.

Behind the scenes, the PAN Foundation has used innovative and flexible approaches to facilitate increasingly efficient assistance services and to establish seamless and streamlined processes for patients and providers. Continued expansion of our provider and specialty pharmacy footprint means we can help more people in need every year.

As we reflect back on our progress during the past decade, we want to thank all of our donors. It is your continued support that allows the PAN Foundation to provide help and hope to more and more patients each year. With our 10-year anniversary on the horizon, we are excited about what the future holds for us, about the new partnerships and opportunities ahead in the next decade to further expand our reach and increase our ability to help more people who are fighting for their health and their lives.

Thank you for being part of our family and joining in our efforts to extend the courtesy of help and hope to so many who need it.

With deep gratitude,

A handwritten signature in blue ink that reads "Kim Schwartz". The signature is fluid and cursive, with a long horizontal line extending to the right.

Kim Schwartz

Chair, PAN Foundation Board of Directors

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About the PAN Foundation

Founded in 2004, the Patient Access Network (PAN) Foundation is an independent, national 501 (c) (3) organization dedicated to providing financial assistance to underinsured patients who are otherwise unable to access specialty medications.



Since 2004, the PAN Foundation has provided more than 200,000 grants to patients, having contributed more than \$350 million in much-needed financial assistance to cover patients' out-of-pocket medical expenses through more than 50 disease-specific programs, giving patients and their families help and hope they need to recover and resume their productive and healthy lives.

Through partnerships with generous donors, healthcare providers and specialty pharmacies, the PAN Foundation continues to help thousands of underinsured patients each year to overcome the burden created by the out-of-pocket costs associated with their life-saving specialty medications.

Helping Underinsured Patients since 2004:

- Through a quick, streamlined application process for patients and easy-to-navigate online portals for specialty pharmacies and providers, the PAN Foundation makes it simple and convenient for patients to access the financial assistance they need.
- The PAN Foundation provides financial assistance ranging from \$500 to \$10,000 per year to qualified patients to help cover co-payments, deductibles, co-insurance and, for certain diseases, insurance premiums and travel expenses.
- By using a state-of-the-art actuary reserve model, the PAN Foundation maximizes the distribution of donated dollars, helping more patients access the specialty medications they need.

Our Mission

The Patient Access Network Foundation offers help and hope to people with chronic or life-threatening illnesses for whom cost limits access to breakthrough medical treatments.

Our Vision

The PAN Foundation envisions a society in which every individual can access needed medical care, offering hope for a healthy tomorrow.



To learn more about the PAN Foundation and hear first-hand from patients, provider partners, Board of Directors members and senior staff about their PAN experience, scan this quick response (QR) code to watch our informational video – *Offering More Than Help and Hope*, or visit <http://www.panfoundation.org/news-article-list/289-offering-more-than-help-and-hope>

PAN Foundation Assistance Programs

The Patient Access Network Foundation helps patients suffering from certain cancers, chronic illnesses and rare diseases to access the cutting-edge medications they need to get well through more than 50 disease-specific financial assistance programs. By helping them today to afford medications that are oftentimes life-saving, the PAN Foundation gives patients and their families hope for a healthier tomorrow.

* Programs opened in 2012

◇ Programs operated in 2012, that are no longer active

* Programs opened in 2013 (as of August 2013)

◇ Programs inactive in 2012, but reactivated in 2013

ONCOLOGY PROGRAMS

Advanced Basal Cell Carcinoma *

Anaplastic Large Cell Lymphoma

Androgen Receptor Inhibitor Treatments for Advanced Prostate Cancer *

Bone Metastases *

Chemotherapy-Induced Neutropenia *

Chronic Lymphocytic Leukemia

Colorectal Cancer

Cutaneous T-Cell Lymphoma

Gastrointestinal Stromal Tumors *

Hodgkin's Lymphoma

Immunotherapy for Genitourinary Cancers *

Lung Cancer (Non-Small Cell)

Mantle Cell Lymphoma *

Metastatic Breast Cancer

Metastatic Castrate Resistant Prostate Cancer (mCRPC) *

Metastatic Melanoma *

Multiple Myeloma

Myelodysplastic Syndrome

Myeloproliferative Neoplasms (MF, PV, ET)

Non-Hodgkin's Lymphoma

Pancreatic Cancer ◇

Progressive Neuroendocrine Tumors of Pancreatic Origin *

Prostate Cancer ◇

Radioisotope Treatments for mCRPC *

Renal Cell Carcinoma

Well-Differentiated Thyroid Cancer

RARE DISEASE & OTHER PROGRAMS

Acromegaly

Gaucher Disease

Homozygous Familial Hypercholesterolemia *

Methicillin-resistant Staphylococcus Aureus (MRSA) *

Retinal Vein Occlusion

Uveitis

Wilson Disease *

CHRONIC ASSISTANCE PROGRAMS

Age-Related Macular Degeneration

Ankylosing Spondylitis

Asthma

Cytomegalovirus

Diabetic Foot Ulcers

Diabetic Macular Edema *

Growth Hormone Deficiency

Hepatitis B

Hepatitis C

Idiopathic Thrombocytopenic Purpura *

Inflammatory Bowel Disease (Crohn's & Ulcerative Colitis) ◇

Kidney Transplant Immunosuppressants

Multiple Sclerosis

Plaque Psoriasis

Postmenopausal Osteoporosis *

Psoriatic Arthritis *

Respiratory Syncytial Virus

Rheumatoid Arthritis

Secondary Hyperparathyroidism

Short Bowel Syndrome *

Solid Organ Transplant Immunosuppressants

TRAVEL ASSISTANCE PROGRAMS

Metastatic Castrate Resistant Prostate Cancer *

PREMIUM ASSISTANCE PROGRAMS

Homozygous Familial Hypercholesterolemia *

Short Bowel Syndrome *



Realizing a Lifetime of Dreams:

Emma's Story

Coming of age in the tiny town of Louisville, Miss., where the only job available was picking cotton in the fields, Emma knew she wanted more from life. A recent high school graduate whose father walked out on her family, Emma had big dreams, and the ambition, drive and determination to achieve them. So when her brother, an Air Force pilot stationed at the Lincoln Air Force Base in Nebraska, invited Emma to come live with him, he gave her the means to make her dream a reality.

