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Welcome

PAF's 2022 Annual Impact Report reflects what we can accomplish thanks to the patients and partners with whom we collaborate in our shared mission to overcome obstacles to care.

You don't have to look far to find a patient in social or financial distress. It is a sad truth that most of us will one day need some form of assistance to overcome obstacles and barriers related to medical care. If you have a chronic or life-threatening illness, you are going to need help from both a family caregiver and a wider community of helpers. This support network of which Patient Advocate Foundation is a part, recognizes the real-world struggles you face and provides the services and resources you need to get well.

It is also a painful reality that race, ethnicity, and socioeconomic status are strongly associated with healthcare outcomes. Other factors—collectively, the social determinants of health—also contribute not only to the likelihood that you will have a chronic disease, but also to the challenges faced in gaining access to and affording the care you need as a result. PAF recognizes that not everyone, everywhere has the same access to healthcare services, or to necessary safety net and social supports.

For every patient you see in these pages, there are tens of thousands more that we helped in 2022. Two of the stories shared by patients on pages 8 (Robert) and 14 (David) illustrate the distress and hopes of so many. Robert described how "the money begins to add up" being a "lifelong diabetic with all the complications

that goes along with that". David has end-stage renal disease and expressed that PAF's case management services are a "knowledge base" where he can go for answers to some issues that have challenged him for years.

These stories and many more like them inspire us to develop innovative approaches to achieve our mission, which has always been rooted in the deep belief that socioeconomic disadvantages should not limit anyone's access to affordable, quality care. For example, we expanded our efforts in 2022 to ensure that communities with the highest levels of chronic disease but the lowest levels of the resources needed to access healthcare are equipped to find critical support that might be available outside their community. We continue to expand our partnerships with patient advocacy groups, community-based organizations, academic research centers, healthcare companies, medical professionals, hospitals and other stakeholders who believe like we do, that together we can uncover and overcome obstacles including lack of transportation, food and housing experienced by the most marginalized communities.

Thank you for all you do to support us and others who assist patients facing significant financial and social needs related to their odyssey through the world's most expensive and complicated healthcare system.

Alan J. Balch, PhDChief Executive Officer

Alam J. Bolch



A Message from our CEO tiny.cc/ceointroduction

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 2022, and we've helped a cumulative total of more than 1.8 million patients nationwide with support provided by more than 200 staff.

Overall Foundation Impact

Total Patients Served in 2022

Increased by 22%

Total Patient Cases	187,359
Case Management Cases	18,838
Co-Pay Relief Recipients	70,883
Financial Aid Fund Recipients	81,070
Patient Services Email Helpline Sessions	16,568

Total Patients Served by PAF Between 1996 and 2022

1,897,708

DIAGNOSES SERVED BY PAF

1049 Distinct Patient Diagnoses

by 40% 652

Distinct Rare Diseases

The Programs Through Which We Deliver Direct Assistance

CASE MANAGEMENT

38
total unique programs

- **6** with focus on Health Equity
- 21 serve patients living with a diagnosis other than cancer
- 17 serve patients living with cancer
- 11 programs are fully administered by PAF for other non-profit organizations
- **4** partnerships with academic research institutions or academic medical centers

FINANCIAL ASSISTANCE SERVICES

15 atient assista

patient assistance programs provide financial support to patients across 185 unique funds

- **54** disease funds assist with medication costs
- 10 disease funds with focus on Health Equity
- **93** funds provide travel assistance to patients
- **37** funds provide cost-of-living assistance to patients _____
- 1 fund provides financial assistance to people impacted by COVID-19

What Our Patients Are Saying...

Each patient directly served by the organization receives a survey and an invitation to share feedback about their experience with PAF. A standardized, postencounter survey instrument, available online or in hard copy and in both English and Spanish, is used across all patient service areas to assess overall patient satisfaction and program impact levels. The 2022 combined survey completion rate was 5%.

"I WAS SO LOST NAVIGATING GETTING NEW INSURANCE AFTER MY DIAGNOSIS.

MY CASE MANAGER WAS SO KIND AND KNOWLEDGEABLE, AND NOW I HAVE A HEALTH PLAN THAT WORKS FOR ME."

-James, HIV

97%
indicated that PAF
provided resolution
to their issue

Overall PAF Staff Rating

4.7_{of} 5

for their communication, knowledge & professionalism

% of Respondents
That Would Recommend
PAF to Others by Program



Case Management



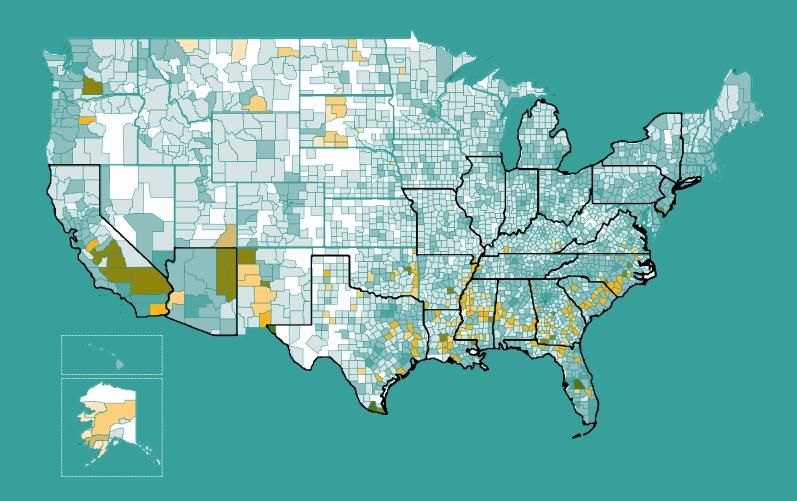
Co-Pay Relief



Financial Aid Funds

Service to All 50 States

PAF served patients in all 50 states, 2 U.S. territories and Washington D.C. in 2022. Using county-based data, the heat map below depicts the locations of patients served through our case management and financial assistance services. The 220 Health Equity counties, and patients served from them, are also represented. These counties were selected as areas of significant focus through the development of a methodology that used the Centers for Disease Control's Social Vulnerability Index (SVI) combined with CDC disease incidence data to identify 220 counties across 31 states with the highest rates of social vulnerability and high rates of multiple chronic diseases.



