2018 ANNUAL IMPACT REPORT



# Putting PATIENTS FIRST

Improving
THE IMPACT



## **OUR MISSION**

Patient Advocate Foundation (PAF) is a national 501(c)3 non-profit organization which provides case management services and financial aid to Americans with chronic, life-threatening and debilitating illnesses.

## **OUR HISTORY**

PAF was founded in 1996 by Nancy Davenport-Ennis and Jack Ennis to help address the issues faced by patients like their friend Cheryl Grimmel, who had to battle not only her breast cancer but for access to affordable treatments. In PAF's first year, Nancy and a part-time volunteer staff of 2 provided case management assistance to 157 patients who faced barriers to prescribed care. Fast forward to 2018, and we've helped a cumulative total of more than 1.2 million patients nationwide with support provided by more than 200 staff.





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"High quality healthcare is not just about treatment; it's about a care plan that considers challenges to daily life – transportation, housing, food security, employment, childcare and self-care."

## **WELCOME**

The 2018 Annual Impact Report is a testament to the patients we serve. They have *entrusted us with their stories and for that we are immensely grateful*.

Our mission is to deliver compassionate, effective interventions that address access and affordability issues experienced by patients as they navigate care in the world's most expensive and complicated healthcare system. We strive to quantify and qualify the experience of vulnerable, underserved people of all kinds while increasing the types of assistance and programs we offer that improve the lives of those battling serious illness right now. We seek to amplify their voices, their experiences, their concerns and their priorities.

High-quality healthcare is not just about treatment; it's about a care plan that considers challenges to daily life – transportation, housing, food security, employment, childcare and self-care. We know that too many people are trying to figure out how to pay for the medications, hospital bills and lab tests while keeping the lights on and putting food on the table. We envision a future in which a care team surrounds each patient and responds to these concerns in a comprehensive and effective way, which is what our case management and financial support programs are designed to do. This report spans those programs as well as additional service areas that are inspired and informed by them: Health Services Research, Patient Education and Health Equity Initiatives.

In these pages you will find the story not only of the patients we helped, but also of the dedicated staff at PAF who help them. I am proud to stand alongside so many others who are committed to serving patients with kindness, accountability and excellence.

And finally, I would like to thank our donors. It is their support that makes our mission possible.

Alan J. Balch, PhD

Chief Executive Officer

Alun J. Bolch

## **OVERALL FOUNDATION IMPACT**

#### **SUMMARY OF PAF TOTAL PATIENT CASES AND CONTACTS IN 2018**

Total Patient Case Count	142,109
Case Management Cases	24,804
Co-Pay Relief Cases	82,106
Financial Support Programs Cases	25,003
Patient Services Email Helpline Sessions	10,196

Total Patients Assisted by PAF between 1994 and 2018

1,218,555



"... PAF not only helped shepherd me through my appeal process but explained my best options, expectations, and next steps at every single point throughout the process ... having been through the appeals process, I have a better understanding of just how important having a patient advocate can be in protecting and intelligently fighting for the rights of patients, who are too often vulnerable ... Thanks for being in my corner, and in all of ours!"

Michael | heart attack

## SERVED PATIENTS IN ALL STATES TOP 10 STATES SERVED FL, TX, CA, GA, NY OH, PA, NC, IL, TN



584
DIFFERENT DIAGNOSES

**19% INCREASE OVER 2017** 

222 RARE DISEASES, a 30% INCREASE OVER 2017



CASE MANAGEMENT
PROGRAMS
SERVED 11% MORE PATIENTS
AND
NEGOTIATED \$22,108,236
IN DEBT RELIEF

#### **SUMMARY OF PAF CASE MANAGEMENT PATIENT CASES AND CONTACTS IN 2018**

**Total PAF Case Management Cases** 24,804 **Total PAF Case Management Contacts** 402,545 Average Contacts Per Case 16.14 Average Issues per Case 1.75



#### AVERAGE MILEAGE TRAVELED FOR TREATMENT

24 MILES **ALL CASES**  20 MILES

37 MILES CASES WITH A TRAVEL ISSUE

 $86^{\%}$  increase in travel distance for those with a travel–related problem

#### **TOP ISSUE CATEGORIES FACED BY PATIENTS SEEKING CASE MANAGEMENT HELP**



Insurance Issues



**Debt Crisis/** Cost-of-**Living Issues** 



**Uninsured** Issues

**NEGOTIATED** \$22,108,236

in **DEBT RELIEF** on behalf of patients

**DISTINCT PATIENT DIAGNOSES** 

490 584

"Thanks so much for your help. It meant so much to end the sleepless nights and not worry with these rent and medical debt situations. So once again thank you PAF from the bottom of my heart."

Colleen | breast cancer

#### **TOP 5 DIAGNOSIS CATEGORIES FOR CASE MANAGEMENT**



Cancers

Chronic or **Debilitating** Conditions



Cardiovascular Conditions



**Nervous** System Conditions



<u>Autoimmune</u> **Diseases** 

#### **CASE MANAGEMENT PATIENTS AGE OF PATIENTS ETHNICITY 2.17%** Birth to 18 20.16% African American 0.52% American Indian/Alaska Native **14.99%** 19 to 35 **2.71%** Asian **28.75**% 36 to 55 1.68% Blended Race **44.80%** 56 to 75 0.29% Caribbean Islander **9.29%** Over 75 **63.26%** Caucasian 10.71% Hispanic/Latino 0.54% Middle Eastern **EMPLOYMENT STATUS** 0.13% Native Hawaiian/Other Pacific Islander 25.80% Disabled **24.57%** Employed INCOME GROUPS **51.42%** Less than \$23.999 2.14% Full-Time Student **27.12%** \$24,000 - \$47,999 0.70% Homemaker 0.74% Minor Child **4.67%** \$48,000 - \$71,999 **26.91%** Retired **10.44%** \$72,000 - \$95,999 2.47% Self-Employed **2.78%** \$96.000 - \$119.999 16.67% Unemployed **3.57%** \$120,000 or More



"I had to have them [PET scans] to detect if the chemo was working. I spent months trying to fix what was happening when my niece found PAF's number.

My patient advocate was an angel and 9 months later I found out that my scans were all being covered.

I couldn't have done it without PAF's help."