Emma moved to Lincoln with one goal – to save up enough money to put herself through college. Shortly after arriving, Emma found a job and began working toward that goal. To her, it felt like everything was falling into place.

All of that would change at a dance a few months later, when Emma met Richard Lewis, another Air Force pilot. After dancing together for most of the evening, Richard asked Emma for her telephone number, and the rest, as they say, is history. Richard and Emma began dating and were married a short time later.

What was once Emma's dream for herself now became Emma and Richard's dream for their family. Rather than saving to put herself through school, she and Richard set their sights on creating a better life for their family, vowing to save up enough to put their children through college.

It wasn't easy, but Richard and Emma worked hard to make their dream a reality. When Richard chose not to re-enlist in the Air Force to avoid being deployed to Vietnam, he moved the family to Chicago, Ill., to take a job at AT&T. Emma started her own Tupperware business, and took classes at the University of Chicago to further her efforts.

Over time, Emma and Richard started making strides toward realizing their dream. The first major milestone came in 1973, just after the birth of their youngest child, when they bought their family home in Chicago's Beverly

With the assistance from the PAN Foundation, Emma can get all of her medications, helping to restore her health and quality of life. As a result, Emma's [non-small cell lung] cancer and arthritis are under control, and she and Richard can concentrate on enjoying the fruits of their labor, the manifestation of their dream – the beautiful, wonderful and successful family they created.

neighborhood. To Emma, the fact that they were able to buy a home in "such a middle-class community" felt like a great personal accomplishment, one she is still proud of today.

Richard was very successful at AT&T, and after getting a college degree through an employee benefits program, he was promoted and had many doors open up at the company. Still, with six children, money was always tight. Emma knew they needed to do more to put all of their children through college.

Although Emma's business was a rousing success, the balancing act of raising a family and owning and operating her business was incredibly stressful, leaving her exhausted. To cope with it all, Emma began smoking cigarettes and drinking lots of coffee – habits that would one day take a toll on her health.



Read the rest of Emma's story by scanning this QR code, or visiting <https://www.panfoundation.org/pan-stories/312>.



Specialty Pharmacy Partner Spotlight:

Florida Cancer Specialists' Rx to Go Pharmacy



Ray Bailey, RPh,
Rx To Go Pharmacy Director

As the specialty pharmacy for Florida Cancer Specialists & Research Institute (FCS), the largest independent oncology/hematology practice in the United States, Rx to Go Pharmacy understands the challenges that many patients face affording their medications they need to feel better. Especially given the recent rise in the development of oral oncology medications, Pharmacy Director Ray Bailey, RPh, and his team know firsthand that for some patients, the out-of-pocket costs for these medications are simply more than they can bear. For many FCS patients, more than half of whom are retirement age and may be living on a fixed income, this created a barrier to access they simply could not overcome without help. That's why Bailey and his team of financial counselors look to the Patient Access Network Foundation to get patients the assistance they need to overcome these barriers and get access to the help they need.

We spoke with Bailey about his organization's work, the changes in cancer treatment and insurance coverage in recent years, the challenges facing specialty pharmacies across the country and how he and his colleagues are utilizing and partnering with the PAN Foundation to overcome them.

Can you tell me a little bit about Rx To Go and how it supports Florida Cancer Specialists and their efforts to provide patients with cutting-edge care?

Ray: Rx To Go is Florida Cancer Specialists' specialty oral pharmacy that provides all the oral oncology therapies for FCS patients and certain supportive care. We're a wholly owned pharmacy inside of the group practice and we operate as an extension of the group practice. We're a centralized pharmacy for our 62 clinics statewide. All oral medications come from our site.

Though FCS patients primarily get their medications through us, patients' [health] insurances sometimes direct them to other places or they can get better co-pays somewhere else, and we facilitate all of that for them. But there's a lot of work that has to get done before patients can get access to these new, very expensive oral oncolytics. We help our patients get access, first and foremost. If we're able to fill it, then we do. But if we can't, my staff's job is to expedite a prescription getting to the place where they're going to get it filled as quickly as possible.

How has the rise in oral oncolytics impacted your patients' ability to access their medications?

Ray: There are a lot of issues associated with access. Some patients are very, very fortunate and they have very generous pharmacy benefit packages that allow them access to any drug no matter how much it costs with very, very low co-pays. But in a lot of cases, payers and large employers have tried to cost-shift some of that to the individual, and they do that in the form of large co-pays and out-of-pockets.

Of particular interest are Medicare patients – since the Medicare Modernization Act in 2003, there's now a prescription benefit for Medicare patients under Medicare Part D. Along with the creation of Medicare Part D came the creation of the "donut hole" – the coverage gap the patient travels through on the way to what's called "catastrophic." Once patients reach the donut hole, they are on their own until they exit it, at which point they have to pay 5 percent of the total cost of the drug as a co-pay for the remainder of the year. And then the year starts over, and the nightmare starts over for these patients that are on oral oncolytics.