Number of Patients Helped by PAF per County

- Less than 10
- 11-250 Patients
- >250 Patients

Number of Patients Served in Health Equity Counties

- Less than 10
- 11-250 Patients
- >250 Patients
- In a county that has patients helped by PAF and patients served in Health Equity counties, the colors will mix

☐ PAF Top 20 Patient Service States

Florida: 14%	Pennsylvania: 4%	Alabama: 2%
Texas: 12%	Tennessee: 3%	Indiana: 2%
Georgia: 7%	Illinois: 3%	Arizona: 2%
California: 6%	Virginia: 3%	Missouri: 2%
New York: 4%	South Carolina: 2%	Louisiana: 1%
North Carolina: 4%	Michigan: 2%	Mississippi: 1%
Ohio: 4%	New Jersey 2%	

Case Management

Our professional case managers provide essential services to help patients diagnosed with chronic and life-threatening conditions navigate equitable access to healthcare and safety net programs. Assisting 18,838 patients with 1,049 distinct diagnoses in 2022, their direct interventions resulted in \$26,392,098 in debt relief secured on behalf of case management patients, a 14.5% increase over last year. The patients we serve come from all walks of life, with one shared experience that unites them - an inability to obtain needed medical care or afford necessities such as food, housing, utilities, and transportation.

Patient Advocate Foundation would like to recognize and thank program sponsor Amgen, for its generous support of the Health Equity Case Management Program.

AMGEN

The level of intensity and effort required to resolve patient cases increased in 2022. Case managers made an average of 23 contacts per case, an increase of 49% compared to 2021, and helped with 1.25 issues per case on average, an increase of 12%. We also saw shifts in who we served and how we served them this year. More than 44% of patients earned less than \$24,000, 25% are retired, 21% are disabled, 52% were 56 or older, and 9% were over 75 (a 10% increase in the patients served from that age group compared to 2021). Cost-of-living issues surpassed insurance issues as the top issue category, with 40% of patients reporting that as a primary issue, an increase of 25% from 2021.

PAF recognizes that connection with one-on-one case management support is particularly important for certain populations that experience social needs gaps associated with the Social Determinants of Health. **The Health Equity (HE) Case Management Program**, launched in 2022, provides social and financial navigation that identifies and responds to obstacles to affordable quality care for patients across 220 counties in 31

states in specific zip codes identified to have the highest rates of social vulnerability and high rates of multiple chronic diseases. Early data comparison between HE and all case management reveals a higher percentage of African Americans (47% HE vs 22% all cases), higher percentage of patients with income less than \$24,000 (61% HE vs 44 % all cases), and higher percentages of disabled (27% HE vs 21% all cases), and unemployed patients (21% HE vs 18% all cases).



Of the 38 case management programs in 2022,

4 were new and 11 were administered by PAF for other non-profit organizations. These innovative, highly collaborative partnerships pair organizational strengths and expand the reach and scope of available assistance for patients and their families.

\$26M+
obtained on behalf
of case management
patients



44%

of all case management patients earn less than \$24,000 10%

increase in patients 75 and older 40%

of all case management patients reported financial cost-of-living issues



40%

increase in distinct patient diagnoses (primarily driven by service to the rare disease community) Key indicators reveal how the type of case management services needed can differ by disease type. For instance, patients served through the Rare Disease CareLine often face issues uncommon to other disease populations, including difficulty obtaining a diagnosis, lack of access to specialized care and providers that treat their condition, and higher out-of-pocket expenses for out-of-network services. The number of distinct rare diseases served by PAF increased by 94% from 2001 to 2022. Of the total PAF cases in 2022 for which at least \$100,000 of medical debt relief was obtained through case management, 41% involved a patient with a rare disease.

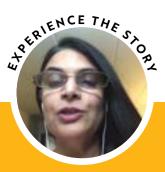


Top 3 Case Management Issue Categories

40% Financial Cost of Living

Insurance Issues

70% Eligibility and Enrollment



A Message from Sarita

Sarita contacted PAF with questions about disability rights and housing.



tiny.cc/pafsarita

New Case Management Programs:

Health Equity Case Management – he.pafcareline.org

Better Together Network to Improve Health Outcomes in South Side Chicago

.....

Triple Negative Breast Cancer, Allied Approach to Improving Social Needs Navigation for Black Women

Chicago Social Needs Navigation Clinical Integration Demonstration Project



"My case manager helped me organize and file my disability forms and contact the offices i needed to... Having someone have my back after an awful year of [difficulties] explaining and getting things done due to my disability...

She really gave me confidence... I am so appreciative!"

- Kristin, Méniére's Disease



PAF engaged in intentional outreach and education activities to increase awareness and utilization of several case management programs that provide specialized assistance to select populations. These efforts resulted in significant patient service growth including:

increase in ALS Medicare Resource Line cases

increase in Rare Disease CareLine cases Donna CareLine cases

increase in ZERO360: Comprehensive Patient Support cases

increase in PanCAN Financial **Navigation cases**

Financial Assistance Services

Co-Pay Relief

Many patients cannot afford prescribed care without financial help. PAF's Co-Pay Relief (CPR) program exists to help improve access and reduce financial distress experienced by eligible, low-income patients. CPR provides direct financial assistance for insurance premiums, co-payments, co-insurance, and deductibles for medications prescribed to treat and manage disease. Launched in 2004, CPR operates in compliance with the guidance provided by the Office of Inspector General while delivering best-inclass service with an emphasis on ease of access and high-quality patient service.



A Message from Robert

I'm a lifelong diabetic and the money begins to add up.



tiny.cc/pafrobert

More than **70,000 patients were approved** for CPR help in 2022, 17% more than last year. Patients were served through 45 disease funds with **\$286,689,672 in grant payments**.

Because where patients live plays a significant role in determining where and how they receive care and support, in 2022 PAF designed and launched 10 Co-Pay Relief Health Equity Funds to direct assistance to specific populations and places experiencing intense social and financial needs.