Ruthie | stage IV metastatic breast cancer



PAFatwork.org/mission

What PAF Does as Told by Case Managers and Patients



Rita Robinson of PAF





## **CASE MANAGEMENT**

The delivery of effective, compassionate case management interventions to patients who have been diagnosed with a chronic, life-threatening and/ or debilitating illness is at the heart of our mission. Our professional case managers help tens of thousands of patients each year, enabling them to have access to physician-prescribed healthcare services, overcome insurance barriers, locate resources to support cost-of-living expenses, evaluate and identify insurance coverage and manage out-of-pocket expenses.

We regularly and systematically assess the needs of patients to inform the development of innovative programs and educational initiatives to address emerging patient and caregiver concerns.

Case management served more than 24,000 individual patients through 19 unique programs; 11 of these focus on people living with cancer while 8 focus on people living with other debilitating conditions. We continue our partnership with the LIVESTRONG Foundation, serving as the administrator of the LIVESTRONG Navigation and the LIVESTRONG Fertility Discount Programs since November 2015, assisting 3,538 new clients and 61 returning clients in 2018 through that initiative.

#### **NEW PROGRAMS LAUNCHED**



Begin Again Foundation supports general case management for patients with sepsis, acute respiratory distress syndrome and toxic shock syndrome. beginagainfoundation.com



Fred Hutchinson Financial Literacy Project provides case management navigation and collects data on newly diagnosed cancer patients to examine the impact of financial toxicity on these patients.

fredhutch.org/en.html

"My 18-month-old son was diagnosed with autism. A genetic test performed on him was denied. I called PAF and they promptly responded. It was approved, and the claim processed."

Gulnara, mother of the patient

#### **TOP NON-CANCER DIAGNOSIS CATEGORIES**

with Individual Disease Breakout

Diagnosis Category	Top 5 Diagnoses Within Each Category
Autoimmune Diseases	Rheumatoid Arthritis Arthritis Osteoarthritis Lupus Degenerative Arthritis
Cardiovascular Conditions	Pulmonary Hypertension Congestive Heart Failure Heart Attack Hypertension Atrial Fibrillation
Chronic or Debilitating Conditions	Osteoporosis COPD (Lung Disease) HIV, AIDS Crohn's Disease Hepatitis C
Nervous System Conditions	Multiple Sclerosis Stroke (CVA) Parkinson's Disease Seizure Disorder Chronic Inflammatory Demyelinating Polyneuropathy

The introduction of several enhancements aimed to improve overall patient experiences.



We introduced an online help request portal on PAF's website, resulting in a 22.7% increase in electronic patient submissions



We offered live case management access through an advanced triage process



We launched a newly designed website offering educational materials in many formats, with self-navigation tools and resources that are user-friendly patientadvocate.org



"When I first contacted PAF we were hundreds of thousands of dollars in debt from balance billing from my husband's life-threatening stroke. After months of dealing with this, (my husband was learning to talk again) I was no longer sleeping from trying to figure this all out by myself... I found PAF online and everything changed! This was a very large and confusing case but my advocate always remained calm and professional. I am thrilled to report that ALL of the balance billing was taken care of! This is a blessing that resulted from me contacting PAF!!!"

Susan, wife of patient

# TOP RESOLUTIONS ACHIEVED BY CASE MANAGERS

- 11% Facilitated/Secured Transportation Assistance
- 10% Obtained Financial Assistance Negotiated Payment Plan/Discount
- 7<sup>%</sup> Facilitated Rental/Mortgage Payment Relief
- 7% Applied for Financial Assistance Patient Assistance Program
- 6% Facilitated Utility/Phone Relief
- 4<sup>%</sup> Provided Guidance Regarding Disability Process
- 4<sup>%</sup> Offset Cost Through Alternative Assistance
- 4% Educated on General Benefit/ Coverage Questions
- 3<sup>%</sup> Facilitated/Located Food Assistance
- 2<sup>%</sup> Applied for Financial Assistance Manufacturer Free Product

"My experience with PAF is miraculous.

After my husband died of colon cancer
I discovered I had no insurance a week
later ... I paid my [premium] ... and kept
my receipt ... I was still told I had no
insurance ... With all options for help
gone, I felt hope with PAF ... In the latter
part of June [my case manager] called to
say, "you won." I broke down and cried
... my insurance had been reinstated ...
All the issues were resolved: debt crisis,
access to care and insurance issues ..."
Stephanie | breast cancer

## **CASE MANAGEMENT**

Our case management interventions continue to reach the nation's most vulnerable patient populations. Roughly half of the patients served by the program earn less than \$24,000 annually and 42% are either disabled or unemployed. The patients we help are also demographically diverse with 37% reporting an ethnicity other than Caucasian and roughly 50% reporting an age older than 56.

PAF's case management program is designed to offer "precision charity" whereby the right help is provided at the right time. Just as every patient's illness has attributes that are unique biologically, immunologically or genetically, so, too, their challenges have attributes that are unique financially, logistically and socially.

Our case management process starts with listening to the patient's or caregiver's needs and concerns. We then document the specific issues they identify using a classification system that recognizes more than 200 unique problems for which a patient may be seeking help. Rarely does any one issue account for more than 10% of the total types of reported issues, which reflects the diversity of the issues patients face. Provided below are the top 5 issues reported to PAF case managers in 2018. Transportation has long dominated the top of this list and 2018 was no exception with nearly 10% of patients reporting an issue with transportation as a reason for seeking help.

**TOP 5 SPECIFIC CASE MANAGEMENT ISSUES** 

Inability to afford utility/shut off notice

# Inability to afford transportation expenses 10% Inability to afford care - hospital/facility cost share 9% Inability to afford care - medication cost share 8% Inability to afford rent/mortgage 7%

6%

The resolutions a case manager works toward on behalf of a patient or caregiver can also take on many forms, a reflection of the complexity of our healthcare delivery system and the safety net resources available to support patients with various types of problems. PAF has a process for documenting the resolutions achieved by our case managers to address the issues identified by patients. Provided in the column on the left are the top 10 most common resolutions our case managers achieved on behalf of the patients and caregivers they helped.