Read the rest of our interview with Ray by scanning this QR code, or visiting

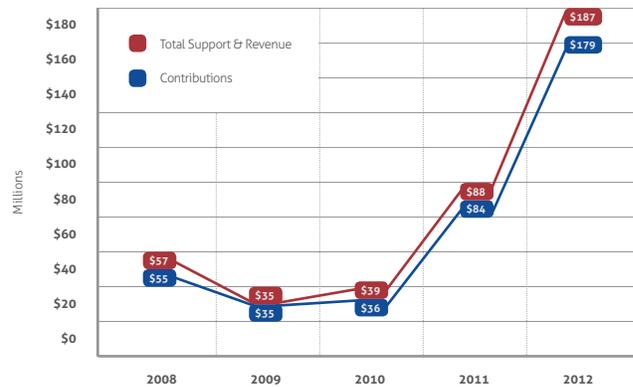
<https://www.panfoundation.org/media-room/314>

Financials and Growth

The PAN Foundation has achieved significant growth during the last two years, with total support and revenue more than doubling each year since 2010. In particular, the growth in contributions has allowed the PAN Foundation to increase the number of patients who could be helped by each program and to expand the number of assistance programs that it operates.

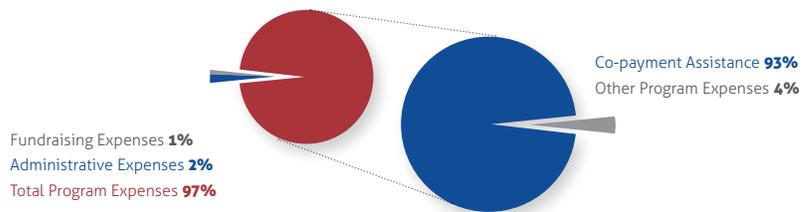
In 2012, the PAN Foundation reported total contributions of \$179.45 million, an increase of 115 percent over 2011 donations. Since PAN's inception, contributions consistently represented more than 90 percent of the PAN Foundation's total support and revenue. In 2012, they represented 96 percent of the total support and revenue.

Thanks to the generous support of our donors, we expect to touch the lives of more than 100,000 patients in 2013 – almost double the 59,000 patients we helped in 2012. A snapshot of financial statistics is presented below. Our financials are presented in our 990 tax return, which can be viewed in its entirety at www.PANFoundation.org.



In 2012, PAN recorded total expenses of \$119.5 million, a 220 percent increase over the prior year.

- Ninety-three percent, or \$108 million, is associated with co-payment assistance.
- Four percent is associated with other program expenses, such as pharmacy cards, outreach activities and educational symposia and fees for operating patient services.
- Administrative and fundraising expenses accounted for 2 percent and 1 percent of total expenses, respectively. For the last five years, the PAN Foundation has spent less than one penny for each dollar of contribution, an extraordinary level of "fundraising efficiency".



No report would be complete in today's environment without reference to healthcare reform. We are monitoring our patient database in light of shifting dynamics as health reform implementation progresses. We expect smaller grants because of the effect of manufacturer rebates, and higher grant volume. The volume increase is a function of the growing use of specialty pharmaceuticals and shift in prescription drug benefit designs requiring more cost-sharing. In anticipation of this shift in the size and volume of patient assistance, we have expanded the number of assistance programs we operate, and implemented several changes in order to be able to efficiently and effectively meet these needs. Consequently, in the face of shrinking grants, we are experiencing continued growth in the demand or need for assistance, which we are proud to say we have been able to meet through our continued growth in revenues.



Read the rest of the PAN Foundation's financials and growth by scanning this QR code, or visiting <https://www.panfoundation.org/images/pdf/2012arpage8financials.pdf>

CHANGES IN FINANCIAL POSITION

Starting this year, PAN records the amount of financial assistance associated with each full grant as program expense in the year that a grant is approved.



✕ **59,283** patients were served in 2012,
✕ **46,334** of whom were new to the PAN Foundation.
✕ = 1,200 patients

41 Total Assistance Programs operated in 2012.

8 of which were new in 2012.

\$179.5m

Received from donors, a **115%** increase over 2011.

HELP

215,453

Number of claims paid out in 2012.



For every dollar donated to the PAN Foundation, **90¢** is used directly in the treatment and medical care of patients.



GENEROSITY



5

Avenues to PAN assistance:



Website



Specialty Pharmacy Portal



Provider Portal



Phone



Manufacturer Reimbursement Support Program

1

Day The number of business days it takes for PAN to make a decision upon receiving an application from a new prospective patient.

238,420

Number of calls received from patients in 2012. In many instances, PAN provided advice and guidance when the patient did not qualify for PAN assistance.

HOPE

81

Number of specialty pharmacies partnered with PAN (at 158 locations).

21,352

Number of providers who helped their patients acquire assistance from PAN in 2012.

24/7

Patients can be enrolled any time of day or night via PAN's state-of-the-art specialty pharmacy and provider portals.



REACH



Finding Light for the Darker Days:

Glen's Story

Glen Tucker knows firsthand that life has ups and downs. He also knows that to be happy and enjoy the life you're given, you have to not only take the good with the bad, but find light in the darker situations. Glen first learned that lesson almost a quarter-century ago when, just after the birth of his son, the company he worked for closed unexpectedly. In the blink of an eye, Glen watched his good job and respectable salary disappear. As a young husband and father, Glen knew he had to find a way to provide for his family. So, when an entry-level opportunity at a bank in Dallas, Texas, presented itself, Glen, his wife and infant son left behind their families, friends and everything they knew in Chicago, Ill., and headed south to start a new life. Glen said he seized the opportunity because he saw it as a way to finally trade Chicago's infamously cold winter for a more favorable climate.