To establish the Health Equity Funds, PAF developed a methodology using the Centers for Disease Control's Social Vulnerability Index (SVI) combined with CDC disease incidence data to identify 220 counties across 31 states with the

highest rates of social vulnerability and high rates of multiple chronic diseases. Financial assistance is provided to eligible patients living in the counties covered by the funds, with residency verified using the patient's home address zip code. All other eligibility requirements and fund operations are the same as CPR general funds. For more information, visit the Health Equity section of our website at copays.org/health-equity.

CPR further expanded service when the American Diabetes Association partnered with PAF to launch a diabetes fund. Critical assistance is provided to eligible patients with diabetes for co-payments, co-insurance and deductibles for supportive medications and therapeutic medications and devices. The fund also assists with medical insurance premiums.

Health Equity
Funds get assistance
to the people and places
who need it most.

10 Health Equity Funds launched by CPR

increase in CPR grant payment totals

70,883
patients approved for CPR help



\$286M+
in total CPR
grant payments

Financial Assistance Funds

PAF's Financial Assistance Funds provide grants to eligible low-income patients for expenses including transportation, food, housing and utilities, and for out-of-pocket co-payments. These funds help patients who have compromised access to necessities, extending a critical safety net of support for patients and their families. Financial assistance specialists managed 242,339 incoming calls in 2022.

Responding to an urgent public need, PAF launched the *Pediatric Amino Acid and Metabolic Formulas Emergency Assistance Fund* in July 2022. It provides financial assistance to families impacted by in-patient hospitalization, emergency room, or doctor visit expenses for a child reliant on these formulas for nutrition and whose access was disrupted due to the shortage.

PAF also partners with other non-profit organizations to manage the administration of their financial assistance and co-pay programs. In 2022, these funds provided assistance to 81,070 patients distributing \$207,536,471 to patients in need, a 57% increase over 2021.





"The application process was very user friendly.

The entire process was easily manageable. When I had questions I received answers in a timely and professional manner, which I was very grateful for because going through this journey of this disease is very stressful and there was absolutely no added stress going through the process of applying for or receiving these funds. Thank you so very much. I can't tell you how much this means to me."



- Susan, Ovarian Cancer

48
new financial assistance funds launched



464K+ grant payments made

\$207M+
distributed to patients
in need



81K+

patients received assistance from PAF's financial aid fund specialists



THANKS SO MUCH TO OUR CASE MANAGER. SHE WAS VERY HELPFUL IN GETTING THE WHEELS TURNING WITH MY HUSBAND'S DISABILITY AND RETIREMENT. IT WAS AMAZING TO SEE HOW BOTH WERE GIVING US THE RUN AROUND AND HAVING US WAIT MONTHS WITH NO RESOLUTION. THEN ALONG COMES OUR CASE MANAGER WHO MAKES ONE CALL TO EACH AND VOILA, THEY BOTH CALLED US. DISABILITY AND RETIREMENT BOTH ARE COMPLETE! THANK YOU. YOU HAVE TAKEN ONE HUGE BURDEN OFF US. KEEP DOING WHAT YOU ARE DOING. WE (ALS PATIENTS AND FAMILIES) NEED YOU."

- Tracey, Wife of Patient | ALS



ALS Association partnered with PAF to offer the ALS Medicare Resource Line. This program provides free and confidential navigational assistance for financial and practical challenges that impact healthcare access for ALS patients.

als.pafcareline.org

Disability Training Series and Complimentary Guidebook: This interactive training offers a step-by-step walkthrough to help you understand what a disability is, types of disability coverage, how to submit a strong disability application, how to appeal a denial and more.

education.patientadvocate.org/resource/disability-training-series

2022 Case Management Data

20% of patients requested help with eligibility & enrollment issues

25% of patients identified as retired

21% of patients identified as disabled



Navigation Impact

PAF's Spring 2022 Survey Initiative captured patient perspectives on health-related social needs across the care continuum.



34%

reported no knowledge about social needs navigation services that could help them work through financial or social concerns

60%

reported that if these services were readily available they would be 'very likely' to use them **76**%

reported that it was 'very important' for these services to be available as part of the care provided to them by their provider

Patient Education & Communications



new educational content pieces created (16 in Spanish)

PAF educational initiatives amplify the reach of our case management expertise by providing healthcare consumers with actionable advice and guidance that improves their experience and empowers their actions to achieve access to equitable, affordable, quality healthcare. Content is available in many formats, including audio, interactive trainings, multimedia resource tools, and print materials to address topics such as insurance benefits and enrollment, denials, and appeals, managing medical expenses and debt, disability, and clinical trials.

The National Financial Resource Directory (NFRD)

37,319
publications directly
distributed via mail, outreach
events or case management
electronic download

The National Financial Resource Directory (NFRD) is our most utilized automated resource tool, providing an immediate list of relevant resources based on customized search criteria, introducing solutions to each user's unique situation.

NFRD users benefit from advice otherwise gained only through one-on-one case management, becoming better equipped to address the financial impact of their disease.

patientadvocate.org/explore-our-resources/national-financial-resource-directory



39,667 searches by ERL users



in matching resources by 59% provided to users

160%

169% increase in average daily content views since new ERL launch

Education Resource Library (ERL)

Our Education Resource Library (ERL) is the central hub for PAF educational publications, webinars, and interactive tools. It arms patients, caregivers, healthcare professionals, and others with critical knowledge and actionable resources. In 2022, the Library underwent a complete rebuild to provide easier, more intuitive access to hundreds of educational titles. The new ERL was launched in September.

Most frequently utilized educational resources include:

Tip Sheet Series: 10 Tips to Help You Get the Most Out of Your Health Insurance

Navigating the Disability Process

Engaging With Insurers: Appealing a Denial

ERL welcome video: education.patientadvocate.org/resource/welcome-to-the-education-resource-library **New ERL:** education.patientadvocate.org

Featured Training:



With Support From the

With Support From the Truist Charitable Fund The new Lighthouse Training Series: Preparing for and Responding to the Financial Impact of Critical Illness was developed in response to patient data indicators that revealed a critical and increased need for educational resources to address financial issues impacting today's patients and their families.