We are unwavering in our commitment to pursue equal access to healthcare for all patients by overcoming one healthcare barrier at a time. At the same time, we develop resources and knowledge to help many patients at once through the delivery of actionable educational resources and the implementation of research initiatives that prioritize the patient voice in support of health system delivery reform to achieve person-centered care.

## **FINANCIAL SUPPORT PROGRAMS**

Through our financial support programs, we provide small grants to patients for a broad range of needs as well as partner with other non-profit organizations to manage the administrative aspects of their financial assistance programs. These programs are designed to mitigate the burden of certain non-medical expenses, including transportation, housing, short-term lodging, utilities and nutritional needs.

We offered nine individual financial support programs during 2018, providing help to more than 25,000 patients, and served multiple disease areas including:

- · Heart Valve Disorders
- Metastatic Breast Cancer
- Multiple Myeloma
- · Merkel Cell Carcinoma
- · Acute Myeloid Leukemia



"I want to thank [the Foundation] for their support and donation towards helping pay my bills when times were tough. They were there when I needed help and for that I'll always be grateful."

Veronica | breast cancer

"... I received funds from the Metastatic Breast Cancer fund to pay my rent.

The process was easy, non-evasive, professional, considerate, and most important, swift! Since my situation was desperate and timely, I did not have to wait long for assistance ..."

Toni | breast cancer









#### **IMPACT OF CO-PAY ASSISTANCE AS DESCRIBED BY PATIENTS**







Reduced Psychological Stress



quality of life)





"You help ease financial stress that comes from this disease. Money stress will kill you."

**Recipient of Co-Pay Relief Services** 



#### **APPROVED DISEASE FUNDS** (as of December 2018)

Alpha-1 Antitrypsin Deficiency (FF) Alzheimer's Disease(FF)

Amyotrophic Lateral Sclerosis (ALS)

Ankylosing Spondylitis Asthma\* (FF) Bladder Cancer\* (FF)

**Brain Cancer** Breast Cancer\*

Cancer Genetic and Genomic Testing Fund\*

Cervical Cancer\*

Chronic Obstructive Pulmonary Disease (FF) Coronary Artery Disease (FF) Crohn's Disease (FF) Cystic Fibrosis Electrolyte Imbalance\*

Epilepsy (FF)
Head & Neck Cancer Heart Failure (FF)

Hepatocellular Carcinoma / Liver Cancer (FF)

HIV, AIDS and Prevention\*

Homozygous Familial Hypercholesterolemia\*

Huntington's Disease Hyperlipidemia

Inherited or Acquired Lipodystrophy\*

Lupus (FF) Melanoma (FF)

Metastatic Bladder Cancer (FF) Metastatic Breast Cancer\*

Metastatic Colorectal Cancer\* (FF)

Metastatic Gastric Cancer\* (FF)

Metastatic Melanoma (FF)

Metastatic Prostate Cancer\* (FF) Multiple Myeloma\*

Multiple Sclerosis\* (FF)

Muscular Dystrophy

Myelodysplastic Syndromes\* (FF) Myeloproliferative Disorder (FF)

Narcolepsy Neoplasm Related Pain

Non-Small Cell Lung Cancers\* (FF)

Ovarian Cancer\* Pancreatic Cancer (FF) Parkinson's Disease (FF) Periodic Paralysis\*

Peripheral vascular disease (FF)

Prostate Cancer\* (FF) Psoriatic Arthritis (FF)

Pulmonary Hypertension\* (FF)

Rheumatoid Arthritis\*

Sarcoma of the Bone Skin Cancer\* (FF)

Stroke (FF) Testicular Cancer Thyroid Cancer (FF)

Ulcerative Colitis\* (FF) Uterine Cancer\* Virology Testing Fund

(\*) Denotes silos that are currently operational and serving new and/or existing patients. (FF) Denotes funds for patients with Medicare, Medicaid or Military Benefits only.







Our Co-Pay Relief (CPR) program can provide direct financial assistance to qualified patients with co-payments, co-insurance or cost-sharing related to any therapeutic and supportive medications, generic or bioequivalent products prescribed to treat and/or manage the patient's specific disease or condition covered by the fund.

CPR operated 30 individual disease funds including Bladder Cancer, Breast Cancer, Cervical Cancer, Chronic Pain, Electrolyte Imbalance, Hepatitis B, Hepatitis C, HIV, Aids & Prevention, Homozygous Familial Hypercholesterolemia, Inherited or Acquired Lipodystrophy, Metastatic Breast Cancer, Metastatic Colorectal Cancer, Metastatic Gastric Cancer, Metastatic Prostate Cancer, Multiple Myeloma, Multiple Sclerosis, Myelodysplastic Syndrome, Non-Small Cell Lung Cancers, Osteoporosis, Ovarian Cancer, Periodic Paralysis, Peripheral Vascular Disease, Prostate Cancer and Pulmonary Hypertension.



#### **New Funds Launched in 2018**

- Asthma
- · Cancer Genetic & Genomic Testing
- · Rheumatoid Arthritis
- Skin Cancer
- Ulcerative Colitis
- Uterine Cancers

Since the launch of CPR in 2004, we have adhered to a set of guiding principles that have created a secure, supportive and sustainable patient service. As a pioneer in the field of co-payment support programs, we operate our program in compliance with the guidance provided by the Office of Inspector General (OIG), while placing the needs of the patients we serve at the center of our program design.

In 2018, we embarked on a CPR patient impact and satisfaction study to understand the ways in which co-payment assistance helps people and their families. The comprehensive analysis identified the reported impact of CPR services with thematic and trend breakdown as reflected in satisfaction surveys, unsolicited testimonials and thank you letters and written feedback from over 2,500 patients and caregivers. Many shared in detail the impact we had on their care and life.



"Caring feeds the part of one's soul that dies when our bodies fail."

> Recipient of Co-Pay Relief Services

## CPR PATIENT IMPACT AND SATISFACTION STUDY

#### **Results**

- Reduction of the family's overall financial strain was the most frequently reported impact of receiving co-pay assistance
- Co-pay assistance reduces financial strain and allows patients to use their very limited resources on necessities to preserve their financial security

#### **Frequently Cited Benefits**

- I had to choose between medication and other needs (food, housing, etc.)
- Saved me from losing my house
- Avoided financial ruin

"I am so thankful for the co-payment assistance you offered. I was hospitalized, diagnosed with cancer, have been the grateful recipient of eight blood transfusions and just completed round one of chemotherapy. Due to my limited income PAF's support will definitely help me cover some of the monumental costs as I fight this disease."