"It was an opportunity to try something different, and escape the cold, so we took it, and never looked back," Glen explained.

Glen and his family took to life in Dallas almost immediately, becoming involved in their church and community. The entry-level bank job that brought the Tuckers to Texas proved to be a good fit and a favorable career move for Glen. A hard worker by nature, Glen worked his way up the career ladder over the next 12 years, eventually being promoted to supervisor and shift manager.

But after more than a decade at the bank, Glen was ready for a change. So, when he was presented with a new opportunity to grow and give back to the community that had become his home, Glen seized it and began working with an after-school program for at-risk youth at the Dallas Juvenile Justice Center. With his no-nonsense attitude, understanding of the value of hard work and infectious cheerful outlook on life, it was a perfect fit for Glen.

"I loved what I was doing, helping local kids who had exhibited 'bad behavior' get their lives on track," he commented.

Glen had been at that position for six years when, in 2008, he hit one of life's darker times – this time involving his health. Though Glen had been diagnosed with Type 2 diabetes more than a decade prior and with hypertension a few years later, he'd been able to bring them both under control through changes in diet and exercise. Or so he thought. Unfortunately, these two conditions took a toll on his body

Thankfully, just when the light grew the faintest and the darkness of their situation threatened to engulf them entirely, the Tuckers found help and hope. Feeling like their financial situation was growing impossible, Glen spoke with a social worker at his treatment facility, who told him that there may be assistance available for his family [for his secondary hyperparathyroidism medication] through the Patient Access Network Foundation.

he had never anticipated – and resulted in Glen developing chronic renal failure.

Glen's diagnosis changed his life, and the lives of his wife and son, forever. The Tucker family's "normal" daily life they'd known for the past 20 years instantly became a thing of the past. Glen began going to a dialysis center to receive treatment for four or more hours every Monday, Wednesday and Friday. This meant that Glen had to quit the job he loved and his family had to adjust to the loss of his income.

"I was going crazy, having just been told that I might die, and realizing that I would need to quit my job," Glen said. "But I knew that my life wasn't over yet. I could keep on living as long as I did what my doctor told me to do."

The Tucker family adjusted to life after Glen's diagnosis – their "new normal" – and Glen's health began to improve. But their journey was riddled with ups and downs as they learned to navigate the myriad challenges of living with a chronic illness and as they weathered the physical, emotional and financial impacts that Glen's disease had on their family.



Read the rest of Glen's story by scanning this QR code, or visiting <https://www.panfoundation.org/pan-stories/313>



TENNESSEE ONCOLOGY COMMUNITY BASED CANCER CARE

Provider Partner Spotlight:

Tennessee Oncology

Tennessee Oncology is a community-based practice that was founded on the belief that every patient deserves the highest quality of care close to home. With more than 35 years of experience treating cancer, the physicians and staff of Tennessee Oncology understand that despite receiving treatment in a familiar environment, their patients still face many challenges.

One of the biggest challenges for many patients is being able to afford the medications they need to get well. To help their patients overcome this challenge, Tennessee Oncology, and its specialty pharmacy, Park Pharmacy, employ a team of patient advocates who work with patients to help them understand their insurance and prescription drug benefits, as well as to assist those patients who may not be able to afford the out-of-pocket costs associated with their specialty therapeutics in gaining access to their life-extending or life-saving medications.

We sat down with Angela Magaha, patient advocate manager, and Stacey McCullough, PharmD, director of pharmacy services, at the Park Pharmacy and Tennessee Oncology to learn more about the work they are doing to provide assistance to their patients and how they are partnering and utilizing the Patient Access Network Foundation to support these efforts.

How do you identify patients who may need financial assistance from a co-pay assistance foundation such as the PAN Foundation?

Angela: Well, as the prescription is being processed, the pharmacy is aware of the co-pay situation on the medication. If the patient expresses hardship or financial need for assistance when the technician is speaking to the patient, then that information is routed to the advocate for support, and he or she looks for foundation assistance programs such as the PAN Foundation.

Have you seen changes in recent years in terms of the number of patients who need co-pay assistance?

Angela: When I started in oncology, Medicare did not have any prescription coverage. So when prescription coverage came through, and the donut hole was created, patients who were on maintenance meds and [have been subsequently] moved to oncology medications were in shock. They don't understand why their co-pay is so high.

So, just talking patients through how their benefits are structured and why this specialty medication co-payment is so different than other maintenance meds that they have taken is just the first step of walking them to an assistance program.

I think the environment of the oral oncolytics has increased – it feels like it's just tripled, the number of oral oncolytics that are available to patients. And I know that the number [of oral oncolytics] is going to continue to grow, so patients are going to have to access oral therapies. It's going to be a very important process – to their regimen and to their treatments that are outlined by the doctors. The environment has definitely changed – insurances are putting more cost-sharing on the patient, and patients often are not even aware of their benefit changes from one year to the next. So if they've been on a medication that had a \$50 co-pay, and maybe their co-pay went to \$500 or something, they're not even aware of the change because they just do not stay in touch most of the time with what or how their insurance is going to change from year to year – very different concept than it used to be.

I actually think this is just the beginning of the changes, but I think we've seen probably more changes in the last five years than I've probably seen in the last 10 years that I've been in oncology.



Read the rest of our interview with Angela and Stacey by scanning this QR code, or visiting <https://www.panfoundation.org/media-room/315>

Continued Help for the Underinsured

In 2012, the Patient Access Network Foundation provided almost 51,000 grants to underinsured individuals who needed cost-sharing assistance for high-cost specialty therapeutics prescribed by a physician to treat a chronic, rare or life-threatening diseases covered by the PAN Foundation.

