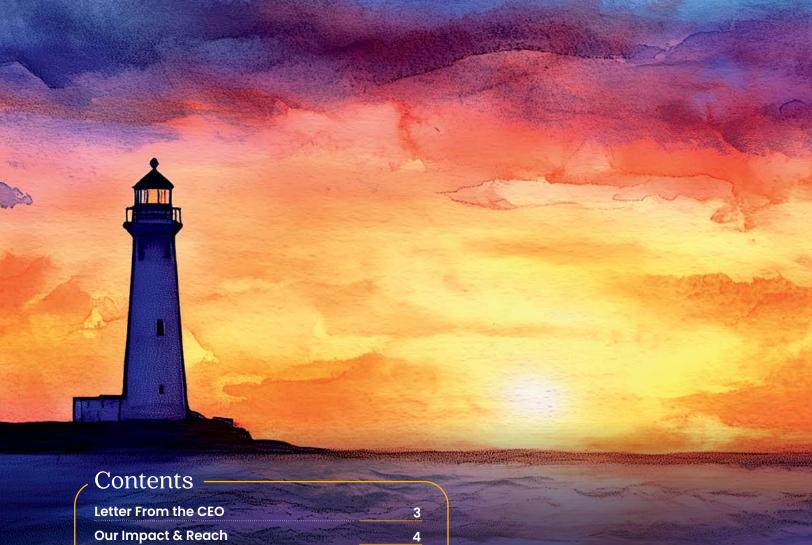
**2024 ANNUAL IMPACT REPORT** 



The leading authority in complex healthcare navigation & whole human support.



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# Our Mission

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

# Our History

PAF was founded in 1996 by Nancy Davenport-Ennis and co-founded by John H. (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 2024 and we've provided direct, hands-on help to more than 2.2 million patients nationwide.

# WELCOME

Every day, people facing chronic and lifethreatening illnesses make impossible choices around paying for necessary medical care or paying expenses necessary for life. Many spend exhausting hours navigating a complex healthcare system, often feeling overwhelmed and alone.

But they are not alone. This year, PAF provided direct support to more than 690,000 patients and families. Their stories—stories that may reflect your own, or those of a family member, coworker, or friend-fill the pages of this report. Through our work, we have connected them to critical resources during moments of crisis and beyond. We've helped them secure insurance and disability benefits, ensuring they have enduring support. We've stepped in to advocate with providers and insurers, facilitating appeals and access to charitable care.

Beyond direct, complex healthcare navigation, we have built an extensive support infrastructure that reaches millions of people in meaningful ways. Our financial support programs provide critical relief during times of hardship to enable patient access, while our extensive library of educational resources and responsive digital content empower patients with knowledge to navigate care. Our Community Engagement and Research teams forge partnerships and initiate projects to address patients' access and affordability challenges, ensuring that their diverse experiences and perspectives are heard and integrated into efforts to improve healthcare. And through a network of healthcare and institution partners, we continue to expand our impact, reaching more people with innovative solutions that make healthcare more accessible.



And we haven't done this work alone. Our impact is made possible by the partnerships we've built across the country with individuals, organizations, and institutions who share our belief that everyone deserves access to quality, affordable healthcare.

When we reflect on both our history and future. I find hope in our commitment to each other and in the partnerships that make our work possible. This report honors all of those who join us in our mission to overcome healthcare obstacles both today, when help is most needed, and in using what we have learned to make things better in the future. Together, we are making a difference. Together, we are ensuring that no one faces the burden of illness alone.

With deep gratitude for your commitment and collaboration,

Alan J. Balch, PhD Chief Executive Officer

Alan J. Bolch

# **OUR IMPACT & REACH 2024**

#### Our Patient Reach

511 + PAGE VIEWS WELCOMED BY PAF WEBSITES

3.1 PEOPLE REACHED THROUGH DIRECT SERVICE, EDUCATION, & OUTREACH

690K+ PATIENTS & FAMILIES SUPPORTED

193K+ PATIENTS RECEIVED DIRECT, SUSTAINED HELP

804 DISTINCT DIAGNOSES

464 DISTINCT RARE DISEASES

\$335M+ DIRECT FINANCIAL ASSISTANCE DISTRIBUTED TO PATIENTS

\$17M+ DEBT RELIEF OBTAINED ON BEHALF
OF CASE MANAGEMENT PATIENTS



2,232,055 PATIENTS DIRECTLY HELPED BY PAF SINCE 1996

# Our Patient Programs

#### CASE MANAGEMENT

27 total unique programs

15 serve patients living with cancer

11 serve patients living with a diagnosis other than cancer

**14** programs administered by PAF in partnership with or on behalf of non-profit partners

4 academic partnerships

#### FINANCIAL ASSISTANCE SERVICES

#### PAF's Co-Pay Relief Program | 60 distinct disease funds

Financial assistance to eligible patients for health insurance premiums, copayments, co-insurance, and deductibles for medications and office visits

#### PAF's Financial Assistance Funds | 18 distinct funds

Financial assistance to eligible patients for non-medical expenses including transportation, food, housing, utilities, prosthetics, and assistive devices

**PAF's Non-Profit Program Administration Division | 94 distinct disease funds**Delivers end-to-end co-pay and financial assistance fund administration services in partnership with and on behalf of non-profit organizations

# What Our Patients Are Saying...

"Working with my case manager was both comforting and highly informative. She taught me so much about Medicaid, hospital policies, and all the support PAF offers to patients and their families. She was extremely patient with my questions and guided me through some difficult choices. I am grateful to have met her."

Laura | Colon cancer

Patients directly helped by PAF receive a standardized, post-encounter survey, available online or in hard copy and in English or Spanish, to assess overall patient satisfaction and program impact.