 ${\bf Meg\ Ann}\ |\ {\it Myelodysplastic\ Syndrome}$ 



For personal assistance please call us toll free at

866-512-3861



Or visit our application portals at **copays.org/gateway** with access for patients, providers and pharmacies

## **PATIENT EDUCATION & EMPOWERMENT**



Our new website offers visitors a dramatically enhanced experience, with expanded menus that streamline navigation, content that is presented in easy-to-digest segments and a quick reference menu to access our main patient service teams.

#### **FEATURES AND HIGHLIGHTS**



MOBILE RESPONSIVE LAYOUT FOR HANDHELD DEVICES



IMMEDIATE LANGUAGE TRANSLATION FOR ALL PAGES



NAVIGATION TO TOPIC-BASED RESOURCES INCLUDING

- Understanding Health Insurance
- Choosing a Health Plan
- Common Barriers Affordability & Costs
- Interacting with Your Physician
- Insurance Denials & Appeals
- Laws & Protections



# PATIENT ACTION COUNCIL ANNUAL PROJECT

Skill-building educational assets newly presented within existing program search tools

"Anyone who has or will be getting healthcare, needs a Foundation class such as this!"

Carrie S., PAF webinar attendee

"Nice format! Well communicated and I very much appreciate having this information as a resource (one which I can go back and review) so thank you for forwarding this presentation."

Beth W., PAF webinar attendee

"Information was explained in a simple, easy to understand way ..."

Susan M., PAF webinar attendee

Extending the impact of PAF's one-on-one services, our education and empowerment initiatives deliver actionable guidance and expert advice on practical healthcare issues in a variety of engaging formats. Sought out and utilized by national stakeholders in their service to various populations, our educational products are designed both to improve healthcare consumers' experience with today's healthcare systems and empower their self-advocacy.

The Patient Education portfolio of materials delivers relevant healthcare intervention for all audiences, including patients, caregivers, healthcare professionals and those that are currently healthy.

#### **NEW DISEASE SPECIFIC CONTENT**

# Breast Cancer Guide: Taking the Lead When it Comes to Your Breast Cancer

A guide to help patients lead their care and treatment by ensuring informed choices from the beginning.

#### **Migraine Matters**

A full suite of educational tools to support people with Migraine Disease and the headache advocacy community. patientadvocate.org/migrainematters

#### **Matters of the Heart**

Curated educational materials to empower the cardiovascular patient and provider community, meeting needs from prevention to survivorship.

#### Heart Valve CareLine Patient Story Video Production & Distribution Project

A documentary-style video capturing the journey of patient Bob Taylor, who was served by the Heart Valve CareLine program.









# THE NATIONAL FINANCIAL RESOURCE DIRECTORY

Relaunched in July 2018 with features for easier use by mobile and desktop users and providing extensive, customizable resources for uninsured and underinsured patients.



Visit our website for more info on National Financial Resource Directory

1,065,244
RESOURCES MATCHED
TO USERS' NEEDS

33,238
COMPLETED
USER SEARCHES

697
NEW RESOURCES
RESEARCHED AND ADDED
TO DIRECTORY

1,007
EXISTING RESOURCES
REVIEWED AND UPDATED
FOR ACCURACY

## **HEALTH EQUITY & COMMUNITY ENGAGEMENT**



More than **2,300** individuals with chronic conditions, caregivers, community navigators and health professionals participated in outreach events to learn about PAF's platform of patient support services.



- African-American Breast Cancer Outreach
- Latina Breast Cancer Outreach
- SelfMade Health Network
- West Virginia Lung Cancer Project
- Lupus Initiative (in partnership with American College of Rheumatology)



# 25 COMMUNITY-BASED ORGANIZATIONS

working closely with African-American and Latino populations disproportionately impacted by breast cancer in Memphis, Houston and Chicago.

35% INCREASE IN CALLS SEEKING CASE MANAGEMENT

for individuals from those metropolitan areas over 2017



#### **SUCCESS STORY:**

Empowering Young Women to Get the Facts About Gynecologic Cancers



at historically black colleges and universities about five main types of gynecologic cancers 1 NATIONAL NETWORK REPORT approved by the CDC Division of Cancer Prevention and Control for

publication





#### **VIEW THE REPORT ONLINE**

tiny.cc/success stories

"Cancer runs in my family and before this event, I
felt scared that I was going to get it too. Now I feel
empowered and know of ways that I can protect
myself. I will pass this along to my friends and family."

D.C. session participant

PAF's Health Equity initiatives address the intersectionality of health with the social, financial and logistical challenges that impact a person's healthcare journey, particularly in disparate and underserved communities.

Local outreach activities helped mobilize communities to address specific healthcare barriers in their communities. PAF is a founding member of the Memphis Breast Cancer Consortium, which released the inaugural *Breast Cancer 901 Community Report* to identify and discuss the status of breast healthcare in the Memphis region, with a focus on availability, access to and utilization of screening to reduce late-stage diagnosis.



#### **WEST VIRGINIA-LUNG CANCER PROJECT**

With West Virginia experiencing the highest lung cancer mortality rate in the country, PAF joined forces with local stakeholders to launch the West Virginia Lung Cancer Project, linking patients with lung cancer to PAF's case management services to overcome barriers and ensure access to lung cancer screenings.

#### **Project activities:**

- Convened the 2nd Annual West Virginia Lung Cancer Conference, Catalyzing Change to Address Lung Cancer.
- Held lung cancer policy forum in conjunction with the Conference to highlight the economic cost of lung cancer and needed infrastructure to support persons at risk.



 Project partner selected for oral and poster presentation at the 2018 American Cancer Society Lung Cancer Roundtable.

#### **SELFMADE HEALTH NETWORK - NETWORKING2SAVE**

Supported by a multi-year cooperative agreement with the Centers for Disease Control and Prevention, PAF's SelfMade Health Network (SMHN) focuses on population health to address cancer and tobacco disparities among populations with low socio-economic status characteristics. SMHN has led efforts that include:

- KY | Supporting the adoption of tobacco-free policies to reduce exposure to secondhand smoke and promote tobacco cessation in blue-collar worksites.
- TN | Providing technical assistance to community-based organizations to address access to mammography screening in rural counties.
- SC | Working with rural health clinics to implement assessment for tobacco cessation as a part of standard operating procedures.
- Technical assistance provided to eight Affordable Care Act marketplace application assistor organizations to incorporate tobacco cessation education into the annual marketplace enrollment process.