By providing cost-sharing assistance, the PAN Foundation is able to help individuals who might otherwise delay the start of therapy or not pursue it at all because the associated out-of-pocket costs would be unaffordable relative to their income. For patients who might begin therapy only to realize that they could not afford the cost-sharing requirements, help from the PAN Foundation allows them to complete their full treatment regimen and avoid a

possible financial crisis, such as a medical bankruptcy, or high credit card costs.^{i, ii, iii} The PAN Foundation also helps individuals adhere to their drug regimens by subsidizing out-of-pocket costs for ongoing therapy, which otherwise might be unaffordable, potentially leading them to skip doses or terminate treatment early. Either scenario can have a negative impact on health.

UPDATE ON THE UNDERINSURED

Researchers at the Commonwealth Fund are credited with developing three indicators of underinsurance based on the percentage of income that various cost-sharing amounts represent.^{iv}

Number of Underinsured Continues to Increase

In last year's report, the PAN Foundation described an underinsured population of approximately 47 million, including almost 29 million adults aged 19 to 64 who were underinsured, despite having health insurance all year. According to the most recent Commonwealth Fund Biennial Health Insurance Survey, there were 30 million underinsured adults in 2012, 1.9 times more than in 2005. Two-thirds of the underinsured adults had an income that was less than 250 percent of the federal poverty level (FPL). In 2012, the FPL was \$11,170 for a single person or \$15,130 for a couple.^v

The Commonwealth Fund survey found that one-third of the underinsured adults with a chronic condition skipped doses or did not fill a prescription to treat that condition because of cost. Research has shown that health outcomes are adversely impacted when high out-of-pocket costs lower a patient's adherence to a drug regimen for chronic conditions, including cancer.^{vi}

Medicare Beneficiaries

The potential that an average Medicare beneficiary could be underinsured is evident due to a high percentage of out-of-pocket spending. The annualized value of the Social Security benefit was \$13,812. In 2012, the median income among all Medicare beneficiaries was \$22,500. It was lower among beneficiaries who are African-American (\$15,252) or Hispanic (\$13,508) and among women (\$20,920).

INDICATORS OF UNDERINSURANCE

1. Deductible amount equals at least 5 percent of annual income.
2. Deductible, co-insurance and co-payment amounts equal at least 5 percent of income up to twice the federal poverty rate.
3. Deductible, co-insurance and co-payment amounts equal at least 10 percent of income, in excess of twice the federal poverty rate.

Medicare beneficiaries are also experiencing the impact of the increased use of co-insurance as more Medicare Part D prescription drug plans are beginning to apply an increased rate of 33 percent co-insurance for specialty drugs during the initial coverage limit period. Medicare beneficiaries who rely solely on Original Medicare coverage for Part B-covered drugs are more likely to be underinsured because they are not protected by the annual out-of-pocket limit that a Medicare Advantage (MA) plan must offer, and they do not have supplemental coverage for Part A and Part B cost-sharing.^{vii}

Monthly out-of-pocket spending on services covered by Part B and Part D represented 26 percent of the average monthly Social Security benefit.

The Privately Insured

The challenge of affording cost-sharing liabilities increasingly affects “middle-class” individuals and families with private insurance because of overall trends in the general economy and the specific changes in the healthcare sector. For example, median income fell 8 percent (in constant 2011 dollars) between 2007 and 2011 – an average of 2 percent per year. At the same time, health insurers introduced several benefit designs that increased cost-sharing, particularly for specialty medications. The changes include the increased use of separate deductibles for the pharmacy benefit and

the major medical benefit, and are applied to each individual with family coverage separately rather than the family as a whole. There has also been a re-emergence of co-insurance rather than flat co-payments, with some plans setting the co-insurance for specialty drugs as high as 50 percent.

The combined effect of lower incomes and higher cost-sharing increases the likelihood of an individual being underinsured and, therefore, requiring patient assistance if diagnosed with a critical or chronic illness.

Benefit Designs Influence Potential for Underinsurance: Medicare & Private Insurers

Medicare beneficiaries can be underinsured specifically for specialty drug therapies for several reasons: the coverage status of the drug (Part B or Part D) and whether or not the beneficiary has some form of financial protection for cost-sharing requirements, either in the form of an annual maximum out-of-pocket limit or supplemental coverage.

Medicare Part B-Covered Drugs:

The cost-sharing requirements for Part B-covered drugs can differ depending on whether the beneficiary is covered solely by Original Medicare or is enrolled in a Medicare Advantage plan. Beneficiaries in the first group are more likely to be underinsured because they are required to pay 20 percent of the allowed charge for the drug, without any annual limit on their out-of-pocket costs. In contrast, the Medicare Advantage enrollees are protected by the maximum out-of-pocket limit, which ends the patient’s cost-sharing responsibility for the rest of the year.^{viii}

Medicare beneficiaries who are less likely to be underinsured are those who have supplemental coverage for Part A and Part B cost-sharing requirements, the most common of which is an employer retirement plan or an individual Medigap plan.

“Full” or “Partial” Extra Help from the Low Income Subsidy (LIS) program, which provides premium and cost-sharing subsidies, varies by income. For both groups, however, the LIS program eliminates the coverage gap.

Medicare Part D-Covered Drugs:

The cost-sharing requirements for Part D-covered drugs differ from those in Part B because of the unique design of the Part D benefit. Moreover, they vary by plan and whether or not the Medicare beneficiary has obtained Extra Help.