97% OF RESPONDENTS WOULD RECOMMEND PAF TO OTHERS

96% INDICATED THAT PAF RESOLVED THEIR ISSUE

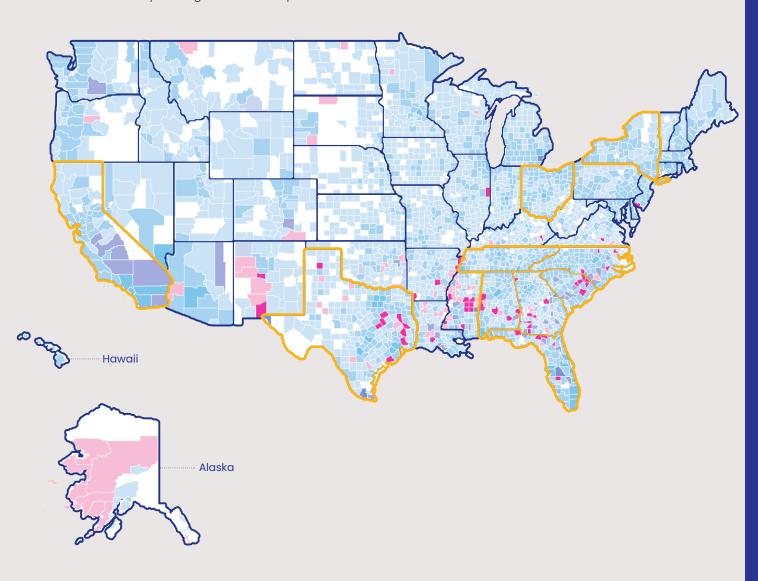
**OVERALL PAF STAFF RATING** 

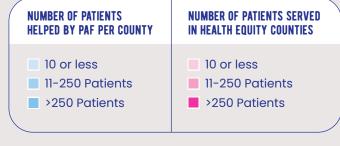
4.8 5

FOR THEIR COMMUNICATION, KNOWLEDGE & PROFESSIONALISM

# **OUR NATIONWIDE PRESENCE**

We helped patients in all 50 states, Puerto Rico, Guam, and the Virgin Islands, reaching 91% of all US counties with direct assistance in 2024. Using county-based data, the heat map below represents the locations of patients served, including the 226 designated Health Equity counties spanning 36 states. These counties were designated as areas of focus through a methodology that used the Centers for Disease Control's Social Vulnerability Index (SVI) combined with CDC disease incidence data to identify those with the highest rates of social vulnerability and high rates of multiple chronic diseases.







# Our Safety Net Ecosystem 0

#### **PAF Case Resolutions for Xiao**



**Expedited disability** approval



Provided extensive education about Medicare eligibility and coverage options



Facilitated Medicare Part D enrollment

**Navigating Administrative** Tasks: Understanding Their Impact on Patients and Caregivers

64%	reported experiencing administrative burden in the past 12 months
<b>55</b> %	experienced burden due to their health insurance
27%	experienced burden resulting from SSDI or SSI processes
<b>57</b> %	respondents were unable to completely resolve their administrative tasks
200/	received professional

View the survey results at tiny.cc/administrative-burdens



**ALS Insurance and Benefits Resource Line** 

assistance to completely

resolve their issues

>> Request assistance online at als.pafcareline.org or call toll free 1-844-244-1306



Our case manager honestly saved my life with her assistance. She made such a difficult system so much easier and more manageable. Helping me and my father through such a hard time in our lives, we couldn't be more thankful. She navigated everything so well and always followed up with me. I appreciate her checking in with me. She truly advocated for us in a system that just likes to throw people in loops."

Xiao | Amyotrophic Lateral Sclerosis (ALS)



# PAF Case Resolutions for Cynthia



Negotiated Medicare approval for ambulatory transport



Researched and provided contacts for available financial aid foundations



Provided Medicare education and resources for maximizing and utilizing benefits

Medicare Patients' Monthly Financial Burden Prior to the Implementation of the '25 IRA

**58**%

of Medicare patients reported that their primary (main) source of household income was social security in the past 12 months

43%

reported that they had no secondary source of household income

38%

indicated that they are already financially stressed and a \$40 increase in their healthcare spending is not affordable

View the full results at tiny.cc/TheTippingPoint

ZERO's relationship with PAF began in 2016. The decision to partner was based on the quality of case management services PAF could offer the prostate cancer community. "We loved that this was a high touch program in that they would contact an insurance agent together, they would contact a utility company together to have those conversations instead of just putting more onus on the patient."

**Shelby Moneer** | VP of Patient Programs and Education, ZERO Prostate Cancer





A VIDEO MESSAGE FROM OUR ZERO36O NON-PROFIT PROGRAM SPONSOR

and took notes. I never had to re-explain anything to her. She was on board with the transportation issue immediately and made a call to the nursing home for me asking for their assistance with my husband's health records to show that he cannot walk and would require stretcher assistance to get to his oncology appointments ... She [helped] get things moving for pre-approval from Medicare for his medical transport and she gave me the names of several places I could check into regarding financial aid. Each ambulance stretcher trip was costing about \$1,600. My case manager is so knowledgeable, caring, and thoughtful."

My case manager was excellent. She listened carefully

Cynthia, wife of patient Lawrence | Stage IV Prostate Cancer

>> Request help at tiny.cc/zero-360 or call (844) 244-1309

# CASE MANAGEMENT SERVICES

# Healthcare Navigation

PAF is the leading authority in complex healthcare navigation. Our professional case managers are at the epicenter of this safety net ecosystem, offering vital support to patients with a life-altering diagnosis. We guide individuals through health insurance options and utilization, connect them with financial resources to help with healthcare and daily living expenses, and facilitate access to essential government and employer-sponsored disability benefits. Case managers also help patients without insurance by assisting them with enrollment

in public programs, private health insurance

plans, and charitable healthcare services.

Our hands-on case management interventions conducted both with and on behalf of patients help reduce the stress individuals experience and ensures successful completion of timeconsuming processes required to access care and benefits.

The impact of these enduring resolutions on patient outcomes are profound. In 2024, case managers directly helped 12,275 patients with 804 diagnoses to address 20,623 distinct issues, resulting in \$17,048,825 in debt relief secured on their behalf. Case managers also responded to 25,742 email Helpline Sessions addressing requests for guidance, clarification, and responsive feedback, an increase of 32% over 2023.

Our work with patients and their families this year revealed important insights into evolving patient support needs and the time investment required to fully address them. The average number of case management interventions needed to resolve a case reached an all-time high of 30 contacts. The elevated contacts and time spent supporting each case are indicators of high case complexity that results from the increased administrative burden placed on patients, further limited resource availability, and an overburdened healthcare system with inadequate infrastructure (data below).

Some shifts in patient demographics were noted and may be reflective of the healthcare institutions and non-profit organizations that referred 68% of case management patients in 2024. While nearly 41% of patients earned less than \$24,000 annually, case managers served patients across the economic spectrum, with slightly more than 6% reporting income over \$120,000 (an 8% increase over 2023).

Thirty percent were employed, 24% were retired, and 22% were disabled (a 6% increase over 2023). The majority (54%) were over age 55, and 11% were uninsured. The percentage of Black patients increased by 4%, representing more than 24% of all case management patients, with increases also observed in those identifying as Hispanic/Latino (8% increase) and Blended Race (20% increase).

# **Delivering Complex**

HANDS-ON SUSTAINED HELP

Case Management

Highlights











↑ All-time high





In a recent PAF survey of participants (n=934), 64% stated that they or someone they provide care for experienced administrative burden resulting from a medical diagnosis in the past 12 months. Over 50% of participants were unable to fully complete their administrative tasks. We know these burdensome processes often delay or prevent care. Our case managers are committed to mitigating these risks for the patients we serve.