#### **INSIDE KNOWLEDGE:**

Get the Facts About Gynecologic Cancers educational event welcome sign, Howard University, Washington, DC



Release of the Breast Cancer 901 Community Report -December 2018



Dr. Stephanie Kennedy, a partner from the University of West Virginia Cancer Institute at the 2018 ACS Lung Cancer Roundtable

## **PATIENT IMPACT**

## THE FOWLER FAMILY | OUR CHILD NEEDED HELP

Scott and Susan Fowler discuss the specialized surgery their son needed and how Patient Advocate Foundation intervened to resolve an out-of-network issue that would have resulted in thousands of dollars in unpaid medical bills and compromised healthcare access for their son.

"Patient Advocate Foundation answered the phone when we had no idea where to turn for help. We didn't know how to navigate our son's insurance coverage and he was in urgent need of a very specialized surgery that was only performed at a facility out of state.

Our case manager stepped in and walked us through each claim and let us know all our options. He then made many phone calls on our behalf to hospitals when things were billed incorrectly, resulting in a huge savings for our family. It was really nice to have an advocate in our corner!"

Susan, mother of patient Zane



PAFatwork.org/fowler





## **BOB TAYLOR** | MY LIFE DEPENDED ON THIS SURGERY

Bob, his daughter Sarah and his family members share their experience with PAF's Heart Valve CareLine program. Their story is just one example of why our case managers work so hard to assist the patients they serve every day.

"... my dad suffered a massive cardiac arrest. Since then, his heart condition advanced to a place of being hospitalized on nearly a monthly basis. When my parents sought a solution, open heart surgery was recommended, but after seeking several second opinions, the risk associated with my dad undergoing a second open heart surgery was profound. Another option presented a non-invasive way to mitigate my dad's condition and reduce the enlargement of his heart to help improve his quality of life. This option, although recommended by two cardiologists from separate hospitals, was not approved by my family's insurance provider. A friend recommended PAF and we were quickly partnered with a case manager who walked alongside of our family every step of the way, navigating a complex system my family would have otherwise stumbled through blindly ... What a weight lifted to know my father could have this surgery and get to spend more good years with his wife, kids, and grandkids. This organization understands compassionate advocacy. Thank God for the Patient Advocate Foundation."

Sarah Taylor Mayhak, daughter of Robert Taylor







PAFatwork.org/taylor











Congratulations to the following new 2018–19 scholarship winners:

Natalia Amaral

Briana Gansert MeKayla Gist Hadley Graham Connor Newsom Joshua Parker Radha Patel Jessa Salvador Abriel Snider Oliver Sroka

Taylor Stone Ryan Witt Purdue University College of Veterinary Medicine
Saint Joseph's University
Greenville Technical College
George Mason University
Harding University
University of Wisconsin
Cornell University
Illinois Wesleyan University
Shenandoah University
University of Florida College of Medicine
Widener University

Transylvania University

## **SPECIAL EVENTS**

#### **PROMISE OF HOPE**

PAF brought together patients, local and national business leaders and community members to celebrate its 17th annual *A Promise of Hope Affair (POH)*. The event was supported by over 25 sponsors, drawing over 350 guests. The event featured a live and silent auction that served as the primary source of funding for the *Scholarship for Survivors* program.

The theme was a *Boots, Suits and Bling* casino night. During dinner CEO Alan Balch described PAF's impact and also introduced Tom and Liz Ema, who shared a compelling story of how PAF's



case management assistance enabled Tom to resume cancer treatment while resolving significant insurance and medical debt issues on his behalf.

Emmy award-winning broadcast journalist Barbara Ciara from WTKR Channel 3 served as the Mistress of Ceremonies and led guests in an engaging live auction that raised over \$50,000 for the Scholarship for Survivors program.

#### **SCHOLARSHIP FOR SURVIVORS**

PAF's Scholarship for Survivors program began nearly 20 years ago and supports young adults whose educational pursuits have been disrupted due to the cost of care centered around a chronic illness. To date, PAF has awarded 95 scholarships, totaling over \$566,000, from which 48 recipients have achieved fully degreed graduation and 20 are still pursuing their course of study.





Oliver Sroka Scholarship Recipient "This scholarship will ... help my completion of my bachelor's degree and ... minimize the financial stress on my family during trying times ... with my unpredictable health."

"The financial burden of medical school can be stressful ... but this scholarship will allow me to spend less time worrying about finances and more time on what truly matters, my patients."

#### **PATIENT CONGRESS**

In September PAF hosted its 19th annual Patient Congress event in Washington D.C. to prioritize the patient voice in support of person-centered care and health system delivery reform.

This year's event featured a "Story Slam" providing attendees with the opportunity to share stories from their experience as a patient, caregiver or provider. Conference training focused on how to more effectively tell those stories and use them in advocacy activities. The Story Slam provided a powerful testament to the issues that people face when they experience serious illnesses and how these experiences parlay into advocacy involvement.

"People don't realize how great the financial impact of having a serious disease can be, and how much it can affect their lives. I'll work with a patient who is a husband and provider and he'll start missing work or building up debt and it changes everything for the entire family. The stories I heard in the Story Slam are the ones that I live every day when people come to me for help."

Lisa Miller, patient advocate for a hematology/oncology practice in Columbus, OH, Recipient of the 2018 Volunteer Advocate Award

#### **BREAKAWAY FROM CANCER**

The Amgen Tour of California is the largest cycling event in the United States, and the Amgen Breakaway from Cancer is the associated initiative created to raise awareness of the broad range of support available for cancer patients nationwide through four national non-profit partners: Patient Advocate Foundation, Prevent Cancer Foundation, Cancer Support Community and National Coalition for Cancer Survivorship.

In 2018, the Tour started in Long Beach and ended in Sacramento, with stages in Ventura, Santa Barbara, King City, Laguna Seca, San Jose, Stockton, Elk Grove, Folsom and South Lake Tahoe.