Part D has different cost-sharing requirements for each phase of coverage, including the deductible phase, the initial coverage limit phase, the coverage gap phase (or donut hole) and the catastrophic phase. The out-of-pocket cost limit in the Medicare Part D benefit is different because there is a true out-of-pocket (TrOOP) limit, which determines when the 5 percent catastrophic coverage phase begins. In 2012, the TrOOP limit was \$4,700. However, unlike the MA maximum limit or employer-sponsored plans, which end the patient’s cost-sharing responsibility for the rest of the year, the TrOOP limit does not end the obligation; it only lowers the co-insurance rate to 5 percent.

Individuals in lower-income households who do not qualify for Extra Help may need cost-sharing support during the “donut hole” or coverage gap period. In addition, some may need financial assistance during the catastrophic phase when the co-insurance amounts are unaffordable for high-cost specialty drugs, despite the co-insurance rate of 5 percent.

Private Health Insurance Benefit

Design: Individuals with private insurance are most likely to be underinsured if their annual cost-sharing requirements exceed 5 or 10 percent of their income, depending on whether it is more or less than twice the FPL. Although private insurers and health plans in the employer, small-group and individual markets have experimented with various approaches to incorporate cost-sharing requirements into their health benefit designs, including deductibles, co-payment amounts and/or co-insurance percentages, and a maximum out-of-pocket limit, most are constrained by the annual maximum out-of-pocket cost limit, which applies to high-deductible health plans (HDHPs) and is set by the Internal Revenue Service (IRS). For 2012, the maximum out-of-pocket limit for HDHPs was \$6,050 for self-only coverage and \$12,000 for self-and-family coverage. HDHPs are required to have minimum deductible amounts, which in 2012 were \$1,200 per year for self-only coverage and \$2,400 for self-and-family coverage.



PAN 2012 Foundation Experience:

Characteristics of Patients Receiving Help from the PAN Foundation

Among the more than 50,000 cost-sharing grants awarded by the PAN Foundation in 2012, 83 percent were awarded to patients with an annual income below 300 percent of the FPL (i.e., the annual income for 56 percent of the approved applicants was, at most, twice the FPL; for 27 percent, the income was between 201 and 300 percent of the FPL).

Seventy-eight percent, or 39,000, of the cost-sharing grants were used to pay the cost-sharing amounts for specialty drugs covered by Medicare Part B and/or Part D. Medicare beneficiaries represent the majority of patients who are helped by the PAN Foundation, in large part due to the original design of the PAN Foundation program and the Advisory Opinion received from the Office of the Inspector General (OIG) in the federal Department of Health and Human Services (HHS).

The Medicare beneficiaries helped by the PAN Foundation received an average of \$2,371 in cost-sharing assistance that otherwise would have been an out-of-pocket cost borne by the patient or patient's family. For 72 percent of these grants, the beneficiary relied solely on Medicare. The majority (45 percent) had unlimited cost-sharing requirements because they were covered only by Original Medicare, while 26 percent were enrolled in a Medicare Advantage plan that had an annual out-of-pocket cost limit, typically between \$3,400 and \$6,700.

The annual income for Medicare patients served by the PAN Foundation was typically less than 200 percent of the federal poverty level (i.e. 58 percent). PAN patients with Original Medicare coverage and no supplemental coverage were more likely to have incomes less than 200 percent of FPL (61 percent) compared to those covered by an MA plan (54 percent).

- Single persons with income less than 300 percent of the FPL have an annual income at or below \$33,510.
- Couples with income less than 300 percent of the FPL have an annual income at or below \$45,390.

The Affordable Care Act and the Need for Cost-Sharing Assistance

The *Patient Protection and Affordable Care Act of 2010* (ACA) has already made an impact on the need for cost-sharing assistance by lowering cost-sharing requirements for MA plan and Part D enrollees and for early retirees covered by an employer-sponsored plan that received a federal subsidy from the Early Retiree Reinsurance Program. In addition, cost-sharing became a new requirement for two newly insured populations, including dependents up to age 26 covered by a parent's health insurance and individuals who obtained coverage through the Pre-Existing Condition Insurance Program (PCIP).

Incomes of Medicare Beneficiaries Receiving a Cost-Sharing Assistance Grant from the PAN Foundation

	Patients with Original Medicare Only	Patients with Medicare Advantage
Income as Percent of FPL	%	%
125% - 200% of FPL	38%	37%
200-400% of FPL	36%	43%
400% of FPL and above	3%	3%

The latter experience is similar to the phenomenon that will be realized in 2014 when millions of currently uninsured individuals receive coverage through a state Medicaid program or a health insurance exchange. Among the newly covered who will obtain coverage through an Exchange, the need for cost-sharing may be higher for individuals with an income above 250 percent of the FPL because they will not receive cost-sharing assistance from the LIS program. This will increase actuarial value beyond the 70 percent associated with a silver plan.^{ix} The actuarial value is the share of healthcare expenses that a health plan covers for a typical group of enrollees. For example, a silver plan is designed so that the health plan will pay for 70 percent of the costs of the covered benefits provided to a typical group of enrollees who would be expected to pay the remaining 30 percent in the form of deductibles, co-insurance and co-payments. While these plans include essential benefits, they are not expected to be as inclusive as Medicare or many commercial or employer-sponsored

insurance plans.

The analysis of the 2012 Experience demonstrates that the PAN Foundation is ready for the type of changes expected in 2014. In particular, PAN expects that the need for cost-sharing support will be influenced by the availability of ACA cost-sharing subsidies, such as those for individuals whose income does not exceed 250 percent of the FPL. For low-income individuals, the cost-sharing subsidy can increase the actuarial value of the plan to 90 percent, the platinum level. While there may be some cost-sharing, depending on whether the plan is offered by a state health insurance Exchange or the federal Exchange, all plans will have an annual limit on out-of-pocket costs.