The series features 6 free interactive presentations, all under 20 minutes. Each session has an accompanying, printable tip sheet.

bit.ly/LighthouseTrainingSeries

Audience Outreach

Corporate communication activities link broad and diverse public audiences to PAF programs and educational resources. These essential activities also identify and respond to communication gap areas through the routine evaluation and research of content engagement and audience preferences, developing and delivering materials to address unmet needs. Providing timely, multichannel communications in a variety of formats supports the goal of developing, growing, and sustaining active online audiences that subscribe to and engage with our content.

717,999
PAF subscribers reached by personalized crafted communications

In December, we launched a new Spanish-language microsite aimed at Spanish-speaking patients and caregivers who seek our services, and those who are not yet familiar with PAF's available support. The new site offers the full array of PAF's Spanish-language resources, along with new community and educational content.

Visitors to the site are greeted with an explainer video in Spanish.

Spanish-language content includes:

Descriptions of PAF's Case Management and Co-Pay Relief services and how to access them

Educational content, including the award-winning Health Insurance Literacy series

Information on medical costs, insurance benefits and enrollments, insurance denials and appeals, disability, and financial resources



More than 400 visitors to our new Spanish site in the first 14 days!

1

Watch the ¡Bienvenido a Patient Advocate Foundation! video at: vimeo.com/767018733 Explore the new site: espanol.patientadvocate.org

You're invited to subscribe

2022 Subscriber Growth & Engagement:

In addition to the resources and publications hosted on PAF's website, we produced and distributed more than 90 personalized, crafted e-mail communications to members of our subscriber groups. Many titles are also shared through our social media platforms, websites, staff intranet, and through direct sharing with community and non-profit partners.

Written/E-Mail Communications:

92 crafted e-mail communications produced and distributed

44% overall open rate 47% higher than 2021

subscribers in new Spanish language group

Video Communications:

New videos produced and released

61% increase in total views

46% increase in total engagement

Visit PAF on YouTube! tiny.cc/pafyoutube



Migraine Matters is an online educational resource tool that offers tailored content to address the needs of patients with migraine and headache diseases, hosting more than 8,000 unique visitors in 2022.

migraine.pafcareline.org



With resources from top nonprofits and clinical experts in the field of cardiovascular treatment and research, **Matters of the Heart (MOH)** is a self-directed online education tool for patients, caregivers, and healthcare professionals. Content focuses on unique challenges associated with cardiovascular diagnoses. MOH had 3,245 unique visitors and 7,471 page visits.

patientadvocate.org/matters-of-the-heart

Patient Advocate Foundation would like to recognize and thank the following program sponsors for their support.

Matters of the Heart



Migraine Matters
/Migraine CareLine





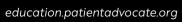
PAF'S CASE MANAGEMENT SERVICE IS SO MUCH MORE THAN THAT TO ME. IT IS A KNOWLEDGE BASE. NOT ONLY WAS MY PROBLEM PROFESSIONALLY ADDRESSED AND SOLVED, BUT I **KNOW SO MUCH MORE ABOUT THE INSURANCE CLAIM PROCESS** THAN I DID PREVIOUSLY. AND NOW I KNOW WHERE TO GO TO FIND ANSWERS TO SOME ISSUES THAT HAVE CHALLENGED ME FOR YEARS. EVERY PERSON WITH A SERIOUS ILLNESS SHOULD KNOW ABOUT THIS SERVICE."

- David | End Stage Renal Disease

Our professional case managers offer one-on-one support to help patients diagnosed with chronic and life-threatening conditions navigate equitable access to healthcare and address financial issues that often result from a diagnosis.

vimeo.com/711735540/5e3e1e3d71

Education Resource Library (ERL) is PAF's central hub for straightforward information in a variety of formats to help patients make informed decisions throughout their healthcare journey. Educational topics include health insurance, disability, denials and appeals, and medical bill management.





2022 Case Management Data

37% of patients requested help with insurance issues

\$26M+ in debt relief obtained on behalf of patients - 15% increase from 2021

3 of the top 5 most frequently utilized PAF educational resources focused on insurance denial topics



Insurance Coverage Impacts

PAF's Spring 2022 Survey Initiative captured patient perspectives on health-related social needs across the care continuum.



38%

reported that insurance coverage problems interfered with their healthcare in the past 12 months 48%

reported that insurance coverage assistance was important to them in achieving their healthcare goals **55**%

said that questions concerning health insurance coverage should be routinely discussed with their care team

Health Equity & Community Engagement

PAF adopted health equity as a strategic priority nearly a decade ago. Each year, we add to this commitment with new programs and objectives to reach people in places impacted by health disparities and social determinants of health. In 2022, PAF launched a Health Equity Case Management Program and a Co-Pay Relief Health Equity Funds program. We also developed an equity-focused value statement and added equity to our organizational core values. These activities further cement PAF's commitment to integrating principles that drive equity across every facet of our organization.

Partnerships in Action

Through our new Health Equity Initiatives (HEI), we expanded efforts to reach racial and ethnic minority populations. These include young adults living with Crohn's disease, irritable bowel disease, and other digestive conditions through a new partnership with Color of Crohn's and Chronic Illness (COCCI) to connect patients

to PAF interventions that address social and financial challenges. The collaboration educates COCCI ambassadors about available PAF case management services. COCCI and PAF shared the stage at the inaugural Health Equity in Inflammatory Bowel Disease Patient Symposium held in Atlanta, Georgia, in July 2022.



Stephanie Stinson (Survivor/COCCI Advocate) and Shonta Chambers (PAF) at the Health Equity in Inflammatory Bowel Disease Patient Symposium in July.



The Race Based Trauma Panel participated in the Equity in IBD Patient Symposium in July.



Participants at 2022 LIVE: Just as We Are Memphis Breast Cancer Event (Partnership with Memphis Breast Cancer Consortium).



direct and/or partner-facilitated PAF HEI virtual and in-person outreach events



2,300 individuals reached with information about PAF's services and resources





SelfMade Health Network (SMHN)

Operated by PAF, the SelfMade Health Network (SMHN) (selfmadehealth.org) continues to expand its efforts to provide technical assistance and training opportunities to enhance the knowledge and skill capacity of CDC-supported National Comprehensive Cancer Control Programs and National Tobacco Prevention and Control Programs staff through two distinct offerings:

- SMHN Training and Technical Assistance Hub to Address Tobacco Disparities (the Hub)
- Quad-Networks HPV Vaccination Learning Collaborative (the Collaborative)

Training and technical assistance activities are designed to provide hands-on support to facilitate implementation of evidence-informed strategies

to decrease tobacco-related disparities and increase Human Papillomavirus (HPV) vaccination to prevent HPV related cancers. Hub participating states include North Dakota, New York, Maine, Connecticut, Ohio, Oklahoma, Utah, Nebraska, and New Mexico. The Collaborative participating states include Florida, Rhode Island, Kansas, West Virginia, and Oklahoma (Cherokee Nation).