>> Find out more about Navigating Administrative Tasks at tiny.cc/paf-administrative

#### Top 3 Issue Categories

20,623 documented case management issues span multiple categories from medical claim denials and network benefit verification to disability benefit denials and lack of transportation to medical appointments.



FINANCIAL COST OF LIVING

Includes housing, transportation, & utility assistance



#### **INSURANCE NAVIGATION ISSUES**

Includes co-insurance/co-pay assistance, coding & billing errors, and prior authorization for medical services



**ELIGIBILITY AND ENROLLMENT** 

↑11% overall increase

Health insurance eligibility screening & enrollment assistance increased by 19%

Patient Advocate Foundation's

Health Equity Case Management Program

PAF's Health Equity (HE) Case Management Program

is designed to reach and assist specific populations and places experiencing intense social and financial needs. In 2024, we helped 640 patients living in zip codes covered by the program understand health insurance coverage options, address coverage issues, connect to resources that help with paying for care and cost of living expenses, and secure income replacement through disability enrollment support.

Highlights from this work include:



54% of HE patients earned less than \$24,000 compared to all case management patients at 41%



48% of HE patients were unemployed or disabled compared to all case management patients at 41%



48% of HE patients were Black compared to all case management patients at 24%



17% of HE patients were Hispanic/Latino compared to all case management patients at 11%



My case manager was very helpful and friendly, and I felt that she cared about my situation. She helped me understand the process of dealing with my insurance company and that gave me more confidence in advocating for myself. She would follow up to be sure that I was able to move forward [with my appeal]. I really appreciate the help during a pretty stressful time."

Scott | Cardiac Condition

PAF Case Management operates 27 distinct patient programs, with 15 supporting individuals with cancer and 11 supporting individuals with non-cancer diagnoses.

Case complexity rose sharply, driving an increased number of case management interventions



804 DISTINCT PATIENT DIAGNOSES SERVED

454 DISTINCT RARE DISEASES SERVED

Cancers continue to represent the largest percentage of case management diagnoses; however, amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS) increased significantly and are represented for the first time in the *Top 10 Diagnoses for Case Management* 



Our partnerships continue to play a key role in increasing the volume of patients with these diagnoses who are connected with our services.

#### Our Non-Profit Support Network

Relationships with PAF non-profit program sponsors and referral networks are highly valued and continue to grow, with a 25% increase in referrals from other charitable organizations in 2024. We are grateful that our non-profit peers recognize PAF's excellence in case management service and entrust their patients with access and affordability issues to us. These partnerships reinforce the strength of our collaborative relationships and illustrate the shared values of compassion, care, and equitable healthcare access for all patients.

PAF partnered with 3 non-profit organizations to administer case management programs with and for them to support the partners' patient populations. PAF had 11 non-profit organization partnerships that provided case management services through multiple disease-specific CareLines.



#### A MESSAGE FROM OUR NON-PROFIT PROGRAM SPONSORS:

National non-profit leaders describe why they partner with PAF to deliver high-impact services and support to their patient communities.

# **NEW PROGRAMS**FOR PATIENTS!



PAF expanded its partnership with the National Ovarian Cancer Coalition (NOCC) to launch the NOCC Navigation Resource Program, which extends the NOCC financial aid fund with PAF case management services. Together, these resources help to ensure access to care for ovarian cancer patients across their healthcare journey.



PAF partnered with the National Multiple Sclerosis Society (NMSS) to launch the Multiple Sclerosis CareLine in 2024. The program connects patients served by NMSS to essential case management navigation and vetted resources tailored to their unique needs.

#### **Medical Debt Case Management**

Program: With support from an existing PAF program sponsor, we expanded help to patients diagnosed with blood cancers, incorporating case management support aimed at alleviating and reducing patient medical debt into existing financial services.



The DONNA CareLine helped me when I needed it the most. I was close to having my power shut off and the Donna fund became available. The application process was a breeze and extremely fast. I would be sitting with no power right now if it were not for the Donna fund. I had been off [work] for over 6 months during treatment for breast cancer. All my accounts had been depleted, and I was running out of savings, really fast."

Maygan | Breast Cancer





#### A VIDEO MESSAGE FROM THE DONNA FOUNDATION'S EXECUTIVE DIRECTOR, A PAF PROGRAM SPONSOR

"This beautiful partnership has transformed the lives of so many [breast cancer] patients ... Knowing that when a patient calls the Donna CareLine and that a case manager from PAF is going to answer that phone, I feel so much hope for that patient."

Amanda Napolitano | Executive Director, The DONNA Foundation

# **CO-PAY RELIEF**

# Co-Pay Assistance Enables Patient Access

The financial impact of a diagnosis can overwhelm a household budget, leaving patients unable to afford necessary care and insurance. PAF's Co-Pay Relief (CPR) program helps reduce financial distress and improve access by providing direct financial assistance for health insurance premiums, co-payments, co-insurance, and deductibles for medications and office visits. CPR operates in compliance with the guidance provided by the Office of Inspector General, ensuring high-quality service with an emphasis on accessibility and patient service since 2004.

CPR provided financial support to **76,304 new and returning patients** through **60 distinct disease funds** with grant payments totaling **\$208,313,191** in 2024.









#### **CPR Is Prepared**

TINY.CC/CPR-YOUTUBE

PAF adapted and prepared its CPR program in anticipation of the additional Medicare Part D benefit changes and the Prescription Payment Plan availability in January 2025. Efforts resulted in an extensively trained PAF staff, well-versed in the benefit changes and their impact on the Medicare beneficiaries we support. CPR funds were extensively evaluated to ensure that annual grant amounts were appropriate to meet the needs of those we will serve in 2025.

Patients we help often credit the Co-Pay Relief Program for extending or saving their lives.

Now you can watch their stories of gratitude and hope on PAF's YouTube Channel.

#### New Funds Bring New Hope

CPR launched 9 new funds, further expanding its service to new patient populations. These funds include the Gaucher Disease Health Equity Fund, Lupus Health Equity Fund, Multiple Sclerosis Health Equity Fund, Spinal Muscular Atrophy Health Equity Fund, Acute Myeloid Leukemia, Diabetes Type 2, Amyloidosis and Bile Duct Cancer funds.

In addition, PAF's new Co-Pay Relief Social Needs Assessment and Intervention Fund created a vital bridge to access for Medicare patients who need Community Health Integration (CHI) and Principal Illness Navigation (PIN) services. The fund offers up to \$300 annually to eligible Medicare beneficiaries screened for and diagnosed with unmet social needs identified by diagnosis codes including Z58 (Problems related to physical environment) and Z59 (Problems related to housing and economic circumstances).