PAN has re-visited its patient assistance model and anticipates the need for more flexibility and fiscal integrity. The PAN Foundation strengthened its financial position and has plans for making modifications to its patient assistance model.

- i A recent survey by the *Commonwealth Fund* found that 55 percent of underinsured adults have had problems with medical bills or accrued medical debt.
- ii David I. Auerbach and Arthur L. Kellermann, [A Decade Of Healthcare Cost Growth Has Wiped Out Real Income Gains For An Average US Family](#), *Health Affairs*, 30, no.9 (2011):1630-1636.
- iii David U. Himmelstein, MD, Deborah Thorne, PhD, Elizabeth Warren, JD, and Steffie Woolhandler, MD, MPH, [Medical Bankruptcy in the United States, 2007: Results of a National Study](#), *The American Journal of Medicine*, Volume 122, Issue 8, Pages 741-746, August 2009.
- iv Cathy Schoen, Sara R. Collins, Jennifer L. Kriss and Michelle M. Doty, [How Many Are Underinsured? Trends Among U.S. Adults, 2003 And 2007](#), *Health Affairs*, 27, no.4 (2008):w298-w309 (published online June 10, 2008; 10.1377/hlthaff.27.4.w298).
- v [Annual Update of the HHS Poverty Guidelines](#), *Federal Register*, Vol. 77, No. 17, January 26, 2012.
- vi Sarah R. Collins, Ruth Roberson, Tracy Garber and Michelle M. Doty, [Findings from the Commonwealth Fund Biennial Health Insurance Survey](#), 2012.
- vii [CMS Landscape Analysis, 2013 Prescription Drug Plans](#), *Centers for Medicare and Medicaid Services*, December 2012.
- viii The annual limits are between \$3,400 and \$6,700 depending on the MA plan.
- ix [Actuarial Value and Cost-Sharing Reductions Bulletin](#), *The Center for Consumer Information & Insurance Oversight, Centers for Medicare and Medicaid Services*, February 24, 2012.

On Behalf of the PAN Foundation, Thank You!

Through the generosity of our donors, the Patient Access Network Foundation has been able to award more than **200,000** patient grants and more than **\$350 million** to more than **160,000** patients to date. In 2012 alone, the PAN Foundation provided almost **60,000** underinsured critically or chronically ill patients with more than **\$108 million** in financial assistance, helping them access their cutting-edge medications today, so they would have hope for a healthier tomorrow.

Had financial assistance from the PAN Foundation not been available, these patients might have had to go without their life-saving, high-value medications, severely impacting the quality of life and well-being for themselves and their families. Fortunately, this was not the case. The PAN Foundation was able to provide help and hope to patients with chronic or life-threatening diseases, a feat that is possible only because of the kind and generous help and support of our donors.

But our job is not finished. Each year, we strive to help more patients and award more grants. And we can't do it alone.

Last year was a record-breaking fundraising year for the PAN Foundation. As we enter our 10th year and look forward to celebrating our diamond anniversary next spring, help us break another record, so that together we can be a source of help and hope to underinsured critical and chronic disease patients and their families for many more decades to come.



Learn more about ways to give by visiting PANFoundation.org/ways-to-give and consider making a contribution today. As the PAN Foundation is a U.S.-based, independent 501 (c) (3) nonprofit organization, donations are tax-deductible and may be designated for specific assistance programs.

Help & Hope for the Duration

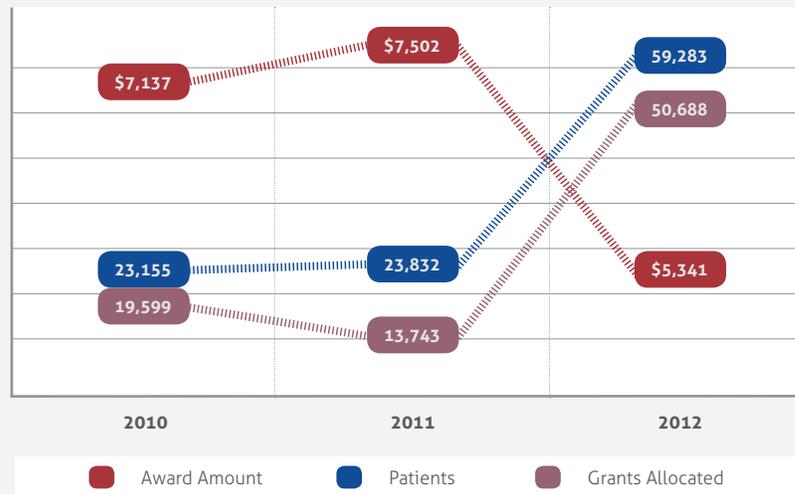


Dear Friends of PAN,

The theme of this year's report has been to focus on our growth over the past few years. That growth comes as a result of the generosity of our donors, support of an independent and well-credentialed Board of Directors, strong partnerships with providers and specialty pharmacies and talented staff. I am humbled by the opportunity to work among sincerely dedicated stakeholders.

Not only is the PAN Foundation growing as an organization, but the need for patient assistance is also growing and changing as the implementation of healthcare reform begins. Earlier, we indicated that we expect higher application volume as previously uninsured consumers embrace health insurance reluctantly or with low enthusiasm, probably migrating to plans with significant out-of-pocket liabilities. This is occurring against the backdrop of significant rebates from manufacturers resulting in smaller liabilities. As expected, we are already beginning to experience a higher volume of requests for assistance for a lesser amount of co-payment assistance – a trend that we expect to continue and to increase steadily as millions more consumers are enrolled in these insurance plans in the coming years.