Collectively state teams have received more than 42 hours of one-on-one technical assistance.

Nearly 600 people representing more than 30 states participated in multiple events including training webinars addressing HPV Policy Strategies and Approaches to Connect with Community Partners in Tobacco Control and Prevention.

Above: The HPV Vaccination Learning Collaborative in its kick-off meeting.

The National Comprehensive Cancer Network (NCCN)

honored Robert Winn, MD, and PAF EVP Health Equity Initiatives and Community Engagement Shonta Chambers, naming them as joint *Partners in Cancer Care* recipients for their work in co-chairing the Elevating Cancer Equity Workgroup, which was convened by NCCN, the American Cancer Society Cancer Action Network and the National Minority Quality Forum.

PAF Health Equity staff contributed to the manuscript, Food Insecurity Among People With Cancer: Meeting Nutritional Needs as an Essential Component of Care, published in the Journal of the National Cancer Institute, September 2022. The manuscript is one of three papers outlining a call to action to address and improve health disparities from a series of webinars sponsored by the National Cancer Policy Forum of the National Academies of Sciences, Engineering, and Medicine. pubmed.ncbi.nlm.nih.gov/36130287

2022 Case Management Service by the Numbers

18,838
Total Case Count

427,333

Total Case Management Contacts

23

Average Number of Contacts per Case

How Patients Find PAF Case Management Services



Cases referred to PAF by other non-profit organizations



Healthcare Organization or Representative



Media and Outreach



Patient previously served by PAF



Increased

Friend/ Family



Government Agency or Representative



Professional Organizations



24% of patients find PAF through media and online/in-person outreach, a metric that continues to grow, increasing 14% since 2021 (which also reflected an increase of 53% over 2020)

Ethnicity

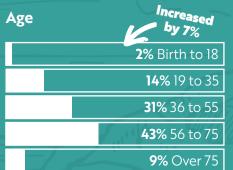
1% American Indian/Alaska Native 3% Asian 2% Blended Race 61% Caucasian 11% Hispanic/Latino .2% Native Hawaiian/Other Pacific Islander

Insurance Status

87% Insured - 13% Uninsured - by 20%

Income

44% Less than \$23,999
29% \$24,000 - \$47,999
13 % \$48,000 - \$71,999
6% \$72,000 - \$95,999
3% \$96,000 - \$119,999
5 % \$120,000 or More



Employment

21% Disabled
30 % Employed
2 % Full-time Student
1 % Homemaker
25 % Retired
3 % Self-employed
18% Unemployed

33% of patients were employed/self-employed with 41% of this group reporting being uninsured

73% of all patients reported household incomes below \$48,000

Top Ways PAF Case Managers Helped Patients

11%	Located rent/mortgage payment relief by 13%
10%	Obtained transportation assistance by 39%
9%	Facilitated medical co-payment relief
9%	Obtained utility financial relief by 21%
8%	Educated on health insurance eligibility and enrollment
7 %	Educated on disability eligibility and enrollment
6%	Negotiated discount on medical co-payments and deductibles
5%	Located nutrition/wellness assistance by 29%

Top 10 Diagnosis Categories

Cancers649	%
Chronic or Debilitating	
Conditions12	%
Nervous System Conditions 69	%
Cardiovascular Conditions 69	%
Autoimmune Diseases5	%
Pulmonary Conditions4	%
Diabetes3	%
Vascular Diseases3	%
Gastrointestinal	
and Hepatology Diseases 29	%
Neuromuscular Diseases 29	%

Top 10 Distinct Diagnosis

Breast Cancer21%
Prostate Cancer10%
Diabetes Type II2%
Stroke2%
Colorectal Cancer2%
Non-Small Cell Lung Cancer 2%
Multiple Myeloma2%
COVID2%
ALS (Lou Gehrig's Disease)2%
Pancreatic Cancer2%

Patients with COVID/ Long-COVID remain on the top 10 distinct diagnosis list

COVID Patient Profile

Compared to all other closed Case Management cases



earn less than \$24K vs. 44% all cases



age 35 to 55

vs. 31% all cases

COVID patients are younger





Service by the Numbers





Patients Approved



Average Contacts per Approved Applicant



\$286,689,6

in Total Grant Payments





Incoming Calls Handled

Total # of Grant Payments



Patients Served by CPR Since 2004

652,995

disease funds assisted patients in 2022

new Health Equity Funds launched



THE BLESSING OF THIS FINANCIAL HELP ALLOWS ME TO TRAVEL TO THE CARDIAC REHABILITATION (55 MILES AWAY) THAT IS SUPERVISED BY MY OWN CARDIOLOGIST. THIS LEAVES MY CARE AND RECORDS IN ONE SYSTEM AND GIVES ME PEACE OF MIND AND CONTINUITY OF CARE. ADDITIONALLY. I CAN NO LONGER DRIVE AND MUST RELY ON OTHERS FOR TRANSPORTATION TO ALL MY APPOINTMENTS. BEING ABLE TO HELP COVER THE TRAVEL COSTS GIVES ME A SENSE OF CONTROL. IT ALSO REDUCES MY FEELING THAT I AM BURDENING OTHERS AND CAUSING EXCESS EXPENSES TO THEM. THANK YOU FOR THE PROGRAM AND THE FINANCIAL HELP."