This first-of-its-kind assistance eliminates a cost barrier to critical navigation services delivered by the patient's healthcare provider.

>> For full details, visit tiny.cc/social-needs



It's hard to express how much gratitude I have for this priceless grant. It will provide insurance coverage when I didn't have any. A million thanks to the caring, thoughtful, generous donors who make this possible."

Lora | Multiple Myeloma

# **SMALL GRANTS, BIG IMPACT**

PAF's Financial Assistance Funds provide small grants to eligible patients to help with various non-medical expenses including transportation, food, housing, utilities, prosthetics, assistive devices, and more. These funds provide crucial aid to patients experiencing compromised access to necessities.





# Non-Profit Program Administration (NPPA)

PAF is uniquely experienced in delivering co-pay and financial assistance fund administration services in partnership with and on behalf of non-profit partners. Since 2009, PAF's NPPA Division has leveraged our expertise in program management, compliance, and patient support to provide end-to-end, efficient, effective program service delivery to our partners and their patients. PAF is the only 501(c)(3) administering Co-Pay & Financial Assistance programs for and with national non-profit partners. 2024, NPPA highlights included:

76,664
PATIENTS ASSISTED

\$122M+
DISTRIBUTED TO PATIENTS

94 DISTINCT DISEASE FUNDS

#### New NPPA Partnerships

Blue Circle Health, through its Blue Circle Foundation (BCF), partnered with PAF to create and administer its Patient Prescription Assistance Program, offering financial aid to eligible Type 1 Diabetes (TID) patients for their medications. BCF, a 501(c) (3) organization, provides free diabetes care, education, and support to TID patients in under-resourced communities in Florida, Maine, Vermont, Ohio, and Delaware.

The Medication Assistance Program (MAP), a partnership between Citizens Health and the Patient Advocate Foundation (PAF), provides financial assistance for medication to eligible patients concerned about affording prescribed treatments. Funded by Citizens Health's 340B savings and other charitable grants, MAP helps patients through Citizens Medical providers. Citizens Health, a non-profit 501(c)(3) organization, is a highly integrated rural health system in northwest Kansas. The MAP program is set to expand to other rural health systems in 2025.

# PAF'S New Financial Assistance Funds

#### Begin Again Foundation Amputee Fund,

in partnership with Begin Again Foundation, offers one-time \$1,000 grants to eligible patients who underwent an amputation resulting from a sepsis diagnosis for expenses related to prosthetics and assistive devices not covered by insurance.

The Begin Again Foundation Southeastern Virginia Financial Aid Fund, in partnership with the Begin Again Foundation, offers one-time \$1,000 grants to eligible patients in Southeastern Virginia diagnosed with sepsis, acute respiratory distress syndrome, or toxic shock syndrome. The grants cover rent/mortgage, transportation, utilities, food, nutrition, and lodging expenses.

The Patric Young Foundation SCI Financial Aid Fund, in partnership with the Patric Young Foundation, offers one-time \$1,000 grants to eligible patients in Jacksonville or Gainesville, Florida, with life-altering spinal cord injuries. The grants cover transportation, housing, utilities, nutrition, home adaptations, and adaptive devices not covered by insurance.

ACS Cancer Care Continuity Fund, in partnership with the American Cancer Society, was launched to support cancer patients and families affected by Hurricane Helene or Milton. The \$500 grant helps cover unexpected storm-related expenses.

The Patient Advocate Foundation Caregiver Support Fund, in partnership with the American Cancer Society, provides \$2,000 grants to eligible caregivers of cancer patients for expenses such as food, housing, utilities, transportation, lodging for treatment, lost wages, and respite care not covered by insurance.

in my darkness." – Mom of patient Noah | Sepsis

>> For full details, visit tiny.cc/paf-funds

"When everything happened to my son, my life was shattered. It was at a point where everything was going wrong. We lived in the hospital for 3 months. [It] was the scariest thing a mother can face.

I always kept my faith and people from [the hospital] have been my light. Telling me about this program was heaven-sent.

I had used up my savings on bills, and since he came home, we have been in a bit of a struggle...When

# PATIENT EDUCATION

# **Empowering Healthcare** Consumers

PAF educational resources and tools empower healthcare consumers with actionable advice and resources to achieve equitable, affordable, and quality healthcare. Our content spans insurance access, medical debt, disability benefits, and more.





7,369 MAILED











NEW AND UPDATED EDUCATIONAL RESOURCES PRODUCED

PAF's Education Resource Library (ERL) is the central hub for our digital educational materials. Content is easily searchable and available in a variety of formats including on-demand video learning series, full-length publications and topic-based pro tip sheets.



INCREASE IN AVERAGE DAILY CONTENT
VIEWS FOR ERL MATERIAL IN 2024

#### The National Financial Resource Directory (NFRD)

is our most utilized automated resource. It supplies users with a list of customized resources based on their selected criteria, introducing enduring solutions to each user's unique circumstance.



MATCHING RESOURCES DELIVERED BY NFRD IN 2024, A 56% INCREASE

#### Featured Resource

PAF launched the "Making the Most of Your Medicare Benefits: A Guide to Navigating Medicare With Confidence" video series, supported by Pfizer. This 12-part curriculum helps Medicare beneficiaries navigate their coverage confidently. Produced with DeafHealth, the videos include American Sign Language, captions, transcripts, voice-overs, and graphics. Topics cover Medicare Parts A-D, Medigap plans, and open enrollment. In just four months, the series gained over 3,700 views.



WATCH THE MEDICARE VIDEO SERIES Sponsored by: this is **living with** cancer" **Pfizer** 

# Matters of the Heart

#### **Notable Project**

Matters of the Heart is an online tool offering patients resources for heart disease prevention and managing financial challenges. With the best resources from top non-profits and cardiovascular experts, it empowers patients to take informed actions in managing their care.

>> View resource at tiny.cc/paf-heart





NATIONAL FINANCIAL RESOURCE DIRECTORY 132% increase

Over 120,129 user searches | View resource at tiny.cc/paf-nfrd

**ENGAGING WITH INSURERS: APPEALING A DENIAL** 

**2,524 views** | View resource at tiny.cc/paf-engaging-insurers

SAMPLE APPEAL LETTER FOR CLAIM DENIAL

1,953 views | View resource at tiny.cc/paf-sample-claim

**MEDICAL EXPENSES: HEALTHCARE SERVICES** 

1,586 views | View resource at tiny.cc/paf-expenses-tips

ACCESSING CARE WITHOUT HEALTH INSURANCE

1,576 views | View resource at tiny.cc/accessing-care

I just wanted to say thank you for creating The National Financial Resource Directory!! It's been extremely helpful and informative! It is especially helpful for individuals like me with multiple disabilities and illnesses and needed different or more assistance than the average individual... So, again, thank you for everything!"