The 2018 race winners were Egan Bernal (COL/Sky) and Katie Hall (USA/United Healthcare).





For more info, visit **breakawayfromcancer.com** 





#### PAFatwork.org/congress

Why I am a Patient Advocate:
The Patient Congress Story Slam



For more info, visit events page patientadvocate.org/get-involved/events/





## **HEALTH SERVICES RESEARCH INITIATIVES**

#### TREATMENT EXPERIENCE CAN VARY BY DISEASE/CONDITION

Treatment service in the past 12 months

	Breast Cancer	Other Cancer	HIV/ AIDS	Hepatitis	Pulmonary Conditions
Diagnosis	26%	18%	7%	<b>1</b> 4%	13%
Planning	36%	33%	4%	7%	11%
Surgery	44%	21%	1%	3%	4%
Radiation	35%	17%	<b>1</b> %	3%	1%
Drug therapy	77%	74%	63%	<b>51</b> %	76%
Medication	43%	23%	43%	38%	25%
Post treatment F/U	43%	32%	23%	19%	32%

#### **IMPACT ON MEDICAL CARE**

What impact did the financial hardship have on your medical care in the last 12 months?



For Care

"These bills started to mount up, forty, sixty, eighty thousand dollars, and I basically started to think, I can't afford to live, and I decided to stop treatment."

Tom Ema | patient

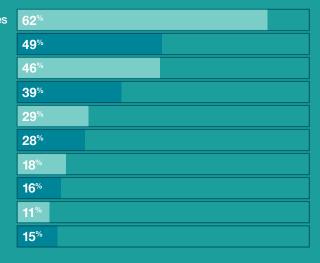
# OUT-OF-POCKET EXPENSES IMPACT FINANCIAL STRAIN AND MAY BE DRIVEN BY DISEASE/CONDITION

Expenses that were the greatest sources of financial strain

	Breast Cancer	Other Cancers	HIV/ AIDS	Hepatitis	Pulmonary Conditions
Insurance-related costs including coinsurance, copayments or deductibles	49%	49%	76%	69%	79%
Transportation, lost wages, time off from work, lodging or caregiver support	11%	10%	0%	3%	2%
Both sources equally	31%	30%	12%	11%	9%
Not sure	9%	12%	11%	17%	10%

## IMPACT ON FINANCES [TOP 10]

What impact did the financial hardship have on your financial situation in the last 12 months? Reduced non-critical expenses
Reduced critical expenses
Credit card/bank loan
Borrowed from friends/family
Utility bills paid late
Unable to afford groceries
Sold assets
Missed rent/mortgage
Missed car payment
Other



While case management services respond to the specific concerns of an individual patient or caregiver, our Health Services Research Initiatives shed light on the broad array of issues patients face during their healthcare experience. We examine how our patients get access to healthcare, how much care costs impact their treatment choices and goals and what happens to our patients as a result of their barriers to care.

This year, insights gleaned from prior initiatives around securing access to safety net services and rising health insurance costs indicated a need for additional research on financial toxicity and distress.

#### The Patient Survey on Attitudes and Perspectives Surrounding Cost of Care

Rising healthcare costs suggest a pressing need for timely interventions to discuss cost of care and mitigate financial toxicity. The healthcare system increasingly shifts cost to patients, but there remains a fundamental lack of understanding of how to deliver, measure and pay for care in ways that are co-created with patients and that incorporate what matters to them, particularly those who are the most financially vulnerable. To address these questions, our 51-question online patient survey to which nearly 1,400 patients responded, explored root causes of financial toxicity, uncovered patient preferences related to cost of care conversations, measured the patient's degree of financial stress and medical debt and assessed perceived financial and material hardship.

#### **Non-Profit Research Partnerships & Collaborations**

- Measuring the Financial Stresses of Childhood Cancer & Survivorship (with Children's Cause for Cancer Advocacy and poster presentation at the ASCO Quality of Care Symposium)
- Treatment Preferences of Lung Cancer Patients and Caregivers (with the LUNGevity Foundation)
- Patient Knowledge and Perspectives Triglyceride Survey (with the American Pharmacists Association)

#### **Expansion of Academic Partnerships**

- Quantifying breast cancer patient preferences and their association with financial toxicity during treatment decision-making (with the University of Alabama at Birmingham, approved in 2018 for project launch in 2019)
- R01: Improving the Reach and Quality of Cancer Care in Rural Populations (with the University of North Carolina at Chapel Hill, submitted and under review)



#### PAFatwork.org/balch

PAF CEO Alan Balch discusses cost of care issues and impact on patient access at the National Patient Advocate Foundation Policy Consortium

#### **SURVEY FINDINGS**

When it comes to having conversations with a medical provider about the costs of medical care, the following were considered very important by 2/3rds or more of survey respondents:

- Knowing that there may be resources or options for reducing costs
- Feeling confident that the provider will still provide you with the best care if you ask about costs
- Knowing the questions you need to ask
- Having access to information about the costs associated with the care you need
- Knowing that the provider is willing to talk with you about the costs of care

HOW OFTEN HAVE YOU HAD SERIOUS FINANCIAL WORRIES IN THE PAST MONTH?

**38%** stated 'nearly all' or 'all of the time'

KNOWING THE OUT-OF-POCKET COST IS IMPORTANT WHEN IT COMES TO MAKING TREATMENT DECISIONS.

62% said 'strongly agree'

HOW IMPORTANT IS IT TO DISCUSS WITH YOUR MEDICAL PROVIDER THE COST YOU HAVE TO PAY FOR CARE?

**66%** said 'very important'

DID YOUR HEALTHCARE PROVIDERS
EXPLAIN THE COSTS ASSOCIATED WITH THE
TREATMENT OPTIONS YOU DISCUSSED?

**61%** said 'no'

## **FINANCIAL STATEMENTS - FISCAL YEAR 2017-2018**

#### **SUMMARY OF TOTAL PATIENT IMPACT IN FISCAL YEAR 2017/18**

Total Patient Cases	158,090
Total Case Management Cases	24,213
Total Co-Pay Relief Cases	89,963
Total Financial Support Programs Cases	34,663
Total Patient Services Email Helpline Sessions	9,251
Total Patient Services Case Contacts	1,465,940

# SUMMARY OF CASE MANAGEMENT IMPACT IN FISCAL YEAR 2017/18 PATIENT CASES AND CONTACTS

Total PAF Case Management Case Count	24,120
Total PAF Case Management Contacts	407,726
Average Contacts per Case	16.9

To ensure the greatest degree of accuracy, the case management data presented above is derived from closed cases.