- Waltrina | Heart Valve Condition

The Structural Heart Disease CareLine helps patients diagnosed with conditions such as cardiomyopathy, congenital heart disease, and heart valve disease, providing one-on-one case management assistance with access to care, financialand employment-related issues.

structuralheart.pafcareline.org/services

PAF's Financial Assistance Funds deliver aid to eligible patients through small grant awards. This support is a critical safety net for patients who cannot afford certain expenses including transportation, lodging, food, and more.

patientadvocate.org/connect-with-services/financial-aid-funds

2022 Case Management Data

11% of patients requested help with transportation - 41% increase over 2021

Cardiovascular conditions ranked **4th** on the top 10 diagnosis categories for case management

9% of patients were over 75 - an increase of 10% over 2021



Cost Impacts Medical Care

PAF's Spring 2022 Survey Initiative captured patient perspectives on health-related social needs across the care continuum.



reported stopping, refusing, or delaying care in the past 12 months due to cost

28% reported that lack of reliable transportation in the past 12 months kept them from medical appointments

reported initiating conversations with their care team about their social needs

are comfortable with their social needs information being a part of their medical record

Health Services, Research, Patient Experience & Evaluation

2022 Survey Initiative Results

64% Female

25% Non-heterosexual

58% aged > 56 years

46% Non-white

72% income <\$48,000

In 2022, our research team continued to explore the unique and aggregate experiences of PAF's patient population. As the healthcare landscape has evolved in response to the COVID-19 pandemic, we examined the impact of health-related social needs with a targeted focus on the Social Determinants of Health (SDOH), financial impact of chronic and complex conditions, and the erosion of safety net support systems. As the needs of our patients shift, we continuously strive to capture their experiences through our survey work and through our Patient Insight Institute learning communities.

Our spring 2022 Survey Initiative collected patient-reported information from 1,675 respondents. Survey topics included understanding the patient perspective on health-related social needs navigation services, the collection and use

of SDOH data, and the incorporation of nonmedical needs into decision support tools. Findings from this survey have been grouped by topic with highlights provided below.

Social Needs Navigation



SDOH and health-related social needs (housing, food security, transportation, etc.) have a considerable impact on the health outcomes of chronically ill patients and may lead patients to delay or stop care. Survey responses show an uneven awareness of patient needs and

the social needs navigation services that can link patients to the support they need. 58% of patients reported being asked questions about their social needs in the past 12 months as part of their treatment journey. **Of those asked questions about their social needs:**

37% reported that their doctor initiated this conversation

59" preferred to have these questions asked verbally during their office visit 77% reported that their doctor was the most trusted person to engage in social needs conversations

21% reported being "extremely comfortable" with social needs information becoming part of their electronic medical record 34% reported no knowledge about the availability of social needs navigation services that could help them work through their financial or social concerns

60% reported that if these services were readily available, they would be "very likely" to use them

76% reported that it was "very important" for these services to be available as part of the care provided to them by their provider

Use of Decision Support Tools



19% reported using a DST to discuss treatment options or care planning with their medical provider

Decision support tools (DST) are an important part of treatment-related decision-making. However, the use of these tools has not been widely opted across the care continuum and they may not take

into consideration both the medical and nonmedical factors patients need to consider when making treatment choices.

45% reported that a DST was "very or extremely helpful" in facilitating a meaningful conversation with their healthcare provider about what was important to them for their treatment and/or care

While 61% of survey respondents reported that their DST included treatment options, far fewer reported the inclusion of critical non-medical factors. The percentage of patients who reported the DST also reported that it included:

44% quality of life

financial impact of treatment

basic needs or social needs (housing, food, transportation)



Patient Insight Institute

PAF's research activities provide the infrastructure and capacity for patients, caregivers, communities, researchers, providers, and policymakers to come together in meaningful ways to shape meaningful projects that can drive health system change. The Patient Insight Institute's focus is ensuring that healthcare is informed by the whole patient experience by giving voice to

those who have been historically underrepresented. Our learning communities provided a space for patients to explore diverse topics such as the COVID-19 pandemic, addressing SDOH in collaboration with pharmacists, as well as the intersection between SDOH and Equity.

patientinsightinstitute.org



Research Project: Understanding the Long-term Impacts of Financial Barriers to Care: Patient-informed Adaptation of a Conceptual Framework for Adult Cancer Survivors

Cancer-related financial hardship is experienced by almost half of cancer survivors in the U.S. and is associated with negative clinical outcomes, including worse patient emotional well-being and heightened risk of mortality. To explore this relationship, virtual, audio-only interviews were conducted using an in-depth, semi-structured interview guide. Preliminary results were shared at Patient Insight Congress and can be viewed at *patientinsightinstitute.org/2022posters*



Publication Spotlight: Academic Partnership Exploring Health Insurance and Financial Hardship during the COVID-19 Pandemic

Uninsured or underinsured individuals with cancer are likely to experience financial hardship, foregoing healthcare or non-healthcare essentials such as food, housing, or utilities. To explore the association between health insurance coverage and financial hardship among cancer survivors during the COVID-19 pandemic, PAF partnered with researchers at the University of Alabama at Birmingham to conduct an indepth analysis of data collected through our Longitudinal COVID Survey. This work was accepted for publication in August 2022.

tiny.cc/covidandcancer

siren

Social Interventions Research & Evaluation Network

Partnership Spotlight: Social Need & Equity Learning Community

This Learning Community is a partnership between the Patient Insight Institute and SIREN to integrate a patient voice and perspective into existing and new projects focused on the intersection of social needs and healthcare. SIREN (the Social Interventions Research and Evaluation Network) is a research acceleration and dissemination initiative at the University of California, San Francisco, whose mission is to improve health and health equity by advancing high-quality research on healthcare sector strategies to improve social conditions.

tiny.cc/equity-learning

PAF's Health Services Research activities in 2022 also included robust dissemination of our findings. These included 9 journal articles, 3 speaker/panelist engagements, and 11 conference/poster presentations. Featured dissemination highlights include:

Offodile, A.C., Gallagher, K., Angove, R., Tucker-Seeley, R.D., Balch, A. and Shankaran, V., 2022. Financial navigation in cancer care delivery: state of the evidence, opportunities for research, and future directions. Journal of Clinical Oncology, 40(21), pp.2291-2294. tiny.cc/PAFnavigationcancer

Balch A, Angove R, Gallagher, K. Standards Development for Person-Centered Decision Support Tools. December 2022 J Clin Pathways. 2022;8(8):12-16. tiny.cc/support-tools