- NFRD User



### **Award Recognition**

Making the Most of Your Medicare Benefits: A Guide to Navigating Medicare with Confidence was recognized with a Bronze Award from the 33rd Annual National Mature Media Awards for clarity and effectiveness in addressing Medicare-related challenges.

>> View resource at tiny.cc/navigate-medicare



# **COMMUNICATIONS**

# Connecting Individuals & Communities to PAF Resources

Corporate communication efforts engage diverse audiences, connecting individuals and communities to PAF programs, resources, and collaboration opportunities while raising awareness. Data helps identify communication preferences, trends, and content gaps, which guide video, audio, and print content creation. We aim to grow and sustain an active online audience that engages with and shares our content, expanding PAF's patient safety net ecosystem.



Powerful new titles, including:





**PAF Helped Keep Catherine** Alive for the Past 8 years >> youtu.be/v6Wv5Pb7O5U





**Inflation Reduction Act Impacts** 2025 Medicare Coverage: What Does it Really Mean for You? >> youtu.be/kU14xeErR\_M

#### PAF's YouTube Channel Hits New Milestones

More people than ever before visited our YouTube channel this year. They explored compelling patient stories, met deserving PAF scholarship recipients, and learned from new educational resources and pro tips. Significant channel construction included curating two new playlists, premiering more than 25 new video titles, and applying features that lead visitors to related site content.

PAF's YouTube channel has achieved remarkable growth in 2024, with 91K views—an increase of 397% from 2023—alongside 1.8K watch hours, up by 325%, and an impressive 1.6M impressions, marking a staggering 999% rise compared to the previous year.

Bravo and thank you PAF! There is power and healing in shared stories!"

- YouTube Visitor





**VISIT THE PAF YOUTUBE CHANNEL & SUBSCRIBE!** 





Patient Advocate Foundation's Annual Impact Report, More Support, More Conditions, More Patients, was recognized with a 2024 Summit International Silver Award for creative excellence in communications and marketing.

### Expanding Reach, Deepening Engagement

In 2024, we focused on activating and growing PAF online subscriber communities. Our approach involved delivering personalized, crafted communications on preferred topics across email, social media, websites, and through community and non-profit partners.



## Expanding Impact: Record Growth In Email & Video Engagement



4,824,768

total emails sent to subscribers with all content preferences

↑17% increase

197M+

emails opened

↑18% increase

AUDIENCE

**50,000** active PAF email subscribers

>3,000 Spanish languag subscribers 1.48M+

crafted emails successfully reached subscribers with PAF news, disease information, and public health preferences

↑38% increase

- with 642,164 opens-32% increase
- 90 distinct emails crafted for these preference areas
- open rates consistently exceed national industry standards

O

231,114

total views of PAF videos

个132% increase

42

new videos produced

↑91% increase



# **HEALTH EQUITY & COMMUNITY ENGAGEMENT**

# Leading the Way

In 2024, PAF deepened its commitment to health equity through thought leadership, community engagement, and strategic outreach. Our work spanned communities, podcasts, national stages, the White House, and even film, fostering dialogue and action on key health disparities.

## Addressing Triple Negative **Breast Cancer (TNBC)**

Building on our 2023 Ignite TNBC Campaign in Chicago, PAF partnered with Elevated Survivorship, Inc. to convene the Chicago Better Together Breast Cancer Disparities Think Tank. The result: The Pink Print Chicago Edition, an action plan addressing mortality disparities in Chicago's Southside. Community-identified priorities include Nutrition/Food Justice, Environmental Justice, Cancer Care Continuum, and Social and Emotional Wellbeing.

PAF led development of But Yet, They Rise, a 30-minute documentary showcasing survivorship of five Black women with TNBC in Chicago. This powerful documentary aims

> to spark conversations about TNBC and drive support for Black women facing the disease.



**WATCH: BUT YET, THEY RISE** 





PAF staff featured at the She Shines conference



Sisters Working It Out 2024 Annual Day of Beauty in Chicago

# Thought Leadership & Recognition

#### **Patient Advocacy Rise Award:**

PAF was honored by the Black Women's Health Imperative/Rare Disease

> Diversity Coalition for leading the first-ever survey capturing the experiences of underrepresented rare disease patients and caregivers. The findings informed the report "Inequities in the Rare Disease Community: The Voices of Diverse Patients and Caregivers."

#### **Politico Health Summit:**

PAF participated in C-Span's televised panel discussion on key health issues for the presidential election.

#### White House Rare Disease Forum:

PAF Health Equity leadership moderated a panel streamed live to 9,900+ viewers.

Above: Alan Balch, PhD (left), CEO of Patient Advocate Foundation and National Patient Advocate Foundation, with Shonta Chambers, EVP of Health Equity Initiatives and Community Engagement accepted the award on PAF's behalf.



Rise Up Atlanta: TNBC is a Serious Matter, community education event with Alpha Kappa Alpha



#### SMHN Advances **Cancer Prevention**

PAF's SMHN is part of a national consortium advancing tobacco and cancer prevention for populations facing health disparities. With CDC grant support, SMHN strengthens national and state cancer control programs, health systems, and non-profits to implement effective interventions and drive upstream changes across the health ecosystem.

In collaboration with the Geographic Health Equity Alliance and Nuestras Adelante Voces, SMHN launched the Tri-Networks Cancer Prevention Community of Practice. National Cancer Prevention and Control teams from Alaska, Colorado, Mississippi, Nebraska, New York, and Oklahoma will provide one-on-one technical assistance to enhance capacity to address cancer disparities among low-income, Hispanic, and geographically disparate communities.

SMHN also offers virtual training and technical assistance to national and state cancer control programs and community organizations. In 2024, SMHN:





A SMHN staff member was appointed to the Michigan Cancer Consortium to support strategies for improving cancer detection, treatment, and survivorship in underserved communities.

# **Expanding Community Engagement**

Representing our core work in community outreach to ensure awareness of PAF resources, we collaborated with diverse partners to connect communities to vital health resources, engaging 3.3K+ individuals.

Not pictured below: Black Directors Health Equity Agenda - National Summit panelist, Health Equity Now: Charting our Course

Global Healthy Living Foundation – Featured guest on The Health Advocate podcast, The Balancing Act of Chronic Illness



Ignite Hampton, PAF's first TNBC outreach event in its home region, planned and implemented in collaboration with city leaders



My Style Matters and PAF team up at the HERitage event

# **BEYOND NUMBERS**

# Our 2024 Case Management Impact

**DIRECT ONE-ON-ONE** CASE MANAGEMENT HELP

**AVERAGE NUMBER OF CONTACTS TO REACH CASE RESOLUTION** 

OF PATIENTS HAD NEEDS SPANNING MORE THAN **ONE ISSUE CATEGORY** 

INCREASE IN REFERRALS FROM OTHER NON-PROFIT **ORGANIZATIONS** 

These indicators reveal a sharp spike in patient need and case complexity this year

#### Why Patients Sought PAF's Help



FINANCIAL COST-**OF-LIVING ISSUES** 



**INSURANCE ISSUES** 



**ELIGIBILITY AND** ENROLLMENT ISSUES

↑11% increase



**PSYCHOSOCIAL SUPPORT** 

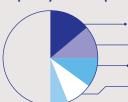


**EDUCATIONAL** 



**GUIDANCE ON EMPLOYMENT LAWS** & PROTECTIONS

Top Ways We Helped Patients (of the 230 distinct resolutions captured)



 $\cdot$  14% located rental/mortgage payment relief

• 11% ASSISTED WITH HEALTH INSURANCE SCREENING AND ENROLLMENT (120% increase

11% SECURED TRANSPORTATION ASSISTANCE

**9**% NEGOTIATED ASSISTANCE FOR MEDICAL CO-PAYMENTS

**6**% PROVIDED INSURANCE NAVIGATION SUPPORT

#### **Our Patient Population**

What Changed in 2024?

**Ethnicity** 

**INCREASE IN PATIENTS WITH NERVOUS SYSTEM CONDITIONS** 

NEUROMUSCULAR DISEASES

**INCREASE IN PATIENTS IDENTIFYING AS DISABLED** 

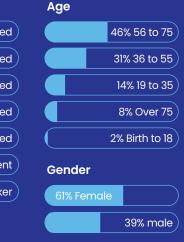
**INCREASE IN PATIENTS IDENTIFYING AS UNEMPLOYED**  **INCREASE IN PATIENTS AGED 56-75** 

# 59% White 24% Black/African American 11% Hispanic/Latino 3% Blended Race 2% Asian 1% American Indian/Alaska Native

.4% Native Hawaiian/Other Pacific Islander







5월10 PATIENT ISSUES INVOLVED:



**CANCERS** 

DIABETES

NERVOUS SYSTEM CONDITIONS

**CARDIOVASCULAR CONDITIONS** 

**NEUROMUSCULAR DISEASES** 

**AUTOIMMUNE DISEASES** 

**PULMONARY CONDITIONS** 

**VASCULAR DISEASES** 

GASTROINTESTINAL

& HEPATOLOGY DISEASES

**CHRONIC OR DEBILITATING CONDITIONS** 

DISABILITY OR HEALTH
INSURANCE ENROLLMENT,
OR OUT-OF-POCKET
MEDICAL EXPENSES

\$7.1M+
SECURED IN FREE
OR DISCOUNTED TREATMENT
FOR PATIENTS

**TOP 10 DIAGNOSIS CATEGORIES** 

71%

8%

8%

6%

5%

4%

4%

4%

3%

2%

5월10 PATIENT ISSUES INVOLVED:



**BREAST CANCER** 

**PROSTATE CANCER** 

**MULTIPLE SCLEROSIS** 

**PANCREATIC CANCER** 

**DIABETES TYPE II** 

**COLON CANCER** 

**OVARIAN CANCER** 

STROKE (CVA)

NON-SMALL CELL LUNG CANCER

ALS (LOU GEHRIG'S DISEASE)

UTILITY, HOUSING, TRANSPORTATION, OR FOOD ASSISTANCE

\$2.9M+
SECURED IN DEBT RELIEF FOR PATIENTS RESULTING FROM OVERTURNED INSURANCE DENIALS

**TOP 10 DISTINCT DIAGNOSES** 



Service by the Numbers



**76,304**PATIENTS APPROVED FOR HELP

# \$ \$208M+



19%

12%

4%

4%

4%

3%

2%

2%

2%

2%

190,304 INCOMING CALLS

↑14% increase





DISEASE FUNDS SERVED PATIENTS

**INCLUDING:** 

19 HEALTH EQUITY



813,258
PATIENTS HELPED
BY CO-PAY RELIEF SINCE 2004



804

DISTINCT PATIENT DIAGNOSES



454

DISTINCT RARE DISEASES







Richard has received financial help for several years from PAF's Co-Pay Relief Program.

# RESEARCH, ENGAGEMENT & EVALUATION

# Partnering to Generate Patient-Centered Evidence



In 2024, we concentrated on forging partnerships and initiating projects that address patients' access and affordability challenges. Through PAF's Patient Insight Institute (PII), we ensure that their diverse experiences and perspectives are heard and integrated into efforts to improve healthcare. Our extensive collaboration highlights our capacity to work with a wide range

of stakeholders to drive meaningful change within the healthcare and research fields. By forming strong partnerships with academic researchers, industry leaders, policymakers, and community organizations, we have strengthened our collective impact.

>> Learn more about these projects at tiny.cc/paf-research











# Qualitative Research Spotlight

Impact of Treatment Options on Selecting the Right Setting for Metastatic Breast Cancer (mBC) Care

Patients diagnosed with mBC require in-person visits throughout their healthcare. In-person visits may cause financial and logistical challenges that affect a patient's health, quality of life, and financial burden.

Focus group participants explored the impact of mBC diagnosis and treatment. Participants (n = 19) were 68% <56 years old, 27% non-white, 47% household income <\$50,000. Most (79%) lived in a household of 1 or 2 people, 16% reported living in a rural location, 52% reported being disabled and unable to work, and all participants had health insurance coverage.

#### Discussions followed three topics:

(1) the best treatment for mBC; (2) the impact of athome care versus mainly in-office treatment; and (3) how mBC diagnosis and treatment affected life plans and relationships.

Personalized care and treatment flexibility were key themes. Patients preferring at-home care cited financial and logistical benefits, including less "time toxicity," while those favoring in-office visits valued emotional support and provider interactions. Trust and communication with providers were central to treatment decisions.



#### **BEST TREATMENT FOR MBC**

Treatment is highly individualized, no true "best treatment"

Insurance limits treatment options

Patients research and advocate



#### **OUT-OF-OFFICE VERSUS IN-OFFICE**

**Patients want flexibility** & reduced travel

Fear of isolation & lack of monitoring for out-of-office treatment

Need for care coordination, overall



#### **LIFE & RELATIONSHIP CHANGES**

Loss of relationships and identity

Strain on relationships from "looking okay"

Strengthened family bonds

# Quantitative Research Spotlight

#### Exploring Healthcare Costs, Financial Strain, and Coping Strategies Among Chronically III Medicare Patients

Healthcare expenses, including provider services, medications, and insurance premiums continue to rise, forcing patients to bear growing financial burdens.