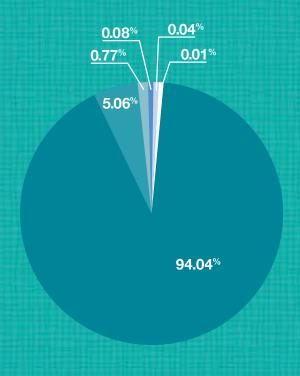
#### Patient Advocate Foundation Statements of Financial Position June 30, 2018 and 2017

	2018	2017
ASSETS		
Current assets:		
General operating cash and cash equivalents	\$ 24,050,994	\$ 18,676,495
Restricted cash and cash equivalents	261,254,275	202,912,026
Unconditional promises to give	30,424,481	450,813
Service contract receivable	514,231	656,282
Due from National Patient Advocate	7,373	7,599
Investments and cash equivalents	1,999,015	1,996,636
Inventories	58,570	27,249
Prepaid expenses	405,146	591,597
Total current assets	318,714,085	225,318,697
Property and equipment, net	4,218,172	5,042,401
Other assets:	50.004	F0 001
Refundable deposits	50,331	50,331
	\$ 322,982,588	\$ 230,411,429
LIABILITIES AND NET ASSETS		
Current liabilities:		
Accounts payable and accrued expenses	\$ 8,650,706	\$ 4,220,674
Deferred revenue	18,203,925	16,448,938
Accrued vacation leave	318,690	150,269
Total current liabilities	27,173,321	20,819,881
Long-term liabilities:		
Postretirement benefits liability	2,451,399	2,184,558
Other liabilities	92,974	75,111
	2,544,373	2,259,669
Total liabilities	29,717,694	23,079,550
Unrestricted	9,557,450	5,422,899
Unrestricted, board designated	1,999,015	1,996,636
Total unrestricted net assets	11,556,465	7,419,535
Temporarily restricted	281,708,429	199,912,344
Total net assets	293,264,894	207,331,879
	\$ 322,982,588	\$ 230,411,429

## **FINANCIAL STATEMENTS - FISCAL YEAR 2017-2018**

Patient Advocate Foundation Statements of Activities Years Ended June 30, 2018 and 2017

			2018					2017		
	Unrestricted	Unrestricted - Board Designated	Total Unrestricted	Temporarily Restricted	Total	Unrestricted	Unrestricted - Board Designated	Total Unrestricted	Temporarily Restricted	Total
Revenues, gains and other support:										
Grants	\$ 3,138,681	· •	\$ 3,138,681	\$ 352,845,740	\$ 355,984,421	\$ 5,733,646	· •	\$ 5,733,646	\$ 202,298,540	\$ 208,032,186
Private and public donations Donated services and materials	158,632		158,632		158,632	135,609		135,609		135,609
Program Administration	19 172 394		19 172 394	•	19 172 394	15 491 426		15 491 426	•	15 491 426
Patient Congress	10,000		10.000		10,000	92,500		92.500		92,500
Promise of Hope	149,858		149,858		149,858	201,945		201,945		201,945
Patient Action Council	150,000	•	150,000	•	150,000	75,000		75,000	•	75,000
Investment income, net	2,917,388	2,379	2,919,767	•	2,919,767	1,125,879	(1,721)	1,124,158	•	1,124,158
net assets released from restrictions: Transfers	1	,	1	•	•	(512,115)	512,115	•	,	'
Satisfaction of program restrictions Financial Aid Awards	271.049.655	•	271.049.655	(271,049,655)		165.292.885	,	165.292.885	(165.292,885)	,
Total revenues, gains										
and other support	296,786,982	2,379	296,789,361	81,796,085	378,585,446	187,661,202	510,394	188,171,596	37,005,655	225,177,251
Expenses and losses:										
Patient/educational services	4,931,805	1	4,931,805	1	4,931,805	6,670,284	•	6,670,284	1	6,670,284
Financial Aid Programs	278,416,531		278,416,531		278,416,531	173,172,689		173,172,689		173,172,689
Supporting services:	14.004.0		14.004.0			0,725,72		0,717,000		0,226,2
Management and general	2,700,616		2,700,616	•	2,700,616	2,111,634		2,111,634		2,111,634
Fundraising	1,079,528		1,079,528	'	1,079,528	975,459		975,459	'	975,459
lotal expenses	292,396,927		292,396,927	1	785,386,927	186,252,314		186,252,314	'	186,252,314
Change in net assets before postretirement benefit charges other than periodic cost	4,390,055	2,379	4,392,434	81,796,085	86,188,519	1,408,888	510,394	1,919,282	37,005,655	38,924,937
Postretirement benefit charges other than periodic benefit (cost)	(255,504)		(255,504)	•	(255,504)	184,625	1	184,625	'	184,625
Change in net assets	4,134,551	2,379	4,136,930	81,796,085	85,933,015	1,593,513	510,394	2,103,907	37,005,655	39,109,562
Net assets, beginning of year	5,422,899	1,996,636	7,419,535	199,912,344	207,331,879	3,829,386	1,486,242	5,315,628	162,906,689	168,222,317
Net assets, end of year	\$ 9,557,450	\$ 1,999,015	\$ 11,556,465	\$ 281,708,429	\$ 293,264,894	\$ 5,422,899	\$ 1,996,636	\$ 7,419,535	\$ 199,912,344	\$ 207,331,879



## **COMBINED REVENUE & EARNINGS**

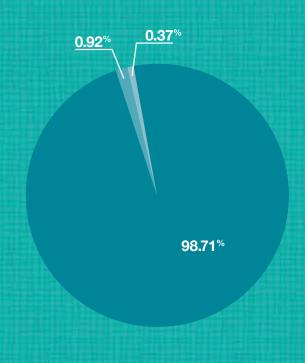
- O Program Grants \$355,984,421
- O Program Administration \$19,172,394
- Interest \$2,919,767
- O Gifts & Contributions \$308,632
- Event Revenue \$159,858
- In-Kind Service \$40,374

**TOTAL - \$378,585,446** 

## **COMBINED FUNCTIONAL EXPENSES**

- **Program Services \$288,616,783**
- Management & General \$2,700,616
- Fundraising \$1,079,528

TOTAL - \$292,396,927



#### **PAF GIVES BACK**

For the 9th consecutive year PAF sponsored a food drive in support of the Virginia Peninsula Foodbank, collecting 4,853 items, and executive leaders volunteered at the warehouse sorting donations, stocking shelves and preparing individual food bags for distribution.