Cooper, K.E., Abdallah, K.E., Angove, R.S., Gallagher, K.D. and Bonham, V.L., 2022. Navigating Access to Cancer Care: Identifying Barriers to Precision Cancer Medicine. Ethnicity & Disease, 32(1), pp.39-48. tiny.cc/accesstocare

Cope, E.L., McTigue, K.M., Forrest, C.B., Carton, T.W., Fair, A.M., Goytia, C., Harrington, J.M., Lowe, S., Merritt, Angove, R. et. Als. 2022. Stakeholder engagement infrastructure to support multicenter research networks: Advances from the clinical research networks participating in PCORnet. Learning Health Systems, p.e10313. tiny.cc/engagementinfrastructure

Caston NE, Waters AR, Williams CP, Biddell C, Spees L, Gallagher K, Angove R, Anderson E, Balch A, Wheeler S, Rocque GB. Patient-reported discrimination among limited-resourced cancer survivors: a brief report. Journal of Psychosocial Oncology. 2022 Nov 30:1-2. tiny.cc/patientdiscrimination

R Angove. Family Caregiving for People with Cancer and Other Serious Illness. The National Academies of Science-Engineering-Medicine. Washington DC. May 16-17, 2022. Speaker: Research Challenges and Opportunities; from a patient and caregiver perspective

R Angove. American Society of Hematology (ASH). Annual Meeting, New Orleans, LA. December 10-13, 2022. Speaker: Patient-Centric Goals of Decentralized Clinical Trials (DCT)

Participant Results

98% felt that day sessions helped them understand the connection between unmet social needs, research engagement and policy that transforms the healthcare system

94% stated that words matter - and these sessions made them think critically about the language used to describe research, policy, and advocacy outcomes

85% plan to spread awareness about our Health Needs Navigation campaign in their communities



Above: 2022 Patient Insight Congress attendees.

Patient Insight Congress

The inaugural Patient Insight Congress, an interactive in-person event dedicated to advancing healthcare initiatives informed by the whole patient experience, was hosted in November 2022 in Washington, DC. Patients and caregivers came together with researchers and health policy professionals to share insights about outcomes that matter most to them and what they would like researchers and government officials to address through patient-centered research projects and policy proposals.

Patient and caregiver panel discussions focused on lived experiences to illustrate why the patient perspective is important. Insight gathering sessions helped identify what matters most to patients, and sessions on elevating patient experiences focused on actionable policy change. The event also featured a "rapid poster walk" that brought patients and researchers together for a curated session of interactive research poster presentations that allowed attendees to learn more about research happening in their communities and ways that the two groups can connect to partner on research design, implementation, and dissemination.

patientinsightinstitute.org/home/patientcongress

Promise of Hope

26 event sponsors

\$247,750 raised

40 scholarships funded

PAF's annual *Promise of Hope Affair* returned to the Newport News Marriott at City Center with a spirited theme of Pirates, Pearls & Poker. The event raised \$133,250 in support of patients served through our case management programs and \$114,500 for the Scholarship for Survivors

program. Speakers included scholarship recipients Lauren Ramer and Dr. Kaela Johnson, and Michael Troutman, scholarship review committee member.

We invite you to join us for next year's gala! promiseofhope.net



PAF Co-Founder John H. (Jack) Ennis, Founder Nancy Davenport-Ennis, President of Operations Fran Castellow with husband Bryan Castellow at the gala. (*Left to right*)



PAF *Promise of Hope* staff committee members.

Scholarships for Survivors

Our Scholarship for Survivors (SFS) program has supported college students whose educational pursuits were disrupted due to a chronic illness since 2000, providing 155 accomplished students with **scholarship awards totaling over \$943,000**. PAF, along with many other gracious funders, has enabled 54 courageous young adults to realize fully degreed graduation. In addition to 19 new awardees this academic year, the program supports 21 returning students with scholarship recipients eligible to receive \$3,000 per school year for four consecutive years.

To learn more about the students, the program or how to donate visit patientadvocate.org/scholarships

Congratulations to the '22 -'23 Scholarship Winners

Abigail | University of Memphis

Alice | University of Maine Farmington

Amani | Louisiana State University

at Shreveport

Audrey | University of Utah

Calli | Hamline University

Caroline | University of Florida

Daisy | Lewis and Clark College

Giancarlo | Emory University

Hima | Florida State University **Karlee** | UNC Charlotte Center City

Kathryn | Roanoke College

Luke | University of Kansas

Madison | Temple University

Mussab | Harvard Law School

Olivia | Temple University

Safwan | Brown University

Sarah | Grand Valley State University

Timothy | Dartmouth College

Zoé | North Carolina Agricultural & Technical State University



A Message from Amani

PAF's scholarship helps her pursuit of becoming a trauma surgeon.



tiny.cc/pafamani

Fundraising Event Champion

We would like to extend our gratitude to the Crystal Joyce Dance Academy and recognize them as PAF's 2022 Fundraising Event Champion.

When academy owner Crystal Joyce's father, Kenneth, was undergoing cancer treatment, she became aware of the healthcare access and financial challenges many patients face.

In February Ms. Joyce held the Showcase for a Cause event, enlisting the help of the school's dance teams to raise funds and awareness in support of cancer patients. Together with the dancers and their families, Ms. Joyce raised \$2,200 in support for PAF through its Champion Your Own Fundraiser Event platform.

Learn how you can host a PAF fundraising event, patientadvocate.org/champion-your-own-fundraising-event



"I am a rising senior at the University of Florida, double majoring in criminology and family, youth, and community sciences. I was diagnosed with Crohn's disease a year ago, though my symptoms began much earlier. I endured extensive hospitalizations and multiple misdiagnoses before doctors could find the root of my extreme stomach pain and nausea. Through my journey, I discovered a calling for helping vulnerable populations through the non-profit sector. I currently work in development for a homeless shelter and serve as a research assistant in a non-profit lab. I hope to channel my experiences with health care, non-profits, and my love for law into a career as a disability rights attorney. Thank you for your support!"