We captured the financial and emotional experiences of chronically ill Medicare patients with the cost of care and coping mechanisms prior to the implementation of the IRA. Our cross-sectional analysis used data from a nationwide survey distributed in June 2024.

Respondents (n=402) were 60% male, 88% >56 years old, 24% non-white, 82% household income <\$50,000, 59% <200% Federal Poverty Level, 17% lived in a rural location. Main diagnoses were HIV/AIDS (36%) or cancer (19%).

Reported primary sources of household income were disability payments (33%) or Social Security income (58%) and 43% reported no secondary income sources. Seventeen percent (17%) reported a decrease in household income over the past 12 months.

#### Patient Coping Mechanisms for Increased Healthcare Costs:















57% RECEIVED CHARITABLE CO-PAY

33% USED CREDIT CARDS

26% CHANGED LIFESTYLE

23% DELAYED CARE TREATMENT

20% CUT SUPPORTIV MEDS

19% SWITCHED MEDICATION TYPE

### **Publication Spotlight**

A proactive financial navigation intervention in patients with newly diagnosed gastric and gastroesophageal junction adenocarcinoma



Gastric and gastroesophageal junction (GEJ) cancer patients are especially vulnerable to financial hardship caused by intensive treatments which can lead to poor outcomes. Few oncology clinics offer financial support or guidance on managing added healthcare costs and household expenses before financial difficulties arise. Our pilot randomized study assessed the impact of a 3-month proactive financial navigation intervention versus usual care. The study aimed to evaluate the feasibility of randomizing patient-caregiver dyads, ensure follow-up survey completion for usual care participants, and gather initial efficacy data for a larger, more rigorous trial. >> For more, visit tinyurl.com/pub-spotlight

# Research & Policy Interns

PII's Summer Internship Program attracted an exceptional pool of 61 applicants from 31 institutions, with both graduate (32) and undergraduate candidates (29).

Three summer interns collaborated to examine healthcare and policy issues in California, Pennsylvania, and South Carolina using Healthy People 2030 metrics.

>> Learn more about our interns at tiny.cc/paf-interns

## Year in Review 2024

Through PAF's Patient Insight Institute, we amplify the voices of patients and caregivers, ensuring the inclusion of those who are often overlooked or underrepresented in research and healthcare reforms. With impactful research and interdisciplinary collaboration, we foster a more equitable patient experience. Join us as we reflect on an extraordinary year of progress and action and as we continue efforts to build real-world evidence that fully represents and supports the entire patient experience.

>> For more, visit tiny.cc/year-in-review

# **EVENTS WITH PURPOSE**



## Collaborating for Healthcare Solutions

Held in Washington, DC, Patient Insight Congress (PIC) 2025 fostered a collaborative environment where 61 participants gathered to discuss strategies to address issues impacting the healthcare system and impeding optimal healthcare access for patients. The event highlighted the importance of shared insights and cooperation in driving meaningful improvements to achieve quality, affordable healthcare for all.

PIC sessions underscored the importance of empowering patients and caregivers to effectively engage with the healthcare system, advocating for systemic changes to better accommodate their needs. Achieving health equity necessitates community engagement and a multi-stakeholder approach, particularly in areas with social vulnerability and limited healthcare system access.

>> Find out more at patientinsightinstitute.org/home/patientcongress



### A Promise of Hope Affair

Patient Advocate Foundation's 23rd annual premiere fundraising gala, A Promise of Hope Affair, was held at the Newport News Marriott City Center in October. We welcomed nearly 350 guests to the Glitz and Glamour-themed event, raising \$111,250 in support of patients helped through our case management programs and \$125,000 for our Scholarship for Survivors program.

Students and scholarship recipients Karlee McMullen (University of North Carolina, Charlotte) and Rowan "Finn" Mott (2024 graduate of Colorado College) captivated guests with their compelling stories of courage in the face of seemingly insurmountable health obstacles. Both expressed gratitude not only for the financial support their scholarship awards afforded but also for the confidence and strength that support inspired during their challenging pursuit of an educational dream.





# **21 EVENT SPONSORS**



\$236,250 RAISED







**175 AUCTION PACKAGES** 

At left: 1. PAF Co-Founder Jack Ennis, PAF Founder and Chair Emerita Nancy Davenport-Ennis, and Congressman Bobby Scott 2. Rachel Brown, past scholarship recipient Dr. Benton Brown, and PAF President of Operations Fran Castellow 3. PAF guests enjoying the reception and silent auction.



## **Supporting Scholars**

Scholarship for Survivors is a highly competitive program supporting college students whose educational pursuits were disrupted due to a chronic or life-threatening illness. Since 2000, the program has provided 206 accomplished students with scholarship awards totaling over \$1 million.

These students haven't let cancer or chronic illness derail them, and with your help, we won't either!

>> Donate and learn more at tiny.cc/scholarships-2025

NEW SCHOLARSHIP AWARDEES

RETURNING SCHOLARSHIP AWARDEES

S3K SCHOLARSHIP VALUE PER ACADEMIC YEAR

**CONSECUTIVE YEARS OF FUNDING** FOR ELIGIBLE AWARDEES

# Congratulations to the '24 - '25 Scholarship Winners



Arisa Stanford University



Ella Ohio State University

John Florida State University



University of California,

Kayla **Duke University** 

Penn State University





Marie Oglethorpe University



Michael









#### **EXPERIENCE THE STORY**

Meet Finn, a recipient of PAF's Scholarship for Survivors award who survived brain & spinal cancer.

# FINANCIAL STATEMENTS

Patient Advocate Foundation financial statements are based on its fiscal year, from July 1, 2023, to June 30, 2024.

2,047,391

# Patient Advocate Foundation Statement of Financial Position June 30, 2024

# Assets Current Assets

General operating cash and cash equivalents \$ 14,546,938
Restricted cash and cash equivalents 184,355,850
Investments 82,333,096
Other Current Assets 20,912,290

Total current assets \$ 302,148,174

Property and Equipment, net 5,367,177
Right-Of-Use Assets - Operating Lease 5,602,912

 Other Assets
 50,331

 Total assets
 \$ 313,168,594

#### **Liabilities & Net Assets**

Post-retirement benefits liability,

#### **Current Liabilities**

Accounts payable and accrued expenses \$ 5,072,565

Deferred revenue 18,360,154

Other Current Liabilities 1,199,751

Total current liabilities \$ 24,632,470

#### **Long-Term Liabilities**

less current portion
Incurred but not recorded liabilities 79,000
Operating lease liability, less current portion 5,235,810

Total long-term liabilities \$ 7,362,201

Total liabilities \$ 31,994,671

#### **Net Assets Without Donor Restrictions**

Undesignated\$ 32,620,605Board designated2,333,096Total net assets without donor restrictions34,953,701

Net Assets With Donor Restrictions 246,220,222

Total net assets	281,173,923
TOTAL LIABILITIES & NET ASSETS	\$ 313,168,594



- 87.4% Grants & Donations \$212,888,260
- 7.5% Program Administration \$18,199,957
- 5.1% Interest \$12,545,181

TOTAL \$243,633,398



- 98.4% Program Services \$269,932,600
- 1.1% Management & General \$3,019,639
- .5% Fundraising \$1,399,746

TOTAL \$274,351,985

### Patient Advocate Foundation Statement of Activities Year Ended June 30, 2024

Operating Revenues Contributions:	Without donor restrictions	With donor restrictions	Total
Grants & donations	\$3,195,787	\$209,120,471	\$212,316,258
Private & public donations	363,846	-	363,846
Donated materials	-	19,695	19,695
Program administration	18,199,957	-	18,199,957
Patient Insight Congress	71,786	_	71,786
Promise of Hope	86,370	_	86,370
Patient Action Council	50,000	_	50,000
Investment return, net	12,545,181	-	12,545,181
Net assets released from restrictions:			
Satisfaction of program restrictions	240,818,971	(240,818,971)	-
Total revenues, gains & other support	275,331,898	(31,698,500)	243,633,398
Operating Expenses			
Program services:			
Patient/educational services	7,719,040	-	7,719,040
Financial aid programs	254,274,596	-	254,274,596
Service contracts	7,938,964	-	7,938,964
Supporting services:			
Management & general	3,019,639	-	3,019,639
Fundraising	1,399,746	-	1,399,746
Total expenses	274,351,985	-	274,351,985
Change in net assets from operations	979,913	(31,698,500)	(30,718,587)
Other Non-operating Changes			
Post-retirement benefit changes	99,549	-	99,549
other than periodic cost			
Change in net assets	1,079,462	(31,698,500)	(30,619,038)
Net assets, beginning of year	33,874,239	277,918,722	311,792,961
Net assets, end of year	\$34,953,701	\$246,220,222	\$281,173,923

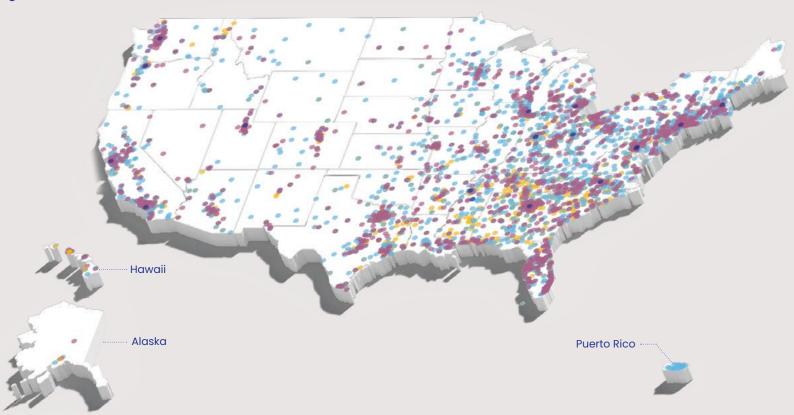
# **OUR NATIONWIDE HEALTHCARE PARTNERS**

# Healthcare Partners in Action

Representing a broad spectrum of partners, this map illustrates PAF's connections to 25,444 institutions across the nation.

These relationships—with healthcare partners, healthcare providers, non-profit advocacy organizations, and others—play a critical role in supporting patient needs and improving access to care.

PAF's national network underscores our commitment to addressing healthcare challenges from multiple angles to bridge gaps in care.



# Healthcare Partners by Type

- Healthcare partners | 31 institutions in 17 distinct locations
- Case management partners | 5,011 institutions
- Co-pay relief institution partners | 7,133 institutions
- Active registered healthcare providers | 13,269 institutions

# **BEYOND THANKFUL**

# For every patient we help, we have you to thank.



"After being diagnosed with papillary thyroid cancer... and not having health insurance, I faced significant difficulties in navigating the process of applying for state assistance. Despite my efforts, I struggled to correctly complete the necessary forms. However, with PAF's guidance and assistance, I was finally able to complete the forms accurately and became eligible for financial assistance. This eligibility allowed me to secure health insurance, which in turn enabled me to proceed with the medical care I urgently needed. Thank you for the invaluable help and support during this critical time. Your efforts made a significant difference in my life, and I truly appreciate everything you have done."

Mojgan | Papillary Thyroid Cancer

Cheris Abbott-Holder
AcademyHealth
Ace Peninsula Hardware
Newport News
Tyler Affinito
AHIP
Nadeem Ahmed
Patricia Aleshire
Laura Allen
ALS Association
American Cancer Fund
American Cancer Society

**AMF York Lanes** 

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Benjamin Anderson
Eric Anderson
Marbrico Anderson
Troy Anderson
Renee Anderson-Russell
Tracy Andrus
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Annexus Health
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Michael Zincone

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In Honor of Nancy Bowman Carla Callaway

In Honor of Gwen Darien Jacqueline Darien

In Honor of Deborah Dunning Judith Garcia

In Honor of Arnulfo Flores Mireya Flores

In Honor of Penelope Rylka Gordon Robert T. Gordon Jr.

In Honor of Joshua and Jennifer Gould Julie Blystad Benjamin Gould

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In Honor of Haley King Dylan Moreland

In Honor of Larry King Kevin King

In Honor of Nancy McGee Jennifer Millard

In Honor of Finn Mott Ann Stenberg

In Honor of my Laurel KNB Communications

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In Honor of Beth Scott Yung Lie

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My case manager was extremely helpful in explaining my disability benefits, and payout and also informing me that because of the disability I was receiving, I would not qualify for Medicaid. The Medicaid office had not informed me of this. Next, she helped me sign up for health insurance coverage [through the Marketplace]. She also gave me information about organizations that could assist me with paying my premium, putting me at ease because I was overwhelmed with the upcoming surgery for my condition. I am blessed to have come across the Patient Advocate Foundation."

**Brigetta** | Neurofibromatosis

#### **Equity Value Statement**

Equity moves us forward, calling us to address the legacy of deeply established societal inequities in healthcare and workplace systems. We identify and eliminate barriers to equitable access in the healthcare systems that our patients utilize and in the workplace our staff experience. We commit to diversity and inclusion strategies that enable equitable outcomes in our leadership, practices, policies, operations, and organizational systems because doing so strengthens our ability to deliver on our mission.

### Acknowledgments

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