## **SUPPORTERS**

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Ace Peninsula Hardware - NN

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Saundria Cardwood

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Inga Charlotte

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> "Thank you for helping me apply for co-pay assistance. Thank you so much, I appreciate it!"

> > Yen | hepatitis C

Lynne Jones

Melissa Jordan

JPMorgan Chase Foundation Nancy K. Jung

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Alan Richardson Johanne Richardson

"Your [Co-Pay] program has given me the chance to live another day, month, year - whatever it may be. I could not have afforded my medication without you."

Rochelle | pulmonary hypertension

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Diana Smith Lorraine Smith Renee Smith Ron Smith

Smithfield Auto and Truck

Smithfield Inn Dave Sorensen Splash Kingdom, Inc. Starbucks - Kiln Creek Hillary Stemple Valerie Stevens



"I was diagnosed with stage 4 cancerous tumors in my brain and my lung, all terminal. For several months, until my coverage kicked in, I had no insurance. The bills skyrocketed and with chemo and radiation treatment I could barely think straight. My PAF case manager was an angel who

walked me patiently through the time-consuming application process, never wavering in her efforts. I can't find enough words to thank her."

David | brain cancer

Susan Stewart-Kellev Ellen Stokes Strongbridge Biopharma Niurka Suero-Tejeda Odell Sumling Sundays Sun Spa Shop Taiho Oncology, Inc. Takeda Oncology Andrew Tao Jessie Tavares Latrina Taylor Barbara Telthorst Teva Pharmaceuticals Texarkana PET/CT **Imaging** Theratechnologies Annekee Thomas TIAA Charitable Inc. Timorah Beales Photography Erin Tindol TopGolf Virginia Beach Anita Torrealba Travel Leaders Michael and Amanda Troutman Robert and Juana Trujillo Stephanie Trunk Nicole Turcotte Kathrina Turner Ton Turner Tysinger Automotive Family

Mark and Denise

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Wildflower Foundation,

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#### **PAF GIVES BACK**

On October 6th, staff members from PAF took part in the CrawlinCrab 5K/Half Marathon in Hampton, VA. "Team PAF" members each obtained donations from sponsors, friends and family for their participation in the run, raising over \$17,000 in support of our Scholarship for Survivors program.





Prostate Cancer

## **SUPPORTERS**

#### **MEMORIAL DONATIONS**

In Memory of Sally "Snippy" Goldsborough Lambert

Rick and Jill Fischer

In Memory of Audrey Kaufman Linda Stoner

In Memory of Carolyn Lowe Bradley and Carol Franc John and Mary Hartzell Josephine Henry Connie Rucker

In Memory of Deborah Buccat Rodney Buccat

In Memory of Dianne Allen Kristine Patterson

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Kav Newman Kathleen Parker

**Brooks and Margaret Robbins** Elijah Roberts

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Chris and Char Lange

In Memory of Flora McGowan Suzanne Gundel

In Memory of James Eggert Leon and Carol LaJeunesse

In Memory of Janice Mahon Baker Family Eyecare David Tolitsky Gary Watts

In Memory of John Keeton Dale and Sarah Smith

In Memory of John Michael Dudash Karen and Kenneth Ross

In Memory of Karen Zema Anthony Zema

In Memory of Kenneth Houk Stephen Lapham

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In Memory of Lori Jean Heston Doreen Heston

In Memory of Marialana Wittman Velikova Veselin Velikov

In Memory of Mary Daniel Mary Goodson

In Memory of Yolande Thomas Mary-Suzanne Wheeler

In Memory of Mildred Parker

Dana Ainge Kara Ankeney Meaghan Baldecci

Children's Hospital of Richmond at VCU

Jimmy and Teresa Davenport Patricia Davenport

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VCU School of Nursing Sunshine Club

Verizon - Burkhart Team

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Mary Wusk In Memory of Norman Farlow

Farlow Marital Trust, The

In Memory of Ruth Morgan

In Memory of Peggy Thompson Connie Corpening

Barbara Benjamin Renee Esslinger John and Dorothy Graf Eugene and Rita Hunckler Landing of Long Cove Terri McDonough Leigh Morgan Elsa Reyna Joyce Schmitt Kristen and Brian Wathen

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In Memory of Sheila Crowe Jehmal Hudson

In Memory of Sheryl Marshall Randall and Linda Woodard

In Memory of Suzanne Littleford Sandra Elles

In Memory of Tom Goodwin Betty Oswill

In Memory of Velda Faye Schuelke Susie Roach

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In Honor of Harvard Vanguard Gastoenterology Watertown Emily Zall

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In Honor of James Nall Robert and Susan Abbott

In Honor of Jan Dunhour Robert and Jo-Ann Reid

In Honor of Kathleen Delfino Barbara Borden Gerald and Barbara Gladnick

In Honor of Kathleen Delfino &

Rose O'Connor Kathleen Kirkpatrick Ralph Kirmser Marla Lewitus Robert and Diane Russell Agatha Trotta

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"... To avoid any problems with our insurance company, I asked before the admission of our daughter to the hospital if our [insurance] would be accepted. The hospital called the insurance and requested permission for admission to the emergency room. The request was approved. Our daughter was hospitalized for 5 days, of which, the first 3 were in intensive care ...

On the 3rd day my husband receives a call from a hospital social worker notifying us that our insurance considered hospital admission as "Out of Network" services ... my husband and I tried to fix the situation without any success ... The intervention of Patient Advocate Foundation (PAF) was decisive so that our insurance finally reconsidered to make the payment of the emergency services that our daughter had during 5 days of hospitalization ... Thank you for all your support!"

Maria, mother of the patient







#### **ACKNOWLEDGMENTS**

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