Higher Volume, Smaller Grants



There is gratification in working with large and growing numbers of patients and their families. But, small or large, our fundamental purpose remains the same -- to address a quirk in our healthcare system that leaves insured patients with critical and chronic illnesses facing unimaginable financial obligations. These are families who believed they planned responsibly. They insured their homes, cars, lives and health. As a general rule, each of us knows our out-of-pocket obligations for the first three. Not so with health insurance.

We labor daily working to assure that all chronic and life-threatening disease patients across the country have access to the same cutting-edge therapies, because we believe that no person should be prevented from getting the medication they need to get better for any reason, especially because of unaffordable cost-sharing. Walking home each evening, I feel good knowing that we have touched hundreds of thousands of lives by bringing these patients and their families the help they need today, so they have hope for a healthier tomorrow. But I go to sleep wondering about those we could not help, dreaming of a day when we can expand our reach such that no patient is prevented from accessing the medication they need because of cost-sharing.

Thanks to the support of all of you, the number of lives we touch continues to grow, and the number that we could not help shrinks. With your continued support, I am optimistic that together we can work towards making this dream a reality one day, providing any patient who needs it with help for today, so they have hope for a healthier tomorrow.

Warmest regards,



Patrick McKercher, PhD, RPh
President, PAN Foundation

PAN Foundation 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 non-governmental organization delivering social marketing, behavioral change, and product delivery to more than 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.

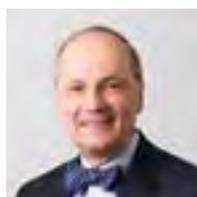


Allan Goldstein, MD, MPH, FACP [Vice Chair], has a clinical background in internal medicine and consults in the areas of consumerism, patient advocacy, provider performance measurement and development of innovative primary care delivery systems. He obtained his medical training at the Albert Einstein

College of Medicine and received a master of public health degree from Columbia University. Dr. Goldstein is board certified in internal medicine and a fellow of the American College of Physicians.



Anita Plotinsky, PhD [Secretary], brings to the PAN Foundation 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 D.C.



Donald Barone, DO, is a course director and associate professor of neurology at the University of Medicine and Dentistry of New Jersey, School of Osteopathic Medicine. A graduate of Rutgers College and Philadelphia College of Osteopathic Medicine, Dr. Barone completed his training at the

John F. Kennedy Memorial Hospital, the University of Vermont College of Medicine Department of Neurology and finally with the Muscular Dystrophy Association of the Columbia Presbyterian Medical Center. Having now spent almost 30 years practicing neurology, with research interests in multiple sclerosis and neuroimmunology, and 20 years as a member of the Kennedy Health Center Board of Directors, Dr. Barone brings a new genre of expertise to the PAN Board of Directors.



Lyn Boocock-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. Boocock-Taylor has worked in the advancement field for 30 years, raising millions of dollars for projects in the Philadelphia area.



David Borenstein, MD, is a practicing rheumatologist in Washington, D.C., and a clinical professor of medicine at The George Washington University Medical Center. He attended Columbia University and Johns Hopkins University School of Medicine, where he completed his medical training. Dr.

Borenstein is a past president of the American College of Rheumatology and the Rheumatism Society of the District of Columbia. He has served on the board of directors and executive committee for the Arthritis Foundation, the American College of Rheumatology Research and Education Foundation. In addition, Dr. Borenstein served on the medical advisory board of the Lupus Foundation of Greater Washington. He is a member of the International Society for the Study of the Lumbar Spine.



Stephen F. Loeb, PhD, is Professor Emeritus with the Division of Health Services Management and Policy, School of Public Health at The Ohio State University. Dr. Loeb 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.



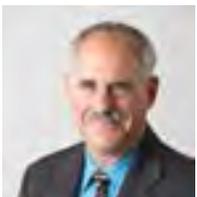
Michael O'Grady, PhD, is a health policy expert with 24 years of experience working with Congress and the Department of Health and Human Services. Throughout his career, he has helped shape significant healthcare legislation on a broad spectrum of issues. He has been instrumental in the

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, Ga. 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 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 health-care 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 at 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 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.



Norrie Thomas, PhD, is an entrepreneur who founded, launched and managed several pharmacy managed care companies. Dr. Thomas helped found one of the first pharmacy benefit management companies; Clinical Pharmacy Advantage (CPA). Norrie Thomas has held

senior management positions at MedCenters Health Plans, Aetna, Clinical Pharmacy Advantage, McKesson, PCS, Eli Lilly, St. Jude Medical, Schering-Plough, and Magellan Health Services. She holds bachelor's, master's and doctoral degrees from the University of Minnesota College of Pharmacy and she studied as a visiting researcher at the London School of Economics. She is one of the founders of the Academy of Managed Care Pharmacy (AMCP). Dr. Thomas holds adjunct faculty positions at the University of Minnesota and Drake University. She is senior fellow with the College of Pharmacy Center for Leading Healthcare Change at the University of Minnesota, where she has successfully executed the "Dialogues in Managed Care Leadership" series since 2009.

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Last year, the PAN Foundation provided help and hope to almost 60,000 patients across the country. Despite their differences in age, appearance, interests and backgrounds, all of these patients had one thing in common: They were in the middle of the fight of their lives, the fight against their illness. You can meet three very different patients united by the common experience of battling cancer in our new video, **Help for the Fight, Hope for the Future**, by scanning this QR code or visiting <https://www.panfoundation.org/news-article-list/295-help-for-the-fight-and-hope-for-the-future-dispatches-from-the-front-lines-of-the-battle-against-cancer>

Hear from another chronic disease patient and his family about the experience battling, and defeating, illness with help from the PAN Foundation. Scan this QR code or visit <http://www.panfoundation.org/pan-stories/284> to watch **Help, Hope and A Healthy Future: Mark's Story** now!



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