Financial Statements

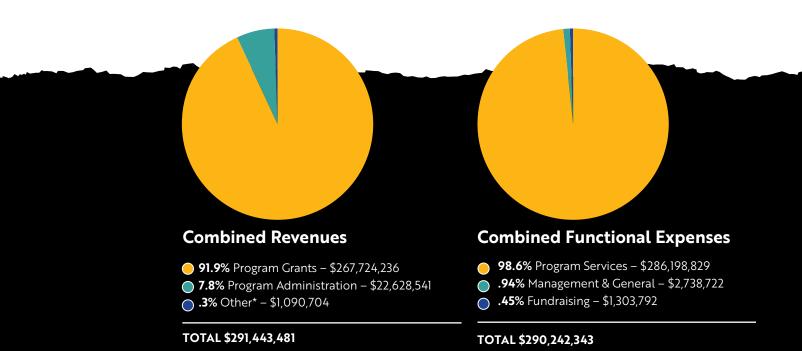
PAF financial statements are based on its fiscal year, from July of 2021 to June of 2022. The program impact reporting in the preceding pages is conducted on an annual basis, from January 2022 to December 2022.

Summary of Total Patient Impact In Fiscal Year 2021/22

Total Patient Cases	179,644
Total New Case Management Cases	19,016
Total Co-Pay Relief Recipients	68,399
Total Financial Aid Fund Recipients	76,967
Total Patient Services Email Helpline Sessions	15,262
Total Patient Services Case Contacts	1,361,604

Summary of Case Management Impact in Fiscal Year 2021/22

Total Case Management Closed Cases	18,923
Unique Case Management Patient Issues	22,771
Total PAF Case Management Contacts	374,555
Average Contacts per Case	20



^{*}Other revenues include interest, gifts & contributions, event revenue and in-kind services

Patient Advocate Foundation Statements of Financial Position June 30, 2022 and 2021

		2022		2021
ASSETS		_		
Current assets General operating cash and cash equivalents	\$	30,689,086	\$	28,356,319
Restricted cash and cash equivalents		285,457,065		287,485,725
Unconditional promises to give Accounts receivable		18,218,453 1,866,173		17,613,158 1,745,868
Interest receivable		83,480		1,743,808
Due from National Patient Advocate Foundation		5,269		37,462
Investments and cash equivalents		62,234,388		62,194,524
Inventories Prepaid expenses		80,194 460,069		72,356 390,886
Total current assets		399,094,177		398,013,252
Property and equipment, net		4,399,051		3,861,164
Other assets		50,331		50,331
	\$	\$403,543,559	\$	401,924,747
LIABILITIES AND NET ASSETS Current liabilities				
Accounts payable and accrued expenses	\$	10,198,425	\$	8,777,237
Due to National Patient Advocate Foundation Postretirement benefits liability, current portion		10,226 73,371		35,162 63,621
Deferred revenue		21,569,093		21,918,604
Accrued vacation leave	_	611,412		574,462
Total current liabilities		32,462,527		31,369,086
Long-term liabilities Postretirement benefits liability, less current portion		2,178,187		2,709,676
Incurred but not recorded liabilities	_	128,825	_	152,603
Total long-term liabilities		2,307,012		2,862,279
Total liabilities		34,769,539		34,231,365
Net assets without donor restrictions				
Undesignated		22,760,908		18,853,500
Board designated	_	2,167,270		2,194,524
Total net assets without donor restrictions		24,928,178		21,048,024
Net assets with donor restrictions				
Restricted by purpose	_	343,845,842		346,645,358
Total net assets		368,774,020		367,693,382
Total liabilities and net assets	\$	403,543,559	\$	401,924,747

Patient Advocate Foundation Statements of Activities Years Ended June 30, 2022 and 2021

		2022			2021	
	Without	With		Without	With	
OPERATINGREVENIES	Kestrictions	Kestrictions	lotal	Kestrictions	Kestrictions	lotal
Contributions:						
Grants	\$ 4,823,132	\$ 262,901,104	\$ 267,724,236	\$ 2,759,204	\$ 294,452,083 \$	297,211,287
Private and public donations	208,487	•	208,487	208,539	•	208,539
Donated services	•	9,720	9,720	•	•	•
Donated materials	31,956	•	31,956	115'6	•	115'6
Program admin istration	22,628,541	•	22,628,541	20,252,430	•	20,252,430
Patient Congress	30,000	•	30,000	000'59	•	000'59
Promise of Hope	185,649	•	185,649	•		•
Patient Action Council	100,000	•	100,000	75,000	•	75,000
Investment return, net	524,892	•	524,892	048'169	•	048'169
Net assets released from restrictions:						
Satisfaction of program restrictions	265,710,340	(265,710,340)		247,409,152	(247,409,152)	1
Total revenues, gains and other support	294,242,997	(2,799,516)	291,443,481	271,470,676	47,042,931	318,513,607
OPERATING EXPENSES						
Program services:				!		
Patient/educational services	6,338,536	•	6,338,536	5,615,958		5,615,958
Financial aid programs	272,403,240		272,403,240	254,199,499		254,199,499
Service contracts	7,457,053		7,457,053	6,289,317		6,289,317
Supporting services:						0000
Management and general	1303,727		1303,727	1,820,387		1,820,387
rundraising	37,000,		27,1,000,1	000,000,1		000,000,1
Total expenses	290,242,343		290,242,343	727,196,992		722,196,961
Change in net assets from o perations	4,000,654	(2,799,516)	1,201,138	1,508,949	47,042,931	48,551,880
OTHER NONOPERATING CHANGES Postretirement benefit changes other than periodic cost	(120,500)	1	(120,500)	1,090,679	•	1,090,679
Change in net assets	3,880,154	(2,799,516)	1,080,638	2,599,628	47,042,931	49,642,559
Net assets, beginning of year	21,048,024	346,645,358	367,693,382	18,448,396	299,602,427	318,050,823
Net assets. end of vear	\$ 24,928,178	\$ 343,845,842	\$ 368,774,020	\$ 21,048,024	\$ 346,645,358 \$	367,693,382

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Alan Balch, PhD, Chief Executive Officer

Principal Writer & Senior Editor

Beth Moore, Executive Vice President, Corporate Communications

Contributors

Alan Richardson, Executive Vice President for Strategic Patient Solutions

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Bill Nason, MBA, Chief Financial Officer

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866.512.3861 | copays.org cpr@patientadvocate.